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JAN GRUE

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Disability and Discourse Analysis

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Published by
Ashgate Publishing Limited
Wey Court East
Union Road
Farnham
Surrey, GU9 7PT
England

Ashgate Publishing Company
110 Cherry Street
Suite 3-1
Burlington, VT 05401-3818
USA

www.ashgate.com

British Library Cataloguing in Publication Data
A catalogue record for this book is available from the British Library

The Library of Congress has cataloged the printed edition as follows:
Grue, Jan, 1981-
Disability and discourse analysis / by Jan Grue.
pages cm. – (Interdisciplinary disability studies)
Includes bibliographical references and index.
ISBN 978-1-4724-3292-6 (hardback) – ISBN 978-1-4724-3293-3 (ebook) – ISBN 978-1-4724-3294-0 (epub) 1. Disability studies. 2. Discourse analysis. I. Title.
HV1568.2.G78 2015
305.9'080141–dc23
2014021251

ISBN 9781472432926 (hbk)
ISBN 9781472432933 (ebk – PDF)
ISBN 9781472432940 (ebk – ePUB)

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Preface

This book is about ways of seeing, talking, and thinking about disability. It employs the analytical strategy of discourse analysis in order to do so, because discourse analysis is particularly well-suited for two things: identifying how different words are used to shape impressions of the same thing, and identifying how some things come into being because of the words we use.

These concerns are absolutely central to Disability Studies, which is a discipline that is predicated partly on exploring the way in which the thing we now call "disability" is produced – through politics, through institutional arrangements, through economic prioritization, and, most certainly, through the use and abuse of language.

In some cases, the approach adopted and advocated by this book overlaps very closely with previous research on disability that was in no way labelled as or understood itself as part of discourse analysis. In particular, the form of discourse analysis I practice is indebted to previous research in sociology – for example, Michael Oliver's (1990: 7–8) classic analysis of the medicalizing perspectives and wordings used in a British census survey. This analysis shows how a particular mode of thought and language, coupled to institutional procedures for gathering knowledge about people, does not so much reflect its supposed object of study as actively produce it.

This overlap in approaches is of course no accident. Oliver does not himself find much use for the concept of discourse, but his sociologically inflected analysis draws on the work of Michel Foucault in the history of ideas – and Foucault certainly did find the concept of discourse useful. Partly from Foucauldian origins, explicit and implicit references to the discourse perspective sprout throughout Disability Studies, which remains an interdisciplinary project.

A key development occurred in the late 1990s and early 2000s, when different forms of discourse analysis were explicitly adopted in important works both from the UK (see the Corker & French anthology entitled *Disability Discourse*) and the US (Snyder & Mitchell, 2000). Here, the discourse perspective was used to extend and develop theories of how disability is produced by linguistic, cultural and narrative structures and entities. The same time period saw a flowering of discourse analysis in other ideologically contested areas that are thematically related to Disability Studies: the study of media representations and media power (Fairclough, 1995), as well as gender (Wodak, 1997), identity (Wodak, de Cillia, Reisigl, & Liebhart, 1999), and racism (Wodak & van Dijk, 2000).

This book draws on these parallel developments. Disability Studies and discourse analysis are fields that matured at roughly the same time and share many concerns: with asymmetric power relations, with marginalization and discrimination, and with the way in which the social categories that reproduce and reinforce these phenomena come into being.

Extending the geometrical metaphor just a little, I will justify the existence of this book – yet more words on disability, when what is most sorely needed is stronger rights, better services, redistribution of economic resources, and social justice – as follows: having developed along parallel lines, the fields of Disability Studies and discourse analysis have not quite converged. This book originated from the observation that gender, race, ethnicity, and sexual orientation all remain more extensively covered in discourse analysis than disability (J. Grue, 2011a), and from puzzlement that this should be the case. Certainly disability shares many analytical features with these topics? Certainly discourse analysis is almost perfectly suited for analysing a topic such as disability?

Yes, and yes. Most likely the explanation for any lacunas is that we – the community of disability scholars and discourse scholars – haven't quite gotten round to fully integrating the fields. There is, after all, much to do. But we are getting there. Significant efforts have been made to integrate disability into the discourse analysis and conversation analysis canon (e.g. Williams, 2011), and there is every reason to think that the critical analysis of discourse, language, and disability will prove fruitful in the years to come.

I believe that the specific contributions of discourse analysis to Disability Studies, or indeed vice versa, arise in the thematic area I have already pointed out: our understanding of how language changes the world (and, indeed, vice versa). The analytical vocabulary of Critical Discourse Analysis – the branch of discourse analysis adopted in this book – is aimed at identifying the exercise of power through language. Moreover, it provides room for the theorization of the role language plays in the social construction of disability.

Both of those topics are essential to understanding "disability", since that linguistic label is intimately tied not only to power relations, but also, at this stage in history, to innumerable attempts to explain, theorize, and model it. Disability is persistently perceived as a *problem* (Hughes, 2012), and that ontological tendency begets solutions, partly in the form of words – or, from the perspective of this book, *discourses*.

The discourse view of different solution-approaches to (the perceived) problem of disability allows for a certain amount of analytic unity in two aspects – with regard to investigations *in* Disability Studies and with regard to debates *about* Disability Studies. For an example of the first aspect: the phenomenon of medicalization becomes an instance of the unwarranted expansion of medical discourse (Conrad, 2007), a process which is important not least because it may obscure non-medical topics (Waitzkin, 1989). As for the second: the sometime lack of fit between UK and US disability theory has been explained in terms of national disciplinary traditions (Meekosha, 2004), for example, the respective traditions' grounding in political-economic as opposed to socio-cultural and identity discourse.

The analysis of disability can be carried out from, among many other alternatives, a social constructionist, a representation-oriented or a critical realist point of view: e.g. Goodley (2010), Snyder & Mitchell (2000) and Wilson & Lewiecki-Wilson (2001), and Shakespeare (2013), respectively. Discourse analysis as adopted by this book embraces elements from all three of these traditions: it maintains a strong belief in the formative influence of words, category systems, and systems of thought upon socially mediated reality, while simultaneously acknowledging the limits of the power of discourse.

Since discourse analysis so often aims to expose hegemonic ideologies as problematic, inconsistent, and paradoxical, it is sometimes forgotten that one of the most significant contributions of discourse analysis is to identify instances where seemingly incompatible positions rest primarily on conventions of vocabulary and usage.

A prominent example of such incompatibilities is the so-called dichotomous relationship between a "social model" and a "medical model" of disability. In parts of the disability field, models are positioned as analytically self-sufficient, mutually exclusive alternatives that should and must explain all facets of disability and disabled experience. Suffice it to say, in this preface, that this book is an attempt to explain the inherent limitations of any single model of disability. Discourse analysis, like disability itself, is about a plurality of perspectives – about rich variation in language, as much as in human capability.

This book draws on material I have worked on for a number of years, as an employee of Oslo University College and the University of Oslo respectively, under projects financed by the Research Council of Norway. The Fulbright Foundation made it possible for me to spend a year at the University of California, Berkeley. I have had the great fortune to work with and learn from very talented scholars at all three research institutions, not only in Disability Studies and discourse analysis, but also in neighbouring disciplines like medical sociology, rhetoric, non-fiction prose studies, and narrative studies.

Thanks are due, for various contributions at various stages to the work behind this book, to: Dag Album, Kjell Lars Berge, Sine Halkjelsvik Bjordal, Inga Bostad, Eivind Engebretsen, Nikolai Fjeld, Arthur Frank, Dan Goodley, Rosemarie Garland-Thomson, Lars Grue, Marit Haldar, Halvor Hanisch, Kristin Heggen, Ida Jackson, Lars E.F. Johannessen, Cathy Kudlick, Kristjana Kristiansen, Olaug Lian, Inger Marie Lid, Erik Fossan Rasmussen, Graham Scambler, Per Solvang, Sue Schweik, Tom Shakespeare, Aksel Tjora, Johan Tønnesson, Teun van Dijk, and Ruth Wodak. I am sure I have forgotten many others. Special thanks go to my editor at Ashgate, Claire Jarvis, and Mark Sherry, the series editor. For any omissions, as well as for any errors in the following, I take full responsibility.

Jan Grue
Oslo, May 2014

Introduction

What kind of stories do we tell about disability? Or, rather, what kind of stories do we tell simply by choosing to use the word "disability"? There is no easy way to get around that word. One path leads to nastier, derogatory words; another leads to euphemism. Possibly we could ask what stories we tell about *people with impairment and chronic illnesses, and their interactions with disabling and ableist societies* – but that is something of a mouthful.

The word "disability" is polysemic, in that it has multiple possible meanings and shades of meaning. It can be (and commonly is) used to refer to a lack or limitation in some capacity of the body, be it mental or physical. It can refer to the outcome of an interaction between a person with an impairment and other entities (people, things, situations) that do not accommodate that person. It can also, by way of metonymic transfer, refer to payments received by people who are classified as "disabled" by one bureaucracy or another. The author Joan Didion wrote about the general connection between narratives and norms, pointing out that stories provide interpretive frames, which then form the basis of moral judgement.

> We tell ourselves stories in order to live … We look for the sermon in the suicide, for the social or moral lesson in the murder of five. We interpret what we see, select the most workable of the multiple choices. We live entirely, especially if we are writers, by the imposition of a narrative line upon disparate images, by the 'ideas' with which we have learned to freeze the shifting phantasmagoria which is our actual experience. (Didion, 1979)

Dictionaries, usually very conservative in such matters, tend to list "disability", "impairment", and "handicap" as synonyms, and to emphasize those aspects of meaning that tie all three words to qualities pertaining to individuals, not to social relationships or structures. Scholars in Disability Studies and disability activists tend to disagree with this approach, but nevertheless have to deal with the inertia of linguistic usage. As I write this, in 2014, I perform a Google search (anonymously and without cookies or a search history, so as not to be directed to my familiar Disability Studies websites). The top results suggest that disability is, to the world, a consequence of impairment (Wikipedia), a governmental programme (the United States Social Security Administration), and a series of benefits (Social Security Disability, Veteran Disability Compensation, etc.). The list of results is skewed towards programmes, benefits, and conservative or medicalizing definitions, for quite a way down. Disability discrimination becomes a topic at number 15, but the Church of Jesus Christ of Latter-day Saints is perched higher up, at number 10.

I do not know whether to call this a sobering look. It is perhaps not surprising that the meaning of "disability" in everyday usage is tied to the kind of economic structures and arrangements that determine life outcomes for millions of people. Searches in large databases of text and talk such as the Corpus of Contemporary American English, the British National Corpus, too, suggest that it is the big hitters, socio-politically and institutionally speaking, that determine the semantic colouring of "disability". Table I.1 reproduces the top ten collocates (i.e. words that frequently appear within five words of the search term, not including articles, pronouns, etc.) for "disability" in selected sources (Davies, 2004–, 2008–).

Table I.1 Collocates of "disability" in three large text corpora

	Corpus of Contemporary American English (~450m words)	**British National Corpus (~100m words)**	**Corpus of Canadian English (~50m words)**
1	SSDI (Social Security Disability)	OPCS (Office of Population Censuses and Surveys)	HANDICAP
2	LOW-INCIDENCE	IMPAIRMENT	IMPAIRMENT
3	COVARIATES	DISABILITY	DISABILITY
4	DYSLEXIA	ALLOWANCE	POSTSECONDARY
5	DISABILITY	PREVALENCE	SEVERITY
6	SSI (Supplemental Security Income)	AGEING	PENSIONS
7	IMPAIRMENT	REHABILITATION	ILLNESS
8	QUARTERLY	SEVERITY	DEVELOPMENTAL
9	PENSIONS	HANDICAP	PENSION
10	RETARDATION	DISCRIMINATION	SHORT-TERM

This emphasis on a handful of social domains, including welfare bureaucracy, pensions and benefits, statistics and surveys, medicine, and education, suggest to some extent what disability is *about* – at least in the Western, Anglophone countries from which the corpora originate. Simultaneously, they tell us very, very little. There is little to be learned from this table, for instance, about *how* disability has come into being as a category and a label associated with these social domains. That explanation has to come from outside of general usage, from the meta-language provided by Disability Studies – whether they be studies in sociology, history, anthropology, art, literature, or philosophy.

To some extent, this book is about the tension between different forms of usage: between the commonsensical, medicalizing, deeply conservative way in which "disability" is spoken, written, and intended in innumerable everyday circumstances, and the critical, querying, conditional way in which it often is understood within what I will very loosely term "the disability field". It is also about the twists and turns of everyday usage, and a little bit, too, about the tension between different forms of usage *within* the disability field. Mostly it is about different ways of conceptualizing disability.

In terms of theory and method, the book is anchored in "Critical Discourse Analysis" (CDA), a direction in language research that is often described as a historically oriented and situated praxis, and is exemplified in the research of among others, Ruth Wodak (2001b; 2005), Paul Chilton (2004), Teun van Dijk (2008; 2009), and Norman Fairclough (1992; 2001 [1989]).

CDA is, very briefly put, about the social aspects of language. It is, of course, not the only form of inquiry that has this concern. Notably, much of the analytical vocabulary of CDA overlaps not only with several sub-disciplines of modern linguistics, e.g. pragmatics, semantics, and conversation analysis, but with argumentation theory, with classical as well as modern rhetoric and with areas in sociology.

This overlap should, I think, be taken as a general reminder that CDA, and its central objects of study, belong to an area of academic inquiry in which multidisciplinarity is both inevitable and productive. However, the overlap with the social sciences, including sociology, is particularly important. The primary purpose of this book's anchoring in CDA is to introduce and establish an analytical vocabulary that is suitable for dealing with discourses. Its main research questions, however, could quite conceivably be rephrased and directed at other entities, such as people or institutions – and such entities will be invoked throughout the book.

"Disability" is amorphous, as a word, as a concept, and as a phenomenon. It can (and should) be approached from many angles. This book begins with the textual angle. It will not, however, presuppose more than a basic knowledge of categories of grammar or textual structure. Discussions of texts, and their structures, are means to a social end – at least in CDA – and many if not most of the central research questions that inform this book originated in the social sciences: what does it mean to be disabled rather than ill? Under what circumstances does someone count as disabled? How does society currently understand the concept and category of disability, and what are the social implications of this understanding?

The book has six chapters. The first two are mainly about the intersection of discourse analysis and Disability Studies, which is to say: they construe the project of Disability Studies as acts of discourse production and discourse analysis. The last four chapters examine different kinds of disability discourse, focusing on examples from some of the social spheres that have already been mentioned in this introduction. The point is to show discourse analysis in action, both as a procedure for empirical investigation and as a strategy for mapping different kinds and forms of knowledge.

Chapter 1 introduces the discourse perspective: its origins in critical theory and critical linguistics, a stripped-down version of its toolbox, and its main analytical implications for the concept and phenomenon of disability. The "toolbox" section discusses the two different meanings of "discourse", i.e. the object/entity and the social/structure meanings, and relates them to key concepts in argumentation analysis.

Chapter 2 applies the discourse perspective to Disability Studies and aspects of disability theory. Some recurring questions in academic approaches to disability, particularly those that have to do with models and analytical paradigms of disablement, are re-analysed as questions about how to signify different social domains and practices in a consistent and comprehensible style of language.

Chapter 3 addresses medical knowledge, medical power, medical discourse, and the so-called "medical model" of disability. The central role of medicine and medical bureaucracies in constructing, administering and controlling the category of disability is discussed in relation to the appeal and utility of medically inflected language for individuals and organizations in the disability field.

Chapter 4 broadens the discussion to include political and economic discourses of disability, still with primary reference to individuals and organizations in the disability field. Different models and conceptions of the phenomenon of disability are discussed relative to political and economic systems and arrangements.

Chapter 5 discusses social discourses and discourses of identity in their relationship to politics, economy, and medical perspectives. Identity is construed as a matter of presenting an argument as well as a story, and finding a way to present oneself within the parameters of and drawing on the resources of different discourses.

Chapter 6 focuses on media representations and pre-packaged story formats and identity templates, arguing that the persistence, expansion, and broad appeal of individualizing, basically reactionary disability narratives – aided by related popular culture discourses – represent an unsolved problem as regards disability identification.

In sum, this is a book about different ways to talk about disability. The quote from Joan Didion at the start of this introduction is intended as a reminder that speaking and writing – talk and texts – are ways of imposing order on chaos. Frequently, though not always intentionally, the imposition of order becomes a structuring in argument and narrative. The purpose of discourse analysis is not only to point out how a phenomenon is represented, and constructed, but also to tease out the implications of such constructions and representations – to ask what social, moral, and political arguments lie implicit in different discourses, and how they come into play.

Language, as Norman Fairclough reminds us, is power. That, of course, is old hat to almost everyone who has tried to think systematically about disability, and it is patently obvious to anyone who has considered the difference between words like "disabled", "handicapped", "invalid", and "crippled". It is also obvious to anyone who has applied for disability benefits or disability services, or who has considered the difference between services for disabled people and services for other kinds of people. The power does not reside in the words themselves, but in us, the language users. All the more reason to keep looking for effective ways to treat the study of language and power as an integral part of Disability Studies, and to keep looking for the ways in which disability – and disablement – is constructed, administrated, and policed through the socially and bureaucratically embedded use of language.

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Chapter 1

Why Discourse Analysis? Disability and Language

Some years ago, while studying at the University of California at Berkeley, I came across a sign on a bathroom stall. The sign requested that I please leave the stall unoccupied, as a courtesy to "the disabled". From a certain perspective, this request could be construed as a little bit puzzling. Not only was it unclear how any disabled people would benefit from the stall leaving unoccupied – specifically, myself; as a wheelchair user, I would have preferred to use it, since it was the only wheelchair accessible stall in the bathroom.

A more reasonable reader, of course, would assume that the sign addressed a non-disabled audience. But not all disabled readers remain reasonable after many years of being talked about rather than being talked to. The building where I live, in Oslo, has a courtyard where parking is strictly prohibited – except in cases of "transportation of goods and the handicapped". The discourse of disability has a long history of not involving disabled people as addressees or people with independent agency, but as clients, recipients, beneficiaries, and transportable goods – as objects and as predicates. As Henri-Jacques Stiker argued a generation ago, disability continues to signify difference and alterity:

> Isn't the first question […] this one: why is disability called 'dis-ability'? […] When we name, we point up a *difference*. […] It is the wonderful clarity of the opening books of the Bible in which God distinguishes, separates, differentiates by naming, to the point where to create is to separate; we also see one being (Eve) come out of another (Adam) but affirmed as Difference even in the name that is cried out. (Stiker, 1999 [1982]: 5)

This book is about disability and language, and its interests are primarily in language in use, as it can be found in social, institutional, and political contexts. It is about the kind of socio-political stories told about disabled people, and about the kind of socio-political stories disabled people tell about themselves. A major premise of the book is that stories and representations also constitute arguments, whether implicitly or explicitly, and so come to express something not only about how the world is, but about how it should be. This requires nuance in analysis:

> [A]n effective approach to the politics of disability narrative needs to be localized culturally and historically. There is no universal narrative that can do justice to the variegated historical patterning of its material meanings. (Snyder & Mitchell, 2000: 164)

Here, the shorthand for such representational, narrative/argumentative, contextualized language is "discourse". We are dealing with *texts*, whether oral or written, *in context*. Texts are coherent symbolic representations of the world, and they are produced by social agents, for other social agents. From this perspective, the study of language is inevitably tied in with the study of society and social phenomena. The discourse perspective makes research questions out of how and to what extent epithets, insults, and slurs denote disabled people and impairments. Those questions must necessarily involve social context, for example, people's social background, comparable trends in abusive language related to sexuality, gender, or ethnicity, and relevant legislation and political action on such questions.

From a discourse perspective it could be just as interesting, however, to examine the grammatical forms in which disabled people are cast in media reports, as compared to other groups. Are disabled people chiefly active or chiefly passive, and under what conditions – in which textual roles? Do they usually appear as victims, as heroes, as the subjects of interviews, as professionals, at the centre or the periphery of stories? A discourse-analytical approach to disability potentially encompasses the full range of language functions, and the full range of interaction between language, language users, and the world, that produce the words, concepts and frames of thought that are integral to disability and disabled experience.

Disability scholars have long been interested in language, partly because so much of the language associated with disability has, in many societies over a relatively brief period of time, changed so profoundly. In Norway, which is my home country and the source of many examples in this book, the current and preferred term for disabled people, *funksjonshemmede*, (literally "those hindered in function(s)"), dates back only about 50 years, and has only recently come to supplant *handikappede*, which in turn forced out *vanfør* ("mis-capable", closer in meaning to "invalid"). Similar shifts, roughly speaking, away from terms focused entirely on bodies and towards terms that have an interactional component, are probably familiar to readers in many countries.

Aside from such glaring examples, however, there is a rich history of disability and discourse studies. In the fourth edition of *The Disability Studies Reader*, Lennard Davis argues that disability cannot be understood without first understanding its prerequisite discourse of normality and the normal. What is meant when someone says or writes "disabled" is not primarily determined by that term itself, but by its relationship to the standard or norm from which it marks deviation:

> [Even] in texts that do not appear to be about disability, the issue of normalcy is fully deployed. [… The] very term that permeates our contemporary life – the normal – is a configuration that arises in a particular historical moment. (Davis, 2013b: 12)

Another example: on the back cover of their anthology, simply called *Disability Discourse*, Mairian Corker and Sally French posed the question of how a social theory of disability might fully incorporate "the multidimensional and multifunctional role of language". In their introduction to that volume, they began to answer that question by drawing on what was then another emerging discipline of discourse analysis. Citing key figures in discourse analysis such as Norman Fairclough, Teun van Dijk, Margaret Wetherell and Jonathan Potter, they argued that Disability Studies must *reclaim discourse* (Corker & French, 1999: 6), an act which entails close linguistic analysis as well as a social theory of language use. Words like "disability" derive their meaning-in-use from their hegemonic opposite numbers, like "normal", but also from their traditional and conventional usage contexts. This suggests the need to bring non-traditional thematic areas within the analytical scope of Disability Studies, and to introduce disability as an analytically relevant concept into new areas.

The Corker & French anthology provides many instructive examples of how language (and other forms of representation, e.g. film) informs and influences the concept of disability. Their work forms, as I see it, part of a broader effort to continually and persistently de-naturalize disability as well as related words and concept. This book is a contribution to those efforts.

Analysing disability from a discourse perspective is a matter of continually redirecting one's attention (and the reader's) to context and usage, partly because usage-in-context has real political implications. In this regard, my view of what discourse is and why it is important differs from, for example, Shakespeare (2013: 2), who sees discourse studies and discourses analysis as focusing representations to such an extent that important political issues become obscured. But discourse analysis is, besides other things, a tool for explicating political issues and conflicts. An example: as I began to write this book, a controversy over rising building costs played out in the Norwegian media. Several major construction companies protested new regulations which mandate universal design in new private residence, arguing: a) that the prohibitive costs would have to be passed on to consumers; b) the regulations were being enforced because of the needs of a very small number of wheelchair users. While the technical and financial aspects of the debate are too complex to recount here, I will point out that the builders' arguments were predicated on a *narrow construal of "the disabled" as wheelchair users* – one related, in key ways, to the bathroom stall sign in Berkeley. This argument, which at the time of writing appears to have persuaded the right-wing Norwegian government, should be met with a number of political tools, including activism, litigation, and lobbyism – all of which operate through discourse.

"The disabled" tend to occupy the communicative position of third parties, even as they become scapegoats. They are an unpredictable quantity – an x-factor. The group of people to which the label refers can be construed as quite large (if they are to be represented as a threat to the economic wellbeing of the nation) or as quite small (if they are making demands). This is a matter of context, and circumstances, which inform language use.

My approach in this book draws mainly on a particular form of discourse analysis – Critical Discourse Analysis (CDA), but I will also refer to works that employ or advance what I think of as an ecumenical discourse-analytical perspective on disability. This includes works that explicitly approach the concept of discourse from other angles than my own, for example from the perspective of literary criticism, cultural studies and narrative analysis (Snyder & Mitchell, 2000), but also works that display similar methodology and analytical purpose to that of discourse analysis while not invoking the concept at all, e.g. Oliver (1990).

In the case of the former, my primary rationale is that "discourse" is loosely defined even in CDA literature, which is commonly described as an "approach" with a "toolbox" (Wodak & Meyer, 2009) rather than a narrow school of research. CDA and the related discourse-historical approach have many antecedents, ancestors and close cousins, both in the social sciences and in the humanities. They employ, *mutatis mutandi*, concepts from literary studies, sociology, and, not least, rhetoric, for good reason: What is essentially an interpretive scholarly effort, with a strong hermeneutical component, should not forgo the use of proven interpretive tools for the sake of a toolkit that is exclusively its own. Drawing on works from closely related scholarly traditions is a source of strength, so long as the aims and constraints of those traditions are kept in mind.

In the case of the latter, i.e. works that do not use the concept of "discourse" at all, Michael Oliver's analyses of the OPCS form sent out to disabled people serves the purposes I have already discussed. In the questions posed on that form, everyday problems are construed as stemming from impairments. In Oliver's rephrasing of the questions, the problems are reconfigured as stemming from the organization of society. The rephrasing draws attention to context and conventions of usage, showing that the location of "the problem" is a matter of how one represents the world, and what direction of argument one employs. This is an example of precisely what discourse analysis should do: Look closely at texts, and tease out the implications of how people, and the world, are represented in those texts.

A Note on Language and Culture

Like many Norwegians, I primarily talk, write and – to some extent – think in Norwegian and English. These two languages both belong to the Indo-European language family, both share a heritage from their common Germanic ancestor, and are spoken, if we restrict ourselves to Norway and England, in societies with many shared features that impact the lives of disabled people and perceptions of disability. These features include a strong and relatively centralized state, a tradition of government-financed health care and welfare services, and a strong civil society of non-governmental organizations representing various segments of the population.

Even in the comparison between these two (fairly) closely related countries, however, significant differences emerge almost immediately. The organization and financing of various governmental and non-governmental operations notwithstanding, differences between the two areas of linguistic practice are evident on the level of classification and conceptualization. In English, the words "disability" and "impairment" are commonly used to refer to a social phenomenon and a biophysical phenomenon respectively. In Norwegian, that distinction used to be less clear, in that the commonly used word for both phenomena was *funksjonshemning*.

To an extent, this reflects the modelling of disability that will be discussed further in Chapter 2. The conceptual distinction between bodily impairment and socially imposed disability is absolutely central to the classical version of the British social model of disability, while the Norwegian "gap" model requires primarily a notion of disablement produced in the interaction between individuals and structures.

However, neither languages nor societies are static. Over the last decade and a half, Norway has adopted more of a rights-based, social model-influence approach to disability, and with it has come the Norwegian equivalent of the impairment/disability distinction: to *funksjonshemning* has been added *funksjonsnedsettelse.* The literal meaning of *funksjonshemning* is "function-hindrance", while *funksjonsnedsettelse* means "function-lowering". In practice, the two Norwegian terms are often confused. "Disability" and "impairment" are of course used inaccurately or interchangeably in English too, but the two compound words in Norwegian add to the problem with their shared first component.

The ongoing changes in Norwegian disability-related language are, from a discourse analytic point of view, indicative of two mechanisms: the way in which social reality both produces and is produced by language (Fairclough, 1992, 2001 [1989]; Fairclough, Cortese, & Ardizzone, 2007). The introduction (first and foremost in governmental/departmental documents) of a distinct term for "impairment" coincides with an orientation towards a rights-based international discourse on disability, but it also overlaps with the slow growth of a Norwegian identity-based disability movement, and the partial success of independent living organizations which are very much invested in promoting disability-related language that focuses on citizenship and anti-discrimination. The social changes are expressed through and formulated in language which promotes and constrains certain aspects of those changes.

Ultimately, the new Norwegian set of words cannot mean exactly the same as the English words. They carry with them their national context of use and their etymology. Moreover, if we accept what has been a fundamental premise of systematic language study ever since the publication of Ferdinand de Saussure's *Cours de linguistique générale* nearly a century ago, namely that the meaning of a word is not contained within the word itself, but depends on its relationship with other words, then the entirety of the Norwegian and English language is potentially relevant for decoding their meaning.

I mention this in order to stress the difficulty of talking, writing, and thinking about "disability" in the abstract. Disability is a concept and a category, but it is also a *word*, and words have a tendency to take on more weight than they can support. "A disabled person" has no clearer referent than "A French person", but both phrases will tend to summon up, in the minds of readers, a referent of some sort. Is your "disabled person" the same as my "disabled person"? We won't know that until we've checked; if we can't check, the best we can do is provide an educated guess. It is not accidental that the World Health Organization calls some groups of disabled people "classic", meaning wheelchair users, hearing impaired people, and visually impaired people (WHO, 2011). Neither is it accidental that the next sentence in its *World Report on Disability* stresses the need *not* to restrict our mental images of disabled people only to the "classic" types.

Definitions of disability vary across the world. This book cannot, and will not attempt to, summarize or systematically examine them all. My examples of language use will be drawn primarily from Scandinavia, the UK, and the US, since these represent the societies, with corresponding languages, with which I am most familiar. Additional examples will be examples drawn from the rapidly growing part of Disability Studies that investigates other societies and languages. Throughout the book, however, I will try to keep in mind – and I will as the reader to try to keep in mind – that disability is not any *one* thing, neither in the world nor in texts. The multiple functions of language, and the ensuing multiplicity of meaning, demand this of us.

Origins of Discourse Analysis

I have already mentioned the problematic definitions of "discourse" and "discourse analysis"; now it is time to attempt a clear definition of both, as well as a brief sketch of their scholarly origins. Since this book is about one type – or rather, certain types – of discourse, the sketch is intended as background, and as a tool for contextualizing the approaches and attitudes to language that define the enterprise of discourse analysis.

First, I'll note that discourse analysis is a *scholarly field*, which emerged a few decades ago, through

> […] the launch of [Teun] van Dijk's journal *Discourse and Society* (1990) as well as through [the publication of] several books, like *Language and Power* by Norman Fairclough (1989), *Language, Power and Ideology* by Ruth Wodak (1989) or Teun van Dijk's first book on racism, *Prejudice in Discourse* (1990). (Wodak, 2001a: 4)

CDA is a field in the sense that it is defined by certain institutions, practices, power relations, and agents. It isn't legally restricted in the way that, say, the medical field is – if you want to practice discourse analysis or say you are a discourse analyst, nobody can prevent you from doing so. However, there are certain symbolic goods that are much more restricted, including university degrees and publication in peer-reviewed journals. Access to these goods, which are necessary in order to be a discourse analyst in good standing – a discourse analyst accepted as such by other discourse analysts – is only available once you have mastered certain conventions of the field and its practices, particularly an analytical vocabulary and accompanying methods of research. The analytical vocabulary and analytical practices, along with many other things, separate the field of discourse analysis from neighbouring fields, as well as providing a sense of commonality among those who do identify themselves as discourse analysts.

The same point, of course, applies to disability research. There are university courses, programmes, and journals in Disability Studies, and there are ways of writing and thinking about disability that are common to some people but not others. Disability is not by any means an exclusive topic of Disability Studies – it is also a topic of medicine and law, in addition to many other fields – and so it is important to keep in mind that fields are not the same as their topic, but represent certain kinds of interest in topics.

The field of discourse analysis is defined partly by an interest in power and power relations as they are produced and reproduced by language. There are many reasons for this. Discourse analysis has, at the very least, origins in *social theory*, the *history of ideas*, and *linguistic research*. I will discuss some of the ways in which these origins influence current practices of discourse analysis, and some of the reasons why they have made discourse analysis particularly apt for investigating phenomena such as disability.

Critical Theory

The "critical" part of "Critical Discourse Analysis" is linked to matters of social theory. It is usually traced back to the *critical linguistics* of the 1970s, more on which later, and sometimes further back, to the *critical theory* of the Frankfurt school of social research. In both cases, the meaning of "critical" ultimately depends on a Kantian notion of critique, i.e. methodical doubt (Kant, 2002 [1788]; 1998 [1781]; 2007 [1790]), but extending the practice of applying such doubt to the legitimacy of social power, relations, and institutions.

Critical theory, which was first adopted as a label by Max Horkheimer (2002 [1937]), questions the capacity of the sciences and scientific institutions to represent the world in a neutral or objective way, and by extension the legitimacy and objectivity of scientific knowledge. The explication of *ideology* is a precondition to new knowledge as well as social change, with ideology understood as the ideas, notions and systems of thought that may shape scientific and philosophical inquiry as well as social practice. All social agents, including researchers and other producers of knowledge, are susceptible to ideological beliefs, and it is the purpose of critical theory to expose those beliefs as such:

> Critical theory often takes the form of a critique of ideology (*Ideologiekritik*) that seeks to explain why social agents accept or consent to systems of collective representations that do not serve their objective interest but legitimate the existing power structure, and exposes the falsity of non-cognitive beliefs (such

> as value-judgments) that are presented as cognitive structures. *Ideologiekritik* is not merely a moralistic denunciation of false perceptions but a cognitive undertaking that seeks to analyse how and why they arise in specific situations or contexts. (Macey, 2000: 75)

Of course, "objective interest" cannot easily be determined; any reasonable proponent of critical theory should be prepared to apply its principles to his or her own beliefs and precepts. Notwithstanding this need for reflexivity, critical theory and disability theory have demonstrated mutual interests, for example in theorizing seminal concepts in late modernity such as normality (Davis, 1997b), personhood (Kristiansen, Vehmas, & Shakespeare, 2009), and citizenship (Pothier & Devlin, 2006). In his introduction to the fourth edition of Routledge's *The Disability Studies Reader*, Lennard Davis writes:

> To understand the disabled body, one must return to the concept of the norm, the normal body. So much of writing about disability has focused on the disabled person as the object of study, just as the study of race has focused on the person of color. But as with recent scholarship on race, which has turned its attention to whiteness and intersectionality, I would like to focus not so much on the construction of disability as on the construction of normalcy. […]
>
> A common assumption would be that some concept of the norm must have always existed. After all, people seem to have an inherent desire to compare themselves to others. But the idea of a norm is less a condition of human nature than it is a feature of a certain kind of society. (Davis, 2013b: 1)

While this book is about the construction of disability through discourse, I will try to heed Davis' precept by stressing that disability is never constructed without reference to something else – usually normality, or normality thinly disguised as "able-bodiedness". In either case, it has long been necessary for disability research to adopt a critical-theoretical approach to seemingly neutral or uncontroversial features of social thought and social organization: The very existence of the categories of "disability research" and, especially, "Disability Studies" indicates that there was something unsatisfactory in the way disability was explored from the standpoint of, primarily, medicine.

Critical theory and Critical Discourse Analysis treat knowledge as power, and assume that power is expressed through the organization, display and use of knowledge. This entails interdisciplinarity. Theodor Adorno, Max Horkheimer, and the Frankfurt School are sometimes described as working in sociology, sometimes in philosophy, sometimes in the study of culture; Adorno and Horkheimer's (1972 [1944]) seminal work *Dialectic of Enlightenment* has a reception history in all these disciplines, and beyond. The naming of fields is less important in this context than is the work carried out in them; as in the case of much social theory, it is crucial to remember what is going on in the society being theorized.

Foucauldian Discourse Analysis

The same observation applies to the work of Michel Foucault in the *history of ideas*, the second tradition crucial to understanding Critical Discourse Analysis. Foucault is a godfather to discourse analysis not only because he frequently uses the term "discourse", but because his studies of institutions, sciences, and categories provide exemplars of the connection between verbal and physical power, and the legitimation of the latter through the former.

Foucault's understanding of "discourse" sometimes approximates "speech" (in French, *discours*), as in "The Order of Discourse", originally given as a lecture to the Collège de France in 1970:

> Here is the hypothesis I would like to put forward tonight in order to fix the terrain – or perhaps the very provisional theatre – of the work I am doing: that in every society the production of discourse is at once controlled, selected, organised and redistributed by a certain number of procedures whose role is to ward off its powers and dangers, to gain mastery over its chance events, to evade its ponderous, formidable materiality. (Foucault, 1981: 52)

In this case, discourse is what is uttered, but discourse analysis is the study of what may and may not be uttered – of the order of discourse. This, the order (or orders) of discourse, is what discourse analysis should criticize; it is the primary subject of critique. What makes it possible, and sometimes obligatory, to say that someone is, or is not, disabled? Why is disability a category and a label with a "ponderous, formidable materiality"?

While Foucault did not address disability specifically, his thought has been increasingly applied to disability topics in recent years (Tremain, 2005). Much as with critical theory, the interests of discourse analysts, disability scholars, and Foucauldians coincide at crucial points. In particular, Foucault's studies of how "the production of discourse" was regulated in with regard to mental illness (Foucault, 1973b), medicine (Foucault, 1973a), and total institutions such as the modern prison (Foucault, 1977), have provided crucial points of departure for the investigation of how people who displayed various kinds of abnormal bodily features or behaviour became discourse subjects.

Foucault's studies often range across vast historical periods (leaving him open to criticism on grounds of detail and accuracy), and his notion of discourse includes language as one among several objects of study. His work, especially as it shifted from historical studies towards theory and the preconditions of knowledge production (Foucault, 1980a, 1980b, 1981, 2002), is not directly applicable to the study of the kind of discourse – texts and documents – that is at the centre of this book. The Foucauldian perspective, much like critical theory, provides background for the CDA enterprise.

By contrast, the third root in this minimal family tree of discourse analysis is a research tradition that focuses almost exclusively on language, studied in minute detail. That is not to say that it lacks social or philosophical ambitions, but those ambitions are directed at a more narrowly defined sort of data and material than either Foucauldian discourse analysis or critical theory.

Critical Linguistics

Critical linguistics is associated with the work of a group of scholars working at the University of East Anglia from the 1970s onwards, scholars who were interested in aspects of language that were not considered part of linguistics proper. While "much linguistic research elsewhere was focused on formal aspects of language [...] which could theoretically be isolated from specific instances of language use" (Wodak, 2001a: 5), critical linguistics emphasized social relationships, power relationships, and the social-interactional features of language. Critical linguistics was explicitly aimed at uncovering the ideological aspects of those features of language that were ostensibly neutral, for example grammar and syntax, particularly in contexts where neutrality was also a feature of the genres from which analytical examples were drawn (Fowler, Kress, Hodge, & Trew, 1979).

The study of newspaper discourse, for instance, provided many examples of how the seemingly objective voice of journalism is in fact a product of a specific social and institutional setting (Fowler, 1991). That focus – on uncovering ideology in genres and communicative situations which were ostensibly non-ideological, has been adopted in Critical Discourse Analysis as well (Fairclough, 1995), and is one of the many reasons why critical linguistics and Critical Discourse Analysis are terms that were, for a long while, used interchangeably. The latter dominance of "discourse analysis" rather than "linguistics" signals, primarily, a shift in analytical interest from features of text to social situations and relations – increasingly taking the study of text as a means to an end, not as an end in itself.

I have discussed critical linguistics, Foucauldian studies of the history of ideas, and critical theory together because they share many salient features. This includes a suspicion of the notion that language can be neutral, a strong interest in the way that ideology shapes utterances and social arrangements. To this could be added their shared origins in the 20th century, which was, of course, a historical period that generated considerable interest in ideology and distrust in authority and asserted neutrality.

However, the features in question, which remain crucial to discourse analysis, also apply to a much older research tradition – namely, rhetoric. There is absolutely no chance of me providing a comprehensive history of a 2,500-year-old tradition of oratorical practice and inquiry into the nature of language in these pages; I will merely point out that for as long as the social and political functions of language have been acknowledged, beginning in the Greek city-states in the sixth century BCE, there have been systematic attempts to chart and investigate these functions. Discourse analysis draws on unprecedented analytical resources, including video and audio recording, access to vast databases of text and talk, and digital tools for organizing and coding data. It is remains closely related, at least in spirit, to a very old tradition of asking who is speaking, with what authority, and to what purpose.

The Toolbox: Discourse Analysis and its Concepts

Modern discourse analysts may align themselves more closely with the humanities or the social sciences, depending on their analytical goals, preferred methodologies, or, most significantly, preferred types of data/material. There are many examples of discourse analysis directed mostly at concepts or practices, and directions in which there are clear-cut affiliations to specific social science disciplines, e.g. political science (Chilton, 2004). While most closely aligned with sociological investigation, the form of discourse analysis adhered to in this book is nevertheless primarily directed at *texts*.

This does not means that concepts, people, institutions, practices, and a number of other things, are incidental to analysis. It simply means that texts come first, texts are in the foreground, and texts are where analytical attention will be focused. This is partly because texts are extensively *reproducible* in contexts such as an academic monograph. People, practices, and institutions cannot be reproduced in text, but must be described, rendered or in some other way represented, in order for them to be analysed. This puts them at a further analytical distance, and in turn makes the analyst's decision, priorities, and judgement more difficult for the reader to test and second-guess.

Since discourse analysis is an interpretive concern, and falls under the social sciences' notion of qualitative research, it is very important that the reader be put in a position to conduct such tests. Do the interpretations seem plausible or implausible? Do the examples appear the same to the reader as they do to the analyst? If not, why not? It should be possible to pose such questions throughout one's reading of a piece of discourse analysis, and to receive a satisfactory answer.

Text, Context and Documents

The concept of "text" is not intuitive. For the purposes of this book, I will follow Norman Fairclough (2001 [1989]: 20), who reserves the term for verbal or written language, i.e. what is spoken or said. This definition ultimately goes back to Michael Halliday, whose branch of language studies, *systemic-functional linguistics*, is an important influence on Critical Discourse Analysis by way of critical linguistics. A full and detailed genealogy of CDA is beyond the scope of this book, however; suffice it to say that Fairclough's definition aims at a distinction between text as *product* and discourse as *process*.

Text-as-product has certain key characteristics: It is composed of linguistic units, which must have something to do with each other. In classical linguistic terminology, the units must be *cohesive* (referring to each other) and *coherent* (referring to the same textual world). The linguistic emphasis means that primarily visual forms of representation aren't included – though films, posters, etc. may be regarded as texts, this will not be the case here.

One reason for this is that this book is largely about disability as a word and concept embedded in social, political, and institutional practice, and that access to these phenomena is most easily obtained through verbal, written texts, i.e. *documents*. A document is a text that comes with certain boundaries and borders already in place, making it easier, in certain ways, to analyse than other texts. Documents commonly have clearly defined beginnings and endings, as well as authors, and explicit purposes – and for those reasons, they usually have recognizable and somewhat predicable contexts, too.

Another reason is that the tools available for analysing documents, but also spoken (and subsequently transcribed) language, are much more precise than the tools available for analysing other kinds of texts. While something is lost in scope by excluding primarily visual texts, much more is gained by focusing on texts that can be described and analysed using the terms of grammar, rhetoric and argumentation theory. Linguistic texts, unlike visual texts, always have some form of *propositional content*, which makes them subjects of a kind of critique that can more easily be tested against the opinions of other people – other analysts and readers.

Both for documents and for other kinds of text, the notion of "context" can be expansively (and etymologically) defined as everything that comes "with" the text (hence *con*, from the Latin). A scrap of paper found on the street seemingly comes with no context; in practice, some form of context can usually be reconstructed, albeit tentatively and with great room for error. Does the scrap form part of a bus ticket, or is it notepaper? If it is notepaper, does it have patterns, or a watermark of some sort? Is the text on it printed, or handwritten? With documents such as the ones that form the majority of data for this book, the questions become more specific and (on the surface) more answerable. Who wrote the text, and in what capacity? Does it have one or several addressees? Is it intended for particular purposes?

Although it is hard to sharply delineate context for many texts, it usually contains a great deal of data, which can be used to ground interpretation and analysis with regard to the texts' *production* and *consumption*. Those two processes point towards the conception of texts as *discourse objects*. While the propositional content of texts – their claims about the world – can theoretically be abstracted from their specific verbal incarnations, a discourse-analytic approach depends on examining any sort of claim or statement in context, and taking into consideration who is claiming what to whom, and in what medium. This makes discourse analysis distinct from many other branches of language study, for instance the philosophical analysis of argumentation (which may consider truth claims and logical consistency with less regard for the social aims and status of the people involved in argument).

Discourse Objects, Discourses, and Orders of Discourse

In practice, a "discourse object" is much the same as a text or document, in the sense that all three contain words, and are symbolic representations of aspects of the world. The key difference is that a discourse object has a temporal dimension; while a text or document may (though must not necessarily) be considered as an object that is unchanging over time, the discourse object changes as it interacts with people, as it is re-contextualized and interpreted under changing circumstances.

For instance, the actual text of the United Nations Convention on the Rights of People with Disabilities remains unchanged since the convention was initially adopted in 2007. But as the convention is signed and ratified by an increasing number of states, its context changes radically, and so does its status as a discourse object. It becomes interpreted by ever more social agents, and is intertwined with ever-greater numbers of national discourses of disability. These facts are not interesting to anyone solely concerned with, say, its arguments about the definition and understanding of disability as a concept, but they are very interesting to anyone who is concerned with changing understandings of disability across the globe.

Our definition of "discourse object" is, of course, deeply problematic. Once the temporal dimension is incorporated, it becomes even more difficult to delimit the context of any given text. Must we, in order to give a fair and accurate interpretation of a text-cum-discourse object, include in our analysis each and every text that refers to it? Must we include every person who has read it, and every institutional agent that influences its interpretation? Clearly this is impossible, but a reasonable compromise is to reaffirm a principle that underlies all good qualitative research and interpretative practice, but is particularly tied to the hermeneutical tradition: *be clear about your interpretive horizon!*

This means, in practice, that discourse analyses are only as good as their capacity to present and critically present their working assumptions and forms of background knowledge. It means that discourse analysts should clarify and openly discuss the kind of decisions they make about context – about the contextual information they include in their analyses, and about the contextual information they exclude.

Such clarifications are particularly important because they may serve to make clear the relationship between discourse objects and what may be termed *discourses*, arranged in *orders of discourse*. The latter term derives from Michel Foucault, in his discussions of the preconditions of producing discourse – the constraints that make it possible to say one thing and not another, and to have that thing be taken as acceptable and potentially true. One discourse – medical discourse, for instance, is interdependent upon other discourses (political, economic, institutional); "orders of discourse" addresses the totality of conditions of discourse production in a society.

In the case of disability, then, we may certainly speak of "disability discourse", which emerges from and in turn influences the myriad of discourse objects in which linguistic signifiers such as "disability" and "disabled people" occur. These discourse objects are benefit applications that are sent out, filled in, returned for processing and either approved or rejected; they are academic essays on disability in history and culture; they are signs informing disabled passengers which buses are accessible and which buses are inaccessible.

Disability discourse is also, however, intertwined with medical, political, economic, institutional, and cultural discourse – to name only a few. The orders of discourse that give meaning to an utterance such as “She is legitimately disabled” cannot be explicated in only a few words – they must at the very least entail an explanation of how “disability” is a category linked to certain (social, economic) privileges as well as forms of stigma.

This makes the study of disability discourse a complicated endeavour. It also makes it very interesting. The historical embedding of the concept of disability – in matters of medicine, political economy, eugenics, cultural anxiety, discrimination, and so on – serves to enrich disability discourse, and to make it a rich topic for discourse analysis.

Discourse and Argument: Claims, Warrants, Grounds

The final tools in the toolbox are somewhat external to discourse analysis; they derive primarily from *rhetoric* and *argumentation theory.* They are intended to identify some important structural features of discourse, namely the ways in which propositional content is arranged, and the way in which the viability of propositions depends upon presuppositions and implicit assumptions about the world.

To adopt such a focus on argument and the structures of argument is not the only way to approach the work of discourse analysis, but it is a sound strategy if one wishes to establish connections between areas of knowledge, and between concepts and the world. Moreover, disability is a topic that is constantly argued about – partly because disability is a matter of rights, resources and priorities, partly because it is a concept contested by many different groups. The exploration of disability discourse may lead off into a multitude of directions; maintaining a focus on argumentation can heighten the level of consistency in the discussion.

Moreover, since the kind of argumentation analysis adopted here is aimed at establishing links between concepts and background knowledge, between specific claims and general grounds, it is also a way of opening the textual elements of discourse objects up to analysis – a way of showing that there is usually more to texts than can be registered on a casual reading.

Critical Discourse Analysis can be said to employ a hermeneutics of suspicion. It has also been criticized for giving too little credit to the average reader, and too much credit to analytical skill. If something is not an obvious and directly accessible feature of a text, can it reasonably be assumed to have real impact? My answer is something of a compromise: close reading can draw out the ways in which issues are framed, connections postulated, and implications made.

The business of measuring discourse *impact* is a tricky one. Since “discourses” must be defined on a heuristic basis – there is no absolute or intersubjectively valid test of where a discourse begins and ends – there isn’t any way to isolate them as causal factors. And even if that were possible, there is no way to run a controlled experiment. Since we are all immersed in discourse from the moment we begin to understand symbolic communication, and from then on remain drenched in discourse each and every day of our lives, we cannot possibly claim that "discourse made me do it" about any specific act or attitude.

What we *can* do is to recognize lines of argument, and ways of framing issues, as they migrate across institutional boundaries, as they spread from politician to politician, and as they move from legislative initiatives into bureaucratic practice. We can note the incidence and widespread use of metaphors that liken immigrants to infectious diseases, the use of economic rationales in debates about health care, or the use of moral language in discussions of illness and disease. Subsequently, we can pose the question: *must* the issue be framed in this way? Is this the *only* line of argument possible? And from such questions arise the need for analytical concepts that isolate the arguments on which discourse is predicated.

The model of argumentation employed in this book is the model originally developed by Stephen Toulmin, and which can be enjoyed in full in his *The Uses of Argument* (Toulmin, 1958). It draws on classical logic and syllogistic reasoning, but rearranges its elements so that they match practical argumentation more closely. Elements of it have since become particularly central to the discourse-historical approach of Ruth Wodak, and demonstrate the shared aims and methods of much scholarly research directed at the social use of language.

The basic elements of Toulmin's model are the *claim*, the *grounds*, and the *warrant.* Claims are articulated explicitly or can be inferred implicitly. In order to become plausible, i.e. to function as tools of argumentation, they must be supported on various grounds, which are in turn acceptable as *grounds* to the reader/recipient.

This last point is crucial, because the connection between grounds and claims also has to be established, either implicitly or explicitly. Mere information isn't automatically a part of an argument, but has to be taken as such. In practice, this means that lines of reasoning and argumentation hinge on what Toulmin calls *warrants*, which establish the connection between (generally accepted) information and (more contested) claims.

Warrants may take the form of logical conditionals, i.e. statements of the if-then variety. "If disability has something to do with both individual bodies and social arrangements, then it must, at least in part, be a socially constructed phenomenon" is a possible warrant which connects multiple grounds (research on bodily impairment and social disablement) with an overarching claim about the nature of disability (it is socially constructed).

This sort of argumentation theory differs from classical analyses in that it privileges claims, trying to trace the way in which claims are grounded or anchored. Classical logic and even rhetoric employed a wider focus, which encompassed the full syllogism or *enthymeme*, i.e. a complete argument – which is, in practice, rarely presented in full.

Topoi

A further link to classical rhetoric can be established by way of the concept of the *topos* (pl. *topoi*), however. Although Aristotle is the commonly cited originator of that concept, he used and described it in such a way as to suggest that it was already a basic oratorical tool, familiar to most rhetorical practitioners.

With its two-and-a-half-millennia history, the topos inevitably has many definitions. However, two main directions have proved useful to discourse analysis, and it is the definitions that point in these directions that will be employed in this book. First, there are *specific topoi*, usually identified with the *loci communes* of Latin rhetoric, and pointing towards the everyday notion of the “commonplace”.

In this definition, topoi are “locations” in which arguments can be found – not new or unexpected arguments, but familiar arguments that are generally relevant to the topic at hand. Commonplaces such as “since they are among society’s most vulnerable members, disabled people deserve our protection” can, in theory, be inserted into almost any form of political discourse dealing with disability issues – and, notably does not entail any particular political stance or line of argument. The “vulnerability” topos can equally well be used as a basis for arguing for privatization of public services, or for nationalization of private services – it’s simply a highly acceptable commonplace in discussions about disability.

In the other definition, topoi are *argumentation schemes*, more closely related to Stephen Toulmin’s warrants. Here, they provide slots where facts and claims can be inserted. Aristotle identified 28 such schemes, with forms such as bigger/smaller and cause/effect.

The point of introducing the topos as a part of discourse analysis is that it provides a crucial link between argumentation, themes, and framing. In practice, topoi as argumentation schemes and topoi as commonplaces tend to blend together. Much of discourse – on disability as on many other topics – consists of textual elements that have originated elsewhere, and is simply adapted for new rhetorical purposes. Quotes and press releases are incorporated into newspaper articles, text from white papers is transformed into law, elements of legal documents are adapted for use in guidelines, and so on.

Topoi are ways of mapping the structures of discourse, and of identifying intertextual and inter-discourse) connections. They are different from the strict part-of-argument definition of “warrant”; topoi don’t always support *claims* directly, so much as they support worldviews. This perspective derives from the topos’ etymological origin: as the Greek for “place”. Disability, being a concept relevant to almost all aspects of society, appears in many places.

Summary

There is no way to do justice to the tradition of Critical Discourse Analysis in a single chapter; this has merely been an attempt to introduce a few crucial analytical tools, and to explain a little about where they come from.

In sum, Critical Discourse Analysis is about the way in which language use shapes the world, and vice versa. It is an attempt to tease out power relations, power use, and power abuse from the source material of text. These stated aims mean that Critical Discourse Analysis has traditionally been very concerned with ethnicity, race, gender, sexuality and, in principle, every social category that is defined partly by uneven or asymmetrical power relations.

In practice, disability has been under-explored from a discourse analysis perspective. But there is a high degree of fit between the kind of analysis of language, representations, and the social world carried out by disability scholars, and the kind of research aims endorsed by critical discourse analysts. The point of this chapter has been to lay out a minimal toolkit as understood by the latter; the point of the next chapter is to use that toolkit to understand the scholarly world of the former.

Phrased differently, I am going to present some of the key elements of Disability Studies *from a discourse analysis perspective* in the next chapter. Partly, this is a strategy for introducing these elements to readers who aren't very familiar with them. Partly, it is a strategy for conveying to more experienced readers what perspective I intend to approach disability issues from.

The discourse perspective entails, as I hope I have made clear, an emphasis on textual structures, on argumentation, and on thematic focus. It in no way ignores the social world, but attempts to use texts as a perspective on that world. George Orwell famously wrote that language ought to be a pane of glass. This was an argument in favour of clarity in writing, and a good one. But on close reading, the metaphor reveals some interesting subtleties. Glass, while transparent, is never *perfectly* transparent. It usually has imperfections, and may be covered in dust and grime that is only visible in strong light. We sometimes treat glass as though it were invisible, while in fact it subtly affects our perception all the while.

That is the central notion of discourse analysis – tools of communication, perception, and cognition are not neutral – and it applies equally well to scholarly traditions such as Disability Studies. Discourse analysis does not, of course, have the final say on what other scholarly traditions get right and wrong, but under the right circumstances, it can provide an outside perspective – a sort of meta-language – for talking about certain claims, warrants, and perspectives. That is the topic of the next chapter.

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Chapter 2

Models, Theories, and Perspectives: A Discourse Approach to Disability and Disability Studies

Discourse analysis explores the social and political role played by language in use; that use occurs to a great extent within the context of *institutions* and *social fields*, i.e. a system of positions that can be inhabited by various agents. The production of discourse may involve the expression of subjective opinion and exhibit idiosyncratic features, but it is also a game played according to certain rules. This dynamic entails a complex and unresolved state of affairs as regards definitions of disability, as was recently pointed out by Simo Vehmas and Tom Shakespeare:

> Debates about the definition of disability have continued for decades: within the World Health Organization, within social science research, and particularly within the disability movement. The difficulty in achieving consensus can be explained partly by the complexity of the phenomenon. Disability is a multifactorial, scalar concept. Wittgenstein's discussion of family resemblances seems relevant to the wide range of manifestations of impairment and embodiment that are aggregated under the single heading of disability. (Vehmas & Shakespeare, 2014: 45)

The complexity exists not only on the level of institutions, but also on the level of individual texts. For instance, the production of a discourse object such as the book you are currently reading – an academic text on disability – involves a number of different agents and social positions, interaction over a considerable length of time, and rules of discourse production that have to do with everything from English grammar in general, and the conventions of Academic English in particular, to the institutional conventions, formal and informal, of academic publishing.

A thorough summary of this process of production would easily fill books by itself, as evidenced by the proliferation of research into the production of knowledge. But a single part of the process can be briefly discussed: at some point, a text which is intended to be a part of academic disability discourse will need to be certified in some way. In the case of book publishing, it will have to be checked by one or several editors as well as peer reviewers, who are, among other things, responsible for checking that the text

1. addresses topics that either fall within the purview of academic disability discourse or can reasonably be said to belong to it;

2. addresses them in a manner in keeping with academic standards of argumentation and citation; and
3. is itself addressed to a community of scholars and students of academic disability discourse.

In other words, this book cannot be about alligators, written in the form of recipes, or addressed to a community of deep-sea divers, without forfeiting its claim to be a part of academic disability discourse.

What exactly defines "academic disability discourse" is a little bit trickier to articulate; even the editors and peer reviewers who decide what it does and does not encompass may have a hard time coming up with an exact definition (certainly one that would be acceptable to all of their peers and colleagues). It is definitely the case, however, that academic disability discourse exists, and that it is more prevalent at the time of writing than at any previous time in history. Disability Studies is an academic field, with journals, study programmes at all levels of education, conferences, research networks, and multiple, relatively well-defined objects of study.

I mention this because a book which applies Critical Discourse Analysis to disability is necessarily both part of and a response to academic disability discourse. This chapter is about conceptions and models of disability that are primarily grounded in academe (though also in law, medicine, politics, and organizational life), conceptions and models that simultaneously try to reflect and to influence what disability is in the world. "Disability discourse" in the very general sense of "all discourse that is somehow related to disability" is too amorphous to be useful – we need more strictly defined concepts (and models). And yet, every definition comes with its own imperfections and brings its own problems. Critical Discourse Analysis does not promise to solve these problems, but it can, through emphasis on context and usage, make them more comprehensible and manageable.

Disability Studies is not a homogeneous field. There are many different schools within the field, several rival theories and models of disability, as well as people working in the field that have a background in and connections to many other academic specialties. Traditionally, the study of disability is strongly influenced by medicine and the other health and health-related sciences and professions, not least the study of rehabilitation. In countries with a moderate or strong welfare state, moreover, it is profoundly influenced by disciplines that inform the work of welfare bureaucracies, including sociology and social work. Some countries have developed rich traditions of Disability Studies linked to cultural and literary studies, whereas others have not.

All of this must at least in part influence a discourse approach to disability, because academic and disciplinary traditions are important engines of discourse production. This chapter will not be able to explore any of the traditions in depth, but it will set out some ways in which different traditions have conceptualized disability as a *different kind of problem*.

Such an approach is not obligatory, nor is it the only productive approach. I've adopted it for two main reasons. First, it illustrates the point that differences in the way different people write and talk about disability has much to do with established interests both in terms of proximate and ultimate goals. A medical doctor has, by reason of his or her profession, a very different set of tools for addressing disability than does a sociologist, which differs again from the tools and language of a disability activist. This doesn't always mean that their interests are opposed, although this *may* be the case in practice. Second, the problem-focused approach allows for a reflexive perspective on the enterprise of Disability Studies, a perspective that is increasingly coming to prominence as the discipline matures. Multiple articles and books published during the last ten or so years have argued that such a perspective is needed in order to avoid field-specific and field-internal debates that have grown increasingly sterile and technical.

Disability is a socially, politically and theoretically complex topic, and any topic that is sufficiently complex in these regards risks discussions that focus on the precision and efficacy of models and terminology. A short and relatively benign example is the discussion about so-called "people-first" terminology in English, i.e. whether it is better to talk and write about "disabled people" or "people with disabilities". That choice may appear trivial to outsiders, whereas people with extensive experience and investment in the disability field may ascribe considerable importance to the choice between labels. The problem-focused discourse approach is unlikely to resolve any debates, but it may serve to point out that such choices are not necessarily based on substantive differences of opinion. Those who prefer "people with disabilities" and those who prefer "disabled people" may agree wholeheartedly that disability is a complex phenomenon which inevitably involve both people's bodies and the societies in which they live, just as there exist doctors and activists who agree about the ultimate goals of, say, rehabilitation processes. Language use is equally capable of obscuring both divergent and convergent interests; this duality is one of the strongest arguments for engaging in discourse analysis in the first place.

Why Theorize Disability?

There are many long answers to this question; most of them tend to be book-length. There is a short answer too; it is "because disability is always-already a theoretically informed concept". One of the signal achievements of Disability Studies has been to show that even ostensibly pre-theoretical examples of usage, for example those in which "a disability" is used simply to mean "any permanent injury or chronic illness" can swiftly be shown to depend on certain assumptions about the social roles of people with some kinds of injuries and illnesses, which in turn depend on certain assumptions about how the world and societies work.

The word "disability", like any word, can be used without theory. But unlike many other words, it cannot be used without denoting a kind of phenomenon or entity that is explicable without theoretical input. This, of course, creates a conundrum when people who do have a theory of disability talk to people who do not have a theory of disability – particularly when they try to convince them that they *should* have a theory of disability. Not having a theory of disability can even be an advantage – as long as one is not oneself disabled, or closely affiliated with someone who is disabled.

There are many other cases where the everyday usage of words does not harmonize with specialist or technical definitions of the same words, and it is common for specialists to accept that their strict definitions will never move into everyday language. But in the case of disability, there is a particularly problematic phenomenon at work, in that the technical definitions are oriented more toward complex relations than toward simple(r) properties.

The everyday usage in which "disability" is an injury, illness or impairment depends upon signifiers linked to individuals, for example hearing aids, canes, and wheelchairs. Relational aspects of disability usually do not. They have to be theorized in order to be made explicable, and this process is time-consuming and arduous. It is nevertheless necessary, because, well, disability is always-already a theoretically informed concept.

The many not-easily-visualized aspects of disability share a common feature: complex features of society such as the organization of the economy, education, health care, and welfare services, are not pre-theoretical even in everyday discourse. There are folk theories of social relationships. There are folk theories of the *causes* of impairment, both physically and, more significantly, morally, but properties of individual people can more easily be treated as naturally occurring phenomena. As soon as disability begins to be defined as a relation, it enters the realm of theory.

This means, in one interpretation, that Disability Studies is a concerted attempt to steer definitions of disability away from the realm of naturally occurring properties, and towards the realm of socially constructed relations. There are many reasons for doing so. Near or at the top of the list is social justice: people with impairments are historically and globally disadvantaged, and most arguments for the relational status of disability are also explanations for how such disadvantage comes about – and may form part of arguments for how to eliminate such disadvantage.

There are many other reasons, however. Exploring disability as a relation can be undertaken from a medical perspective, in order to better understand chronic illnesses or impairments. Such explorations can be undertaken by people interested in racism, sexism, or other mechanisms of discrimination and oppression, not for the sake of ultimate interest in disability, but because disability is a factor which often comes into play in the context of such mechanisms.

Theories of disability tend to be grounded, then, in fields of inquiry. They have genealogies, which involve people, institutions, forms of knowledge, and purposes of theorization. Over time, of course, social theories interact, change, and evolve. Since they must be put into words, and since even authors that are much in agreement tend to use different formulations of similar principles, both subtle and dramatic differences constantly arise. It is rare to find an author who will defend exactly the same theoretical principles he or she espoused ten years previously, or would not, at the very least, revise those principles in order to account for more recent criticism.

For this reason, it is perhaps inadvisable to do what I am about to do, which is to summarize some notable directions in disability theory. Nevertheless it is necessary, in order to establish a baseline for examining and analysing discourse. My initial assumption is that disability theory qualifies as such by *hypothesizing about what disability is and how it is produced*. This should not be a very controversial assumption (although you never know), but it is too inclusive for many practical purposes. It is possible to articulate a theory of disability which restricts itself only to individual bodies and their physiology, although such a theory would be alien to almost everyone who has any experience with disability and disabled people. My second assumption is that disability theory, as relevant to Disability Studies, *hypothesizes about what disability is and how it is produced, in social, cultural, and historical context*. The list of adjectives at the end of the last sentence could be extended for quite a while – certainly by including politics and economics – so I am defining "context" in an open-ended way here.

With these assumptions in mind, I am going to adopt an inclusive stance towards the current landscape of disability theory. This is, I think, a necessary strategy. The 2013 edition of Lennard Davis' *The Disability Studies Reader* includes sections with the following titles: historical perspectives, the politics of disability, stigma and illness, theorizing disability, identities and intersectionalities, disability and culture, and fiction, memoir, and poetry. Although theory ostensibly has its own section, many if not most of the book's chapters draw on and contribute to the theorization of disability. There is no single theory of disability, nor is there likely to be one.

This need not be a cause for concern. As is often pointed out (in academic discourse), the word "theory" is etymologically rooted in the Ancient Greek word for "seeing", for making something visible. A theory of disability is valuable insofar as it makes disability better understood, more clearly seen. This criterion can be met in pluralist fashion. A theory of disability is satisfactory to the extent to which it makes at least one previously-unseen aspect or relationship visible.

Disability Theory and the Internationalization of Disability Studies

I am a Norwegian author, writing for an Anglophone audience about which I can make a limited number of assumptions. My background in Disability Studies is largely shaped by the Scandinavian, British, and American approaches to disability. Those approaches do not share a common theoretical foundation or even a homogenous disciplinary basis: disability researchers in Norway as well as in the UK or the United States may be trained in literature, sociology, political science, or anthropology.

Still, though disability research does not float free of geographical concerns or geographical influences, it is a highly internationalized discipline. Like many small academic fields it depends, for innovation and intellectual growth, on extensive contact across national borders: there simply aren't enough disability researchers in any single country. As a Norwegian researcher, I have been strongly influenced by the two Anglophone traditions. Literature from the UK and the US is often referenced in Norwegian work, Norwegian researchers often publish both in Norwegian and in English. Moreover, ideas from both the governmental and non-governmental spheres in the Anglophone world travel to Scandinavia, and so it becomes pertinent to use analytical tools from that world in order to understand their impact in new environments.

This dynamic makes it difficult to draw sharp lines between schools of Disability Studies on the basis of linguistic, cultural, or national divides. The following discussion of different schools as well as models is, of necessity, based on generalizations and constructs. But this isn't wholly problematic, because constructs and generalizations can be causal agents in their own right. They just need to be accepted as *sufficiently real* by a *sufficient number of people*. If there exists a notion of substantive differences between different schools of Disability Studies, then those differences *are* real, for most intents and purposes.

This is the perspective from which I will make a claim about the discourse of disability in the US, UK, and Scandinavian fields, respectively. I will make the claim, which has quite a bit to do with Disability Studies in general, and with disability theory in particular, first in categorical form, so that it can form a basis for a more nuanced discussion:

US Disability Studies conceptualizes disabled people as an ethnic-cultural minority, UK Disability Studies conceptualizes disabled people as an oppressed class, and Scandinavian Disability Studies conceptualizes disabled people as the beneficiaries of welfare state programmes and interventions.

Now, the above claim is simplistic, but it is not entirely misleading. Practitioners of Disability Studies in the three countries/regions tend have different baseline assumptions about the role of disabled people in society, because they live, work, and interact with different kinds of societies. They tend to make different assumptions about how disability is produced, partly because the mechanisms of production are different – sometimes subtly, sometimes drastically.

At the same time, all three positions have some essential assumptions in common, in that they treat disabled people as a group that is partly constructed and produced by external pressures. That is part of what allows there to be an idea of Disability Studies across national boundaries. The marginalization of ethnic-cultural groups may have some of the same results as the oppression of a social class, even if the mechanisms are understood differently, and proposed remedies will differ accordingly.

To the extent that the three-part claim is true, it reflects both different views of society and different research traditions. The people who concern themselves with how to make welfare services more effective are sometimes in contact with the people who try to end social oppression, but they are usually *different* people;

neither are they the same people who try to understand the dynamics of ethnic-cultural group interaction. They think, write, and speak in different kinds of language; this means that they interact with and are parts of different discourses.

This, at least, is a hypothesis aimed at understanding why different strands of Disability Studies run in very different directions – and at understanding why Disability Studies in North America can seem quite different from Disability Studies in Europe. It is a commonplace among Scandinavian academics that the distance between university circles and policy circles is much smaller at home than in the US. Even if the commonplace is sometimes misleading, it will likely shape the kind of analyses deployed and the kind of language used by Scandinavian academics, if they perceive themselves as more likely to be listened to in political contexts. Discourse analysis assumes that texts, both in everyday and technical and specialized situations, are profoundly influenced by the notion that authors have of their potential or implied readership.

So, *how* true is the claim that there are (at least) three different strands of Disability Studies, each with its own conception of disabled people? Disability Studies even in one country, for example the UK, is many things. It has certainly been strongly influenced by a socio-materialist conception of disability, one that is most strongly associated with the work of Mike Oliver, Colin Barnes (Oliver, 1990; Oliver & Barnes, 2012), Paul Hunt (1966), Vic Finkelstein (1988, 2001), and with the UPIAS manifesto (UPIAS, 1976). This conception is suffused with historical-materialist analyses, and even though the books and articles that explicitly adopt a "social model" explanation of disability and define it in such terms have since been criticized (e.g. Shakespeare, 2006a; Thomas, 1999), there is considerable scholarly inertia at work. As in most of the humanities and social sciences, it is hard to effectuate a true paradigm shift: disciplines add topics and themes to their roster more frequently than they eliminate them. The early focus in British Disability Studies on economics, class, and oppression still provides a list of topoi to which researchers can consent or with which they can disagree, but which still serve as part of the tacit knowledge of their readership.

The same discourse-historical argument applies to Disability Studies in the US and Scandinavia. Foundational texts in the American field, even texts with a clear sociological orientation such as Irving K. Zola's *Missing Pieces* (Zola, 1982) tend to place greater emphasis on mechanisms of identification. The premier American journal, *Disability Studies Quarterly* (*DSQ*), stresses its cultural orientation by accepting not only academic articles but also cultural commentary, creative works, eulogies, tributes, and reviews not only of books but of films. By contrast, a Scandinavian Disability Studies journal such as the *Scandinavian Journal of Disability Research* publishes many articles by researchers in special education and the health sciences. The production of disability discourse occurs in a dynamic relationship with the constraints provided by publishing outlets; journals' and publishers' criteria change as new works are published, but such change is usually gradual, not least because of the conventions of academic argument and obligations to cite previous work.

A seminal work, even if it eventually becomes chiefly a target of criticism, may continue to generate citations, thus maintaining a central or canonical position. One such example is Erving Goffman's book *Stigma* (1963), which continues to be cited for its insights into the social-interactional reproduction of alterity and, yes, stigma, even as it is criticized for being overly focused on the individual, uninterested in the role of social structures, and insufficiently political (Abrams (2014) provides a recent discussion of these critiques of Goffman as they relate to North American Disability Studies).

The three-part claim was included here first and foremost, however, because it provides an example of how disability *can* be viewed from three complementary, mostly separate perspectives. All three perspectives try to explain marginalization, and, in doing so, finding remedies for marginalization. They are rooted in academic disciplines that have at least some orientation towards social issues, even if US Disability Studies is more strongly oriented towards the humanities, and UK/Scandinavian Disability Studies is more rooted in the social sciences and in some cases health and education.

This isn't, then, going to be an extensive discussion of who belongs to what school of Disability Studies, and which model of disability is dominant in which country or region. It is going to be a discussion of different discourses of disability, and how they shape perceptions of their central phenomenon. It is also a reminder that theorized concepts of disability have proved to be immensely rich tools for exploring society and culture. This does not mean that there is a consensus about what disability theory is *for.* It means that they have many actual and potential purposes.

Researchers or Activists? A Note on the Purposes of Theories and Models

There is a perpetually fraught relationship between the roles of disability researcher and disability activist, occasionally capable of creating considerable tension within the same person. A lot of the disagreement is linked to the choice of which "model" of disability to adopt, i.e. over which explanation provides the most credible account of how disability is produced, and the best hope for eliminating mechanisms of disablement. The British social model, in particular, has been presented variously as a tool for political analysis and activism, and as a theoretical instrument for explaining disability as a product of complex social mechanisms.

In some cases, these dual roles strengthen each other. Activists and researchers can collaborate on, for example, investigations into the lives and perceptions of disabled people. Participatory research has, under the slogan "nothing about us without us", been a key component of much of Disability Studies.

In other cases, however, the roles of activists and researchers are at odds. As political tools and tools for activism, models of disability tend to be presented and framed in language which doesn't allow for the nuances of academic investigation.

In research, most models, including the British social model, must be heavily adapted in order to be applied across different topics and themes.

This is one of the reasons why models, and theories, should be distinguished from discourse. Models of disability, taken as schematic, explanatory tools, are parts of discourse, are elaborated in discourse, and are usually embedded in discourse. Theories, too, draw on discourse in order to produce meaning, while discourse is usually too complex and too variable to be reducible to either theories or models.

To conceive of disabled people as a minority, a class, or special category of citizen is to assume a theoretical position. To conceive of disability as a form of oppression perpetrated upon people with impairments, thus creating a class of disabled people, is to construct a model of disability. Discourses of disability are produced (and consumed) in specific contexts, and can be influenced by models and theoretical positions to varying extent – they may or may not consistently employ or be guided by them.

All told, this is a reminder that theories *and* models of disability should be discussed and employed with a notion of purpose clearly in mind – a reminder which also applies to the usage of different kinds of disability discourse. Medical discourse on disability, for instance, may be viewed as instrumentally useful or politically reactionary depending on whether one's purpose is physiological description or social critique.

"Foundational Truths": Four Models of Disability

The title of this section is borrowed from Lennard Davis' preface to the second edition of *The Disability Studies Reader*, published at a time of theoretical consolidation for Disability Studies. Davis, in summing up the previous ten years, proposed a second wave of scholarship:

> In this era, the foundational 'truths' come under new scrutiny. A second-wave of scholars, many of them younger, is coming into the field with the safety and security of having a field to enter, having an identity to discuss, and having a body of knowledge with which to deal. But there will always be contradictions and disparities in any field of investigation. The second-wavers will ask questions and make new assertions about the 'truths' of the field. We can see this questioning already occurring in the areas of identity formation, the differences (rather than the similarities) between impairments, the seeming incompatibility between models (notably those of the United Kingdom and the United States), questions about the relation of theory to praxis, and the role of the intellectual vis à vis the activist. (Davis, 2006: xiii)

The foundational "truths" in question are very similar to the claims I made a few pages ago: *US Disability Studies conceptualizes disabled people as an ethnic-cultural minority, UK Disability Studies conceptualizes disabled people as an* *oppressed class, and Scandinavian Disability Studies conceptualizes disabled people as the beneficiaries of welfare state programmes and interventions*. So what does it mean to put them under new scrutiny? Not to abandon them entirely, but to examine them for fitness of purpose. This means paying particular attention to "seeming incompatibilities", not in order to point out inconsistencies in prevailing theories, but in order to point out ways in which differences in discourse and usage sometimes obscures unity of purpose. Critical Discourse Analysis has a *productive* notion of critique.

This notion entails a need for highly contextualized approach to models of disability as well as an ecumenical approach to disability theory. The point of models, from a discourse-analytical point of view, is to develop tools that have explanatory power in one social domain or other, i.e. to explain how a phenomenon is signified. This point of view means that any approach to models of disability or disablement should be particularly attentive to the scope, range, and applicability of such models, and makes it a likely conclusion that at least some of their "seeming incompatibility" derives from the notion of *universal validity.* Universally valid models can only be successful at the expense of potential rivals, whereas locally relevant models can be integrated in various ways. The impulse towards developing a single model, derived from a grand unified theory of disability, may well be corrosive past the point of utility.

The fact that there is no single dominant theory of disability, but an array of different approaches, grounded in, to name a few examples, literary analysis, sociology, anthropology and Marxist political economy, may be ascribed to the emergence of Disability Studies in different countries at different times. As academia grows ever more transnational (and Anglophone), this fact becomes less of an observation about traditions, and more of a complaint about hindrances to cooperation and dialogue.

In Norway, there is a long tradition of research on disability, which has been deeply grounded in the needs and priorities of the welfare state, and relatively independent of, for example, developments in the United States (though less so of British research). In later years, however, the Anglo-American disability rights movement has gained greater currency in Norway, complete with pride marches, Independent Living initiatives, and, as of 2009, an anti-discrimination law that refers directly to, among other texts, the Americans with Disabilities Act. This history is reflected in the Norwegian notion of what a model of disability should be and what it should be capable of doing. The dominant paradigm, the relational or "gap" model in which disability is theorized as a gap between the capabilities of the individual and the demands of society, is fit for certain purposes, the most important of which is to identify areas of adaptive improvement. The gap model's notion that "disablement" can effectively be eliminated through the simultaneous adjustment of individual capacities and social demands is an ideological position that requires a large degree of mutual interest between individual and state.

Although anti-discrimination measures apply in some areas and fields, the simultaneous provision of various state benefits directed towards the individual (direct payments, medical supplies, rehabilitation efforts, etc.) *and* efforts toward social change on a general scale (universally accessible transportation, equal access to education, non-discriminatory hiring practices, etc.) has, historically, been legitimized less as legal protection for a particular minority and more as a state strategy for securing the inclusion and full social participation of citizens. It is a strategy which is not particularly amenable to strong anti-discrimination measures directed at universal access, but much more amenable to specially developed solutions for various groups of disabled people. So long as there is a strong focus on the shared purpose of individual-directed and state-directed interventions, both types of action remain good alternatives.

This means that Norwegian research on disability, to the extent that it accepts and works from the gap model, speaks a language that is different from US Disability Studies. And this discrepancy is matched by a discrepancy in the kinds of topics and themes that are studied. For one example, disability culture and art are comparatively ignored. Whether this lacuna is due to the structure of the gap model, or whether the gap model has assumed its current form due to the lack of research on art and culture is not wholly resolvable. I will, however, note that those who *do* attempt to study the topic with a basis in the gap model are faced with a quandary: the current Norwegian model is well-suited to describing Norwegian conditions with respect to the political, economic, and social spheres. The US minority model seems better-suited to cultural topics, but the two models are "seemingly incompatible". So where do researchers who are interested in social, political, economic, *and* cultural topics turn?

The following overview of four models of disability should be read with the above passages in mind. As with the claims about three different forms of conceptualization, I am presenting here a generalized, schematic view – in order to highlight the too-schematic, too-general aspect of models of disability as they are usually laid out. They *can* be thought of primarily as tools for specific purposes; oftentimes, they are presented as global ideological frameworks. It is the latter interpretation which results in grand incompatibilities.

The Social Model

The analysis of disability that is codified in the *British social model* remains strongly influenced by neo-Marxist sociology and the belief that political-economic forces and structures are paramount in shaping society. The model was pioneered by the Union of the Physically Impaired Against Segregation, and first articulated in the form of a manifesto entitled *Fundamental Principles of Disability* (UPIAS, 1976). It was subsequently developed in the context of academic sociology. Disability was interpreted as a form of economic and political oppression enacted on people whose bodies did not conform to the needs of industrial capitalism (Barnes, Mercer, & Shakespeare, 1999; Oliver, 1990, 1996b, 1996c).

This analysis has been expanded through historical studies that trace the parallel emergence of a strong boundary between work and home life and the increased institutionalization of physically and mentally impaired people (Gleeson, 1999b, 2001b), and work in human geography that documents the significance of the built environment in constructing spaces that effectively divide the population into disabled and non-disabled groups (Gleeson, 2001a; Imrie, 1996, 2001; Imrie & Kumar, 1998).

The British social model has proved particularly valuable in focusing attention on the systemic factors that shape the meaning of disability, particularly those that have to do with political economy, without necessarily targeting individual bodies. It has been considerably less successful in theorizing impairment as a bodily and embodied phenomenon. This has been acknowledged as a challenge by both the key proponents of the model (Oliver, 1996a) and those who have subjected it to criticism with the aim of extensive reform and revision (Shakespeare, 2013).

One of the founding – and recurring – problems with the social model is that it has been slow and reluctant to embrace the aspects of disability that are intrinsically embodied, because the discussion of these aspects have been viewed as politically counterproductive or devoid of interest in a Marxist theoretical framework. A frequently raised criticism of the model is that it has been constructed around an ideal disabled person, a male wheelchair user belonging to a dominant ethnic group, who suffers no significant health problems because of his impairment. Although this construct is problematic in and of itself – in particular the presumed absence of health problems – it may be equally significant that the British social model simply wasn't developed as a tool for dealing with embodiment. Mike Oliver acknowledged as much in *Understanding Disability,* more than 15 years ago (Oliver, 1996c).

The Minority Model

The *minority model*, which is more strongly identified with research done in the United States (Linton, 1998; Longmore, 1985), has also been referred to as a social model. This is no accident; on both sides of the Atlantic, disability activism and research drew on the intellectual currents of the times, and the role played by class consciousness and the labour movement in the United Kingdom is to some extent mirrored by the American civil rights movement and growing awareness of discrimination due to race and ethnicity. Social concerns were at the forefront in both cases, and I use the term "minority model" chiefly for clarity.

If the publication of the UPIAS manifesto in 1976 is sometimes presented as the *origo* of the disability movement in Britain, a similar American moment may, perhaps, be discerned in the occupation of Health, Education and Welfare offices in nine cities in 1977 (Longmore, 2003: 105–107). Significantly, this action was directed toward the expansion of civil rights to cover the needs of disabled people, and the demonstrators who occupied the San Francisco offices were aided by, among others, members of the Black Panther Party (Schweik, 2013).

In the decades that followed, the minority model of disability was applied through activism and lobbying that ultimately led to the Americans with Disabilities

Act in 1990, but it was also applied in academic studies that positioned disability as a form of complexly embodied identity that is not *a priori* positively or negatively charged (see Siebers, 2008, for a summary of this position). The influence of the minority model can also be felt in studies that position themselves more directly as anthropology, cultural history or literary criticism and explore disability as a motif or narrative device, albeit one with social and political ramifications (Kohrman, 2005; Petryna, 2002; Schweik, 2009; Snyder & Mitchell, 2000, 2006).

The minority model, in which disability is theorized partly as a form of cultural otherness, probably fits the case of Deaf people best. The capital D is intended to mark deafness as a cultural and linguistic identity, one which in the United States is strongly tied to Gallaudet University. In Scandinavia, research has been conducted on the way Deaf people wholly reject the disability label, seeking instead parallels with gay and lesbian communities (Breivik, 2007). A parallel development can be found among people and relatives of people with autism, who are currently advancing the concept of neurodiversity as a marker of cultural identity (Antonetta, 2005).

The minority model has been less successful in, and may not be as well suited for, explaining the continuing economic and political marginalization of disabled people, a phenomenon which (in the United States) has persisted and very possibly increased during the time since minority rights-based legislation was first introduced (Colker, 2005; Davis, 2002; Krieger, 2003).

It also seems to be the case that minority rights ideology is, in many countries, an option for what is effectively a small minority of people who might count as disabled. Although Disability Pride marches have become a regular feature of some communities, the movement is both less visible and less comprehensive than the, in some other respects comparable, gay rights movement. Although a discussion of the reasons for this lie beyond the scope of this chapter, it should probably be noted that a large proportion of the people who count as disabled in the context of most forms of legislation have either hidden impairments or chronic illnesses. The minority strategy seems to appeal more strongly to people who are either not in a position to “pass” as non-disabled in any case, or who consider their impairment to be a form of biological difference to be valued, not “fixed” or “healed”. For many disabled people, however, their impairment is something very undesirable indeed, not something to be put at the forefront of their social identity.

The Gap Model

The *gap model* does not take a position on this issue, but simply acknowledges that a proportion of the population will at any given time have either impairments or illnesses that place certain restraints on their functional capacities. Disability is explained as the gap between those capacities and the opportunities offered by society and its institutions; disability is therefore something that can and should be addressed by the full spectrum of policy tools, ranging from medical intervention, when appropriate, to anti-discrimination measures directed at employers, academic institutions, commercial entities, etc.

The gap model, which remains identified with policy and research in the Scandinavian countries (Tøssebro, 2004), can be linked to several institutional arrangements that, for example, allow for welfare benefits to be paid to people who are deemed medically incapable of working in order to secure a given standard of living (Stone, 1984). It is somewhat under-theorized; what actually constitutes a satisfactory closure of the gap is an open question. I mention the gap model here not primarily for its theoretical contributions, but because it is the model that seems the most aware of the importance of state bureaucracies in the social construction of disability, e.g. in recent Norwegian disability rights legislation (Barne- og likestillingsdepartementet, 2009). It is also a point of departure for discussing the fourth and possibly most problematic model.

The "Medical Model"

It is difficult to find any discussions of the *medical model* that are not critical or wholly dismissive of it; Shakespeare (2013) points out that the term may be used as a slur word, and has been used this way for some time (Kelly & Field, 1994). Some discussions primarily criticize medical terminology and medical power, while some accounts conceptualize the model as a cognitive prison one can be "stuck in" (Brisenden, 1986). In fact, it is an open question whether the medical model is a model as seen from within – by the people who might use it as a tool. It might instead be a projection, i.e. an externally construed distillation of some of the most negative aspects of the broader phenomenon of *medicalization* (Illich, 1976; Zola, 1972, 1977). The medical model is, in this capacity, the nemesis of advocates that employ all the three models discussed above. It is described as reducing every aspect of disability to bodily impairment, prescribing only medical treatment and normalization as appropriate interventions, and denying agency to disabled people while reserving power for medical professionals.

This description no doubt accurately reflects the inhumane treatment experienced by disabled people in hospitals, rehabilitation centres and other institutions over the course of the last few centuries. I question, however, the wisdom of continuing to refer to the procedures and practices of medicalization as a *model*, at least outside of historical studies, because the end result of this strategy may be to keep alive the illusion that it provides a theoretically viable perspective on disability. Nevertheless, the "medical model" as it pertains to disability has more than 20,000 hits on Google Scholar, and continues to be referenced as an explanatory system to which some people subscribe – although never, or hardly ever, the people who are discussing it.

The Rhetoric of Models

The above divisions do not constitute an accurate taxonomy of the disability field. Rather, the social model, minority model and gap model are something like theoretical poles by which various researchers and activists navigate, as well as principles that guide legislation and disability policy. The British social model, in particular, has become a political-ideological yardstick according by which actions and statements can be measured.

Unfortunately, none of the models can explain disability in a satisfactory way on their own. Among the main objections to each of the first three, somewhat overstated, is that: a) the social model does not properly acknowledge biophysical causation; b) the minority model does not account for economic and political causation; and c) the gap model assumes to an utopian extent that the gap between ability and expectation can always be closed – that there is no need for a distinct social role of disability. The medical model, of course, is usually articulated so as to be by definition invalid as an explanatory instrument.

One way of positioning the models is to apply the analytical tools of the *rhetorical situation*, a concept introduced by Lloyd Bitzer (1968). Briefly put, this form of analysis will treat the models as rhetorical responses to particular *exigencies* or communicative emergencies, under particular *constraints*, directed towards particular *audiences*. For instance, the gap model has been continually constrained by the framework of the Scandinavian welfare state, in which compensatory measures have been achieved as frequently through ordered, corporative negotiations between the state and various interests groups as through open conflict. The idea of securing individual rights that have to be enforced through the legal system is less familiar; this is mirrored by the gap model's non-adversarial conceptualization of the situation of disability. The state and the individual are assumed to share the same basic goal and to constitute an audience with shared interests.

The minority model, by way of contrast, is oriented towards a more select audience, and constrained by the historical facts of a more hostile and remote state. It is therefore, perhaps, unsurprising that it emphasizes the aspects of disability that are constitutive of a community that is built on shared experiences of exclusion and oppression, as well as on forms of cultural and artistic expression that have little or nothing to do with the state.

Notwithstanding their different contexts and rhetorical orientation, the models function to some extent as competing paradigms – e.g. as gatekeeping mechanisms for journals. They also exert considerable influence in the production of discourse in that they form the basis for consultative statements on legislation and policy, provide a framework for activism and cultural initiatives, etc. The question is the extent to which the models become restraints rather than tools, restraints both on action and thought.

Models and Topoi

Models can be represented in relation to particular goals with reference to the topos. This is because of the topos' dual status as an *analytical* category that describes the parts of argumentative discourse that link up with the *doxa* or background knowledge of the audience, and a site of *invention* that determines the type of discourse than can be produced on a given subject.

In the context of Disability Studies, I'm mainly interested in topoi that frame disability as a particular kind of epistemological object. A strong tendency in the development of theoretical models, even a necessary stage, is the rigorous definition of the object at the centre of the model. But particularly in the case of the British social model, a definition which "locates the causes of disability squarely within society and social organization"(Oliver, 1990: 11) is far less problematic in the context of political action than in the context of philosophical and scientific explanation.

Applying topical analysis, viz., looking at the way in which arguments are made about the purpose and application of Disability Studies, runs certain risks. The topos is remarkably resistant to simplifying or even unifying theorization. A historical overview (Gabrielsen, 2008) substitutes any one definition with "optics" through which the different "facets" of the topos can be viewed. Another researcher abandons the possibility for a unified theory of the topos:

> Topics sometimes referred to modes of inference, sometimes to aspects of the subject under consideration, sometimes to the attitudes of an audience, sometimes to types of issues, sometimes to the generic headings for rhetorical material, and sometimes to several of these alternatives. It was possible to sort out some of these strands and recognize them as coherent resources for an aspect of argumentation, but it was difficult to understand how any of them could provide a unified theory. (Leff, 2006: 206)

It is, however, precisely at the juncture between "modes of inference" and "aspects of the subject" that the topos proves its value as a way of looking at disability. When the British social model "locates the causes of disability squarely within society", it highlights both certain aspects of what it is to be disabled – e.g., being excluded from certain buildings, services, and social roles – and permits inferences about how this situation can be altered by means of social change (Oliver, 1996c; Oliver & Barnes, 2012). When the medical model operationalizes methodological individualism, an exclusive emphasis on the biophysical aspect of disability severely restricts the range of possible inferences. Hence Mike Oliver's rephrasing of a survey form, in which questions like "What complaint causes your difficulty in holding, gripping or turning things?" are replaced with questions like "What defects in the design of everyday equipment like jars, bottles and tins causes you difficulty in holding, gripping or turning them?" (Oliver, 1990: 7–8).

The key here is the *bridging* function of the topos, which is recognized by Ruth Wodak:

> […] 'topoi' or 'loci' can be described as parts of argumentation which belong to the obligatory, either explicit or inferable premises. They are the content-related warrant or 'conclusion rules' which connect the argument or arguments with the

> conclusion, the claim. As such, they justify the transition from the argument or arguments to the conclusion. (Wodak, 2001b: 74)

In the Oliver example, the topos of *social/societal causation* justifies the conclusion that *design is at fault* from the data that *there is difficulty in holding, gripping or turning things*. But the topos of social/societal causation only explains *some* aspects of disability. It is germane to some purposes, but not to all. Explaining the socioeconomic dimensions of disability creation cannot be completely separated from discussions of bodily impairment – or vice versa, as public health professionals know.

Models and Dichotomies

There is a tendency, shared of course by many other disciplines, for Disability Studies to turn towards dichotomies. The social model is built on the binary opposition between bodily impairment and societal disablement; the medical model classifies people into *healthy* individuals and *pathological* individuals, divides the *normal* from the *abnormal*, and matches *illness* with *treatment*. From such conceptual pairings, numerous topoi can be generated – e.g. people are either sick or healthy, normal or abnormal, employable or unemployable.

Such topoi can become life-defining. Paul Longmore recounts his experience of being trapped between two fields – two arrangements of topoi. US policy in the 1970s allowed for financial aid towards education for disabled people, but defined disability rigorously and dichotomously as “the total inability to engage in “substantial gainful activity”” (Longmore, 2003: 236), making financial assistance incompatible with part-time work. Employers, however, are unlikely to hire anyone who entirely lacks work experience.

Conversely, the social model’s key dichotomies, such as *access/barriers*, *disablement/enablement*, and *personal tragedy/systemic oppression* are apt for analysis of many political and socioeconomic arrangements, but become problematic to the point of uselessness when applied to many forms of social interaction. On the face of things, the different models of disability should be applicable to different situations. Within Disability Studies, however, they are often perceived as mutually exclusive. This must be explained with reference to their epistemological ambitions – they are theoretical constructs as well as activist tools, and they are meant to have full explanatory power.

That ambition – the hope for a Grand Unified Theory of Disability – is far from harmless. A case in point is the debate over Tom Shakespeare’s *Disability Rights and Wrongs* in 2006, and over that book’s criticism of the British social model. Shakespeare, who has been a prominent figure in UK Disability Studies since the 1990s, wrote that:

> I have come to the conclusion that the British social model version of Disability Studies has reached a dead end, having taken a wrong turn back in the 1970s,

> when the Union of the Physically Impaired Against Segregation (UPIAS) social model conception became the dominant UK understanding of disability. (Shakespeare, 2006a: 2)

The debate that followed was acrimonious and heated. Mike Oliver, who is a quadriplegic, wrote that Shakespeare, who has achondroplasia, "fails to understand the critical reality of impairment and the effect it has both on life and academic work" (Sheldon, Traustadóttir, Beresford, Boxall, & Oliver, 2007: 232). Other critics were even less hospitable. Shakespeare was criticized, among other things, for advocating a return to the medical, individual or personal tragedy model – which, let's not forget, has rarely been defended under those names.

In the second edition of the book, *Disability Rights and Wrongs Revisited*, Shakespeare revised his arguments. Following a number of years working for the World Health Organization, he concentrated his arguments on the potential disability research holds for social transformation in developing as well as developed countries, and stressed his commitment to an interactional understanding of disability, one which "balances medical and social aspects". He argues that such an understanding is already implemented in much modern disability research, and is ultimately necessary in order to conduct empirical research without undue ideological bias (Shakespeare, 2013: 78).

In many fields, including the civil sector, social and medical topoi necessarily interact all the time. An example from my own research is FFO, the largest Norwegian NGO. It is a federation that is built on social model principles and goals, while its member organizations all employ medico-diagnostic criteria for their individual members. It seems that the medical and social models are *not* in conflict in this context, because the social model suggests and identifies overarching political-ideological goals for FFO that cannot be specified, developed or reached without knowing the details of FFO's member organizations' individual members' impairment (J. Grue, 2009).

In this particular, practical context, the social model cannot become politically effective without an appeal to medical knowledge. Simultaneously, it is difficult to frame a large-scale political project in the disability field without recourse to the social model – and social theory – because of the limitations of the medical approach. The question, then, is how to approach Disability Studies in general and theorizing about disability in particular, and how to make the most out of those enterprises.

Opening Up Disability Theory: Two Examples

Any theory of the construction of disability will never entirely or precisely fit every empirical example, but must be continuously tweaked, readjusted and improved. As the paper-producing machinery of journals, peer-reviewers and reciprocal citations has been built in the disability field, so the social model, the minority model and to some extent the gap model have become effective turbines for generating academic discourse.

Analysing or re-describing the models of disability as engines of discourse does not, however, preclude viewing them as historically significant and effective agents of social change. But through their increasing entrenchment in a distinct academic field, they are reifying disability as a phenomenon of epistemological interest first and a socio-political disadvantage to be ameliorated second. That way, insularity lies.

I'd like to analyse a premier example of theoretical work in Disability Studies, in order to look for points of engagement. Tobin Siebers' *Disability Theory* was received (Davidson, 2008) as a state-of-the-art summary of current US thinking on disability. The book is very much in the minority model tradition, and criticizes (a simplified version of) the social model for "leaving [the body] out of the picture" (Siebers, 2008: 25) – but nevertheless argues strongly in favour of a politicized identity of disability, one that than be employed to effect the changes in the environment that the social model is primarily geared toward identifying.

The problem for analysis, then, is to identify some key topoi of this minority model text that can be shared with the social model. Preferably these should be topoi that are fundamental to the theoretical aim of the book, whose aims and purposes are presented as follows:

> *Disability Theory* pursues three interlocking agendas. First, it makes an intervention from the perspective of Disability Studies in some of the major debates of the last thirty years in critical and cultural theory. My objective here is to […] demonstrate for critical and cultural theorists how Disability Studies transforms their basic assumptions about identity, ideology, politics, meaning, social injustice, and the body. […]
>
> Second, I offer an extended discussion of the broad means by which disability relates to representation itself. This second agenda may also be thought of as an intervention in the field of theory […]. A focus on the disabled body encourages a more generous theory of representation […].
>
> Third, this book theorizes disability as a minority identity, one whose particular characteristics contribute to the advancement of minority studies in general. (Siebers, 2008: 1–3)

I'll note two things in this extract, one very briefly and one at greater length. The first thing is that Siebers calls for interdisciplinarity and for more engagement with critical theory, and that the arguments in this chapter are in some measure a response to that call.

The other thing is that Siebers presents a macro-level argument in favour of Disability Studies as such. The title of his book is telling – he is attempting to define and frame a discipline. We see a consolidation similar to that which is signalled in the second edition of *The Disability Studies Reader.* Siebers' macro-level claim "Disability Studies is real, and worth doing", is warranted partly by its direct political potential, but mainly by its value to other politically oriented academic pursuits.

In the following analysis, I employ the argumentation schemes of Stephen Toulmin, as developed in *The Uses of Argument* (1958). In other words, I'm focusing on the topos-as-warrant. The kind of topoi I'm looking at are the ones that set out the purpose and direction of Disability Studies. Taking his own words as data (from the quote from pp. 1–3, above), Table 2.1 shows Siebers' own implicit justifications for doing academic work on disability, on the macro-level assumption that he finds such work to be worthwhile.

Table 2.1 Tobin Siebers' justifications for Disability Studies

Data	Warrant/Topos (implicit)	Claim (implicit)
"Disability Studies transforms [the basic assumptions of critical and cultural theorists] about identity, ideology, politics, meaning, social injustice, and the body"	Pursuits that improve on critical academic disciplines are useful per se.	Disability Studies is a pursuit that is beneficial for disabled people.
"[Disability Studies promotes] a more generous theory of representation"	Pursuits that improve on academic theories are useful per se.	
"[Disability Studies will] contribute to the advancement of minority studies in general"	Pursuits that advance minority studies are useful per se.	

Given that topoi are elements of knowledge that are accepted or taken as given within certain groups, spheres or communities, it is interesting to note that the topoi that Siebers draws on are germane to academia in general and the humanities in particular. Though he is elsewhere critical of the social model, he doesn't appear to have any particular quarrel with it. Topical analysis, here, is a way to explicate the assumptions that underlie arguments, particularly those assumptions that have to do with the field from which arguments originate and towards which they are directed. It isn't a strategy for undermining the arguments of others, but a way to investigate the bases of misunderstanding by clarifying points of origin.

In the case of Disability Studies, I believe that there is a majority of cases in which conflict arises through disagreements about terminology, not substance. But there are certainly genuine conflicts of interest, too. Consider, for contrast, *Fundamental Principles of Disability*, published by the Union of the Physically

Impaired Against Segregation in 1976 and mentioned earlier in this book. Although this group of activists eventually produced several seminal figures in the sociological study of disability in the United Kingdom, its attitude was sceptical, if not outright hostile, towards research efforts, particularly sociology, because sociologists "would oust the medical profession and replace them as the dominant group in the field" (UPIAS, 1976: 18) while maintaining an oppressive stance towards disabled people:

> A whole new generation of researchers and testers will be created to administer the incomes policy [to which UPIAS is opposed].
>
> The scene facing every physically impaired person, then, is of an army of 'experts' sitting on panels which are set up all over the country. These 'experts', armed with the latest definitions and tests for measuring, will prod and probe into the intimate details of our lives. They will bear down on us with batteries of questions, and wielding their tape measures will attempt to tie down the last remaining vestige of our privacy and dignity as human beings. To calculate the 'degree of disability' they will be forced to snoop and spy. (UPIAS, 1976: 18–19)

The topoi, then, are shown in Table 2.2.

Table 2.2 UPIAS' justifications for Disability Studies

Data (explicit)	Warrant/Topos (implicit)	Claim (implicit)
"These 'experts', armed with the latest definitions and tests for measuring, will prod and probe into the intimate details of our lives."	If research is carried out by external "experts", it isn't for the benefit of disabled people but for the benefit of other agents and institutions.	The study of disability is a pursuit that is potentially oppressive to disabled people.
"To calculate the 'degree of disability' [the researchers] will be forced to snoop and spy."	Snooping and spying doesn't produce beneficial knowledge, only information that can be misused.	

It is symptomatic, and perhaps surprising, that these sentiments were articulated by a group that comprised both future activists and future researchers. But the familiar tension between knowledge as a goal in itself and knowledge as an instrument for improving the world is particularly strong in Disability Studies, probably because the divergent epistemological principles are equally crucial to the enterprise at hand (Oliver, 1992).

I've provided two examples of how presuppositions about disability, the academy, and the activity of research surface as parts of argument in writing that subscribes to different models of disability. I've provided a more general argument that models are necessarily embedded in different rhetorical contexts. The upshot of this is that the models should not be perceived as incompatible until a sufficient number of attempts have been made to *make* them compatible. As the contexts where disability is discussed increases arithmetically, the production of texts about disability increases geometrically. This entails the need to be aware of the language that is used, and the assumptions and presuppositions that follow. The making of the world into text – whether the text of regulations or of proclamations – is hugely influential on the daily lives of disabled people, as we will see in the following chapters.

There are very few practitioners of Disability Studies that are not on some level aware of the political aspects of their work. Indeed, the case could be made that Disability Studies is in and of itself a macro-level argument for wholesale social change. In this interpretation, Disability Studies provides the data and the warrants for specific claims about the ways in which society has to be altered. The accompanying epistemological dilemma is one that is familiar from other activist contexts – and indeed from Critical Discourse Analysis – should research on disability ultimately be guided by the quest for knowledge or by political goals?

The answer to the dilemma must be pluralism and the expansion of the conversational circle. The evolution of the social model of disability from a roughly hewn tool for identifying oppressive structures to a sophisticated but dogmatic set of theoretical precepts has not only been accompanied by acrimonious academic debates, but also by the reification of a false dichotomy between itself and a medical model which may never have been actively embraced by anyone. Because of the tendency for theory to breed orthodoxy, the social model has become a focal point of conflict for people who substantially agree on any number of significant political issues. To some extent, the same applies to the minority model.

This is particularly damaging because Disability Studies is not in any real sense a large, established or particularly prestigious discipline. In 1997, Lennard Davis wrote that

> [It] has been virtually impossible to have a person teaching about disability in the humanities. […] Disability has been seen as eccentric, therapeutically oriented, out-of-the-mainstream, and certainly not representative of the human condition – not as race, class, or gender seem representative of that condition. (Davis, 1997a: 2)

In 2006, he viewed the situation this way:

> Disability Studies is taught throughout the United States, the United Kingdom, and the world. […] The efforts of many scholars and activists have come to fruition in the birth of a fully legitimate area of study and discussion. (Davis, 2006: xiii)

In 2013, he was still more optimistic:

> I can say that disability is not only accepted but also has become very much a critical term in discussions of being, post-humanism, political theory, transgender theory, philosophy, and the like. (Davis, 2013a: xiii)

Yet it is hard to say whether the situation for disabled people outside the university has improved. It is imperative, therefore, to strengthen the links not only between Disability Studies and sympathetic disciplines, but to allies in fields outside of academe. If that is to happen, then Disability Studies cannot be a search for the one true theory, but must be a discipline in which a plurality of models are adapted both to one another and to the issues at hand.

"There's No Such Thing as Models, Only Individual Authors and their Documents": Towards Ecumenism in Disability Theory?

Well, no. There *are* models. But the "minority model" of one author is not that of another author, not in the same way that a single model in physics or mathematics may be employed identically by different researchers. The British social model as articulated by UPIAS in 1976 is not the same as the model advocated by Mike Oliver in 1990, or by Mike Oliver in 2013. One form or another of the Scandinavian gap model has been in play in Norway for nearly half a century, though it has only recently been theorized as such, and explicitly compared to the British model. There is no US researcher who "owns" the minority model, but there are many who interpret the notion and put it to productive use.

These are all reasons why I hesitated to introduce a group or set of models in the first place. I hesitated because I have tried to teach students of disability how *not* to reduce their analysis to the question of "social v. medical model", only to discover, in exams and term papers, that this is what they did anyway. We are caught out by recognizable and familiar topoi. We like our dichotomies. Fine, then. Perhaps we need to have them, in one form or another. It is nearly impossible to talk about disability without reference to a group of models. But let us try as best we can to remember their limitations, and to strive for ecumenism.

The final reason for this is there simply isn't much of a chance of a *resolution* of the issue of disability theories and models. Recently, Christopher Riddle argued that the debate over how to define disability must be concluded, and soon:

> While many Sociologists in the United Kingdom argue that the British 'social model' is the only effective means of understanding and advocating on behalf of people with disabilities, many Bioethicists and Philosophers have embraced an 'interactional approach' to disability. It is imperative that this debate draws to a close. (Riddle, 2013: 23)

Riddle's main reason for ending the debate is efficacy in policy, particularly health and social policy. His main argument runs in favour of an interactional model, against (his version of) the social model. Citing Matilde Leonardi et al., he summarizes the benefits of an interactional model as follows:

> [U]nderstanding both the health and the environmental aspects of disability allows for the examination of health interventions that improve functioning as well as interventions to change the environment to improve participation of people with disabilities. (Riddle, 2013: 24)

Riddle's argument resembles previous arguments put forward by Shakespeare and Watson a decade earlier (Shakespeare & Watson, 2001), and by Crow five years before that (Crow, 1996): the "classical" version of the British social model does not account for impairments in a satisfactory way, and this lacuna creates fundamental problems for the social model's analytical capabilities as well as for its political efficacy.

These criticisms are substantial and important, they must be included in any discussion about disability, and it is crucial to acknowledge, as Riddle does, that the immense practical and theoretical work done in the disability field has resulted both in quite functional models of impairment and disablement (e.g. the ICF), and in theoretically sophisticated interactional models of disability and disablement. This does not mean that the British social model and its history will cease to exist. Disability Studies is a concern of the social sciences and the humanities as well as a sister discipline to the medical and para-medical sciences; those branches of inquiry have yet to exhibit any paradigm shifts (in Thomas Kuhn's sense of the words) and are unlikely ever to do so. Disability is never going to be "solved", much as the debates over the best way to talk about disability are never going to be "resolved". There are too many vested interests both inside and outside of academe.

"Settling the debate" presumes that roughly the same cast of people are involved in discussing roughly the same thing, but this is not the state of affairs in the disability field. As we will see in subsequent chapters, it is unlikely that there is even a unitary sense of what "the social model" of disability is across subfields and professions. Models change according to the discourse in which they are embedded, and according to the purposes of those who use them. And from a certain point of view – the discourse point of view – there is no longer such a thing as "the British social model".

I will argue here from analogy. Arguably, the "medical model" of disability is rarely defended as such – as a viable and useful way to model disability *and* as something called "the medical model". To paraphrase Margaret Thatcher: there is no such thing as the medical model, only individual doctors and individual people with impairments. The "medical model" as a phrase tends to characterize *the practice of medicalization*, not any form of *theoretically coherent or explicit attempt to define disability as a purely medical matter*. In scholarly literature, "medical model" is just as damning a term as "socialist" is a damning epithet in

US politics – and just as divorced from the actually held ideological convictions of actual people.

This does not obviate the need to identify and amend practices of medicalization, which remain widespread (and may well be on the increase, for all we know, as diagnostic diversification and biomedical optimism continue apace). But it does imply a less-than-Manichean approach to the issue of theories and models.

Quite possibly, a similar shift in discourse has affected the "social model" as well. When using the scare quotes, I direct attention at the status of the "social model" as a signifier. I then direct attention at a Google Scholar search I performed on 5 February 2014, using the terms "social model" and "disability" (and using my browser's anonymous mode, to prevent cookies and search history from influencing the result). Excepting an anomalous search result with only two citations, out of the top ten works returned from the search, a clear majority were either explicitly critical of what they termed the "social model", or attempted to implement major theoretical revisions of it (Burchardt, 2004; Crow, 1996; Gabel & Peters, 2004; Goodley, 2001; Hughes & Paterson, 1997; Shakespeare, 2006b; Shakespeare & Watson, 2001). Two works explicitly defended the "social model" as currently understood, without substantial revision (Barnes, 1998; Barnes & Mercer, 2004).

This is hardly comprehensive evidence. But I submit that the social model, over time, because of extensive revisionist efforts criticism from Shakespeare, Watson, Hughes, Paterson, Crow, and many others, is in fact no longer the rigid and dogmatic construct of the mid-1980s that it is sometimes claimed to be. That construct is defended by very few people and useful to even fewer. Instead, since the social model is not trademarked and does not belong to any single scholar or group of scholars, it has, de facto, evolved. From a discourse perspective, the social model is what the majority of scholars and other language users say it is.

In many cases, "the social model" is used and understood in ways that adhere very loosely to "classic" definitions. Pragmatically speaking, usage may in many cases be closer to definitions of an "interactional model" as defined by Riddle et al. Interviewing professionals in Norwegian NGOs for my dissertation in 2008, I discovered that: a) they were familiar with the term "social model"; b) they found it useful to describe their professional stance on disability; and c) they defined it in whichever way they found convenient (J. Grue, 2010).

The same point applies partly to scholarship as well. Much research that nominally adheres to the "social model" is in fact quite concerned with impairments and impairment effects as causes of disablement. This is partly due, of course, to the revisionist and reformist efforts of, for example, Carol Thomas. But it is also due to the *weight of bodies*. If, as according to Husserl, the phenomenological essence of something is that which cannot be thought away from the experience of that thing, the bodies represent the phenomenological essence of disability. Either the social model survives as a flexible analytical tool which privileges socio-economic causes of disablement but preserves a place for bodies and their impairments, or it dies as an inflexible attempt to think away something that is at the essence of what is being thought about.

What I am saying is this: the differences between the social model and the interactional model may not be as large as disability theory sometimes makes them out to be. There are, of course, substantial differences, but they could perhaps be conceived more usefully in terms of interest, orientation, preferred subject matter, and so on, than in terms of epistemological and ontological divides.

Riddle points out that there are well-formed and weighty critiques of the social model, e.g. from Simo Vehmas, that haven't been responded to by social model theorists. I hypothesize that this is the case because there isn't much of a response to be made. Essentially, the debate is over. Ecumenism won.

The next question – if we are at all concerned with theories and models of disability – can perhaps be best illustrated with a scene from Tim Burton's animated film *The Nightmare Before Christmas*, which, apart from its unfortunate use of a classic mad-professor-in-wheelchair stereotype, represents an interesting look at issues of embodiment and the capability for happiness. In the scene in question, the protagonist Jack Skellington, the Pumpkin King of Hallowe'en Town, is attempting to unravel the mystery of Christmas (a holiday and form of bodily experience with which he is entirely unfamiliar). He has acquired a number of Christmas decorations, and is systematically subjecting them to chemical analysis. Regarding one of the processes closely, he observes: *interesting reaction ... but what does it mean?* Ultimately, he only discovers the meaning of Christmas through a catastrophic attempt to embody Santa Claus – empirical experience trumps laboratory investigation.

So it is, currently, with much theoretical work on disability. Well, almost. The next question isn't *one* question, but legion – and very much informed by the intersection of theoretical points with empirically grounded discourses. So what kind of model *can* we work with? What kind of disability theory can we accept, and what part of Disability Studies does this book align itself with?

My approach probably falls somewhere between social constructionism and critical realism. It takes written and spoken language as its primary data, but analyses that data as it is embedded in its communicative context, including individual and institutional agents, communicative purposes and materials, as well as ideological and historical background. A key assumption is that discourses are ways of signifying social fields. This implies that the disability field can be signified in multiple ways – particularly through texts that are embedded in powerful institutions, and that create socially significant subject positions for disabled people.

A further implication is that models of disability, including the World Health Organization's International Classification of Functioning, Disability, and Health, the US minority model, the British social model, and the Nordic gap model, can all be viewed as ways of signifying disability. That they are sometimes assumed to be incompatible has partly to do with their origins in and connections to different institutions and fields, and are geared at signifying different *aspects* of disability. The next two chapters deal with social fields that are essential to the modern construction of disability, partly through discourse: medicine and politics.

Chapter 3

Medical Discourses of Disability

This chapter deals with medical discourses of disability. Roughly speaking, they are discourses in which medical language and medical knowledge are in play, in which the topics under discussion are bodies, diseases, diagnoses, and cures, which is to say that they are discourses that signify issues to do with bodily problems and limitations in ways that are comprehensible to the institution and practice of medicine.

The field of medicine has a strong and enduring connection to disability, and the status of that connection is both contested and problematic. One way to explain the problems at hand is to pose the question: *are disabled people necessarily ill?* Another way is to ask: *is disability analytically reducible to illness*? A third way is to posit that disability is a problem that can chiefly or exclusively be resolved through medical means.

These questions and assumptions have guided much thought on disability, particularly throughout the previous century. Medicine has been a readily available way to think and talk about the lives and experiences of disabled people – and an inevitable way to do so, since disabled people have been under the control of medical institutions and practices, and have had access to help and services only by means of medical certification. Medicine has performed regulatory, disciplinary and controlling functions in the disability field. Medical language has been positioned as the most solid and most reliable tool for the classification and description of causes of disability, which is another way of saying that medical knowledge has been positioned as prior to knowledge about disability.

The absolutely central position of medical knowledge, language, and power in the disability field means that medical discourse has also been at the centre of struggles about how to understand and define disability in new ways, particularly from the 1970s onwards. In different ways, the three models discussed in the previous chapter, the Scandinavian gap model, the British social model, and the US minority model, can be viewed as attempts to supplant a previous, medical model.

That story, of medical models being confronted and supplanted by other models, is often told with the World Health Organization's first *International Classification of Impairments, Disabilities, and Handicaps* (abbreviated ICIDH; WHO, 1980) as an example. The ICIDH had the subtitle *A manual of classification relating to the consequences of disease*. Its system of terminology and classification provided the grounds of a discourse in which "disability" was defined as the consequence of "impairment", which was in turn defined as "biomedical abnormality". This neat and orderly system of direct causality both for individuals (abnormal bodies cause abnormal social lives) and for discourses (social phenomena are ultimately reducible to medical phenomena) eventually made the ICIDH a very effective target for reanalysis. Its formalization of a pure medical model of disability occurred relatively late in the history of the disability field, i.e. at a time when the analytical tools needed to dismantle it had already been developed in many activist and research communities.

The story of the ICIDH and its shortcomings is a familiar one in the disability field because it is a story of successful deconstruction. Its essence is that the classificatory system as well as the explanatory mechanisms adopted by the WHO were roundly and thoroughly criticized, that disability activists and scholars were prompted to further develop counter-discourses, and that these efforts led, among many other things, to a much revised version of the ICIDH in which a much more holistic approach to disability was adopted.

The elaborate version of the story is too complex to recount here. Instead, I will focus on two aspects of it. One is the relationship between medical discourses, medical models and other models of disability. Another is the relationship between impairments and chronic illnesses. In both cases, *dichotomies* come into play. Medical models of disability are sometimes held to be antithetical to Disability Studies, in much the same way that chronic illnesses are represented as wholly different from impairments. In this way artificial barriers are erected between forms of language as well as forms of experience. Medical discourses of disability are particularly instructive in showing the relationship between the word and the world.

The Problem of Medical Power

> Many people are disabled by chronic and/or life-threatening illnesses, and many people with disabilities not caused by illness have chronic health problems as consequences of their disabilities; but modern movements for the rights of people with disabilities have fought the identification of disability with illness, and for good reason. This identification contributes to the medicalization of disability, in which disability is regarded as an individual misfortune, and people with disabilities are assumed to suffer primarily from physical and/or mental abnormalities that medicine can and should treat, cure, or at least prevent. (Wendell, 2013: 161)

There are many things to unpack in this quote from Susan Wendell, a scholar whose work has for many years probed the intersection between illness and disability. In an article whose point is partly that disability is not reducible to illness nor vice versa, she stresses that the suspicion of medical discourse in the disability field has much to do with the *totalizing* potential of medicine. What the disability movement reacted against is “the identification of disability with illness”, because such this identification leaves very little room to talk about things that are unrelated to illness.

In turn, however, parts of the disability movement have embraced a totalizing attitude of their own: "there is anxiety to assure nondisabled people that disability is not illness" (Wendell, 2013: 165) because it is perceived as risky to open the door, even a little, to medical explanations for disablement. Therefore, disabled people hesitate to talk publicly about issues to do with individual bodies, health, and illness; therefore, people with chronic illnesses do not always feel at home in the disability movement.

Medicine has been described, in one classical analysis, as an institution defined by autonomy and control (Freidson, 1970). While sensitive to political and economic influences, it is nevertheless a highly distinct social sphere – one in which, outside of the military, power relations are at their most asymmetrical, hierarchies are at their most rigid, and the use of language is at its most rigid and, well, clinical. Medicine is the home of many total institutions – somatic and psychiatric hospitals, nursing homes, and rehabilitation units, for instance – and of many relations defined by formal and informal authority.

Moreover, medicine provides crucial influences upon identity formation and production. To be ill is to inhabit the sick role (Parsons, 1951), which entails voluntary and involuntary removal from the obligations and privileges of daily life. To be ill is to be concerned with getting well, and a defining feature of many impairments is the presumption that they are *permanent*. The arrangements, activities and discourse of the medical field are all geared towards the expectation or possibility of cure, and the goal of cure is presumed to trump all others.

The early years of the modern disability movement, in the middle of the twentieth century, coincided with the ascendancy of medical professional autonomy. Many of the foundational texts in Disability Studies take medical power over disabled peoples' lives as a given, referring to "the medical profession [as] the traditional, dominant group" (UPIAS, 1976: 18) in disability, going on to attack medically legitimized, involuntary institutionalization and segregation of disabled people (Zola, 1977) and to point out the many ways in which medicalization functions as a form of social control (Oliver, 1990).

The antidote to medical power has, as Wendell points out, been an emphasis on the political rights of disabled people. In socio-political discourse, disabled people are not striving primarily towards better health, but towards higher social, political, and economic status, and towards greater degrees of participation and control. *A priori*, there is no reason why these goals should be incompatible with medical discourse as such, only the narrower phenomenon of *medicalization*, i.e. the application of medical discourse to topics and issues that could plausibly belong to other forms of discourse. In many practical instances, medical professionals appear as what the LGBTQ movement has termed "allies" – people who are not themselves part of the disability movement, but share many or most of its goals and precepts. The contentious issues are medical imperialism, the medical field's inherent power asymmetries, and, of course, the numerous historical examples of abuses of medical power.

Medical Discourse or Medical Model?

These issues are serious enough that a strong attack on medical discourse was perhaps inevitable. From a historical perspective, it is not hard to see why medical discourse should remain a crucial factor in the lives of disabled people. Medicine documents temporary and permanent bodily malfunction, regulates access to the socially sanctioned sick role and to economic privilege, and exercises authority over people both inside and outside of institutional settings. The same factors make the counter-reaction just as natural. And key documents such as the ICIDH have provided a focal point for criticism, which is to say: the notion of a coherent and totalizing *medical model*.

Does such a model exist? That depends to a great extent on which epistemological status we wish to give it. In scholarly literature, it is first and foremost a target of attacks – that is to say, the search phrase "medical model of disability" yields, from academic search engines like Google Scholar, almost exclusively articles and books that are *critical* of the medical model, sometimes referred to as a so-called model or what is often called a model.

This in itself is interesting; it tells us that a "medical model", in that specific phrase, is not primarily something that is actively promoted – it probably does not refer to a concerted intellectual attempt to understand disability in exclusively biomedical terms. And of course, opponents of the medical model do not necessarily ascribe such explicit intentions to the medical community. Rather, "the medical model" refers to separate practices and ideological preconceptions that add up to an implicit or partially explicit frame of understanding – effectively, a discourse – in which all the factors relevant to understanding disability can be found in the medical field and addressed in medical terms.

Thus, "the medical model" is a problematic entity. If one assumes that medical professionals operate entirely in accordance with such a model, then medicine is largely suspect and criticism of medical ideology should be at the centre of Disability Studies and disability activism. But if the medical model is unstable, distributed across many forms of social practice, and very rarely explicitly endorsed or followed, then it is less clear if the "medical model" is a useful and productive concept.

My own view tends towards the latter position. Medical discourse is where words meet bodies. The experience of this meeting can be severely painful when the words do not fit, and have sharp, painful edges. This explains, perhaps, some of the difficulty of finding unitary language for the disability field as a whole. To paraphrase Tolstoy: all ordinary bodies are alike, but every extraordinary body is different in its own way. Medical and clinical language rarely captures the subjective experience of such difference. Moreover, medical language tends to restrict – as has been repeatedly pointed out by disability scholars and activists – the possibility for *change* to individual bodies.

There is a corollary to these observations, however: not only clinical language, but also socio-political language can seem alien and distant from people's life-worlds. In some cases, for people with impairments but perhaps particularly for people with chronic illnesses, it is even more difficult to find a home for oneself in socio-political disability discourse than in medical discourse.

By this I refer to the fact that much of socio-political disability discourse is predicated on one of two ways to construe the group identity of disabled people: as an oppressed class, or as a marginalized minority. I both cases, to actively identify as disabled means partaking of and embracing the kind of stigmatized identity that is rarely sought out by anyone. In the case of many people, the strategy of identifying as ill (and temporarily so, whether for the short or long term) allows for the preservation of another, more positive form of identity. If the only thing that can improve the status of disabled people is social change, and social change is a long time coming, then perhaps it is better to be ill, and to hold out for an individual cure.

This instability on the level of individual people – the room for manoeuvring between identities of illness and identities of disability – is to some extent reflected on the level of organizations. As I'll subsequently discuss, there are many national disability coalitions that are considerably more socio-political in their orientation than their medically-inflected member organizations. There are many pragmatic reasons for this. Firstly, medical diagnoses shape relationships with the health services and are a strong predictor of health outcomes, and so become a strong incentive for individuals to organize themselves. Secondly, ultimate socio-political goals such as better welfare services and better physical accessibility can be shared by a plenitude of diagnostic groups, without serving as a proximate reason for individuals to group together.

The reverse argument could be made – individuals are perfectly capable of organizing themselves for single-issue political purposes – but in practice this doesn't seem to happen as often in the disability field. What happens is that individuals can have a primary identification with a medically-defined organization, which in turn has a secondary affiliation with a socio-politically defined umbrella group.

This makes for a system of mixed, or, as I've put it elsewhere, interdependent discourses (J. Grue, 2011c). It also allows for a state of affairs in which people can, effectively, be disabled without realizing it. As individuals, they can engage primarily with medical discourse, while simultaneously being part of an organization framework that operates, and sets its goals, according to a social model of disability.

For this reason, I prefer "medical discourse" over "medical model" when it comes to concepts as analytical tools. "Medical discourse" is a way to think about, talk about, argue about and act in relation to disability; it is not an intellectually consistent or rigorous attempt to provide a causal explanation of how disability comes into being, or to reduce disability exclusively to biophysical mechanisms.

A consequence of this view is the stance that it is wholly understandable that individual disabled people employ and engage with medical discourse. This fact does not then have to be explained as an instance of false consciousness or as a result of symbolic oppression. If people continue to do so, perhaps it is necessary to ask, first, what communicative needs does medical discourse address, and second, how may medical discourses of disability be viewed as amenable to the life goals of disabled people.

The Limits of Medicine: The Case of Assistive Technology

Such questions do not have blanket answers, and there are many examples that succinctly illustrate the limits of usefulness for medical discourse. I'll discuss two of them – one short and one long.

Medical discourses inevitably exert influence on the disability field; there are many and extensive borderlands, however, between medicine and its neighbouring spheres. On an autobiographical note, I once spent many hours looking for a provider, in the United States, of what I personally thought of as *assistive technology.* Search terms are not necessarily good indicators of anything beyond patterns in language usage, but they have to be mastered in order to find one's way in a foreign country. In my case, I had to realize that items that I didn't consider particularly medical – for instance, a so-called *reacher,* which is essentially a metal rod with a pair of claws on one end – nevertheless belonged to the category of "medical supplies".

In Norwegian, this is not the case. Almost all forms of assistive technology belong to the category of "hjelpemidler", which literally translates as *ways of helping* ("ways" as in "ways and means"). Of course, the nomenclature has much to do with infrastructure and economics. Assistive technology in Norway has long been a domain of the Labour and Welfare Administrations division. Items ranging from wheelchairs to grab bars have been provided without any form of co-payment. In the US, by contrast, to the extent that assistive technology is covered, it is covered by a variety of entities – not the least of which is different forms of health insurance.

Is assistive technology a topic that is amenable to medical discourse? To an extent, certainly. Many forms of assistive technology – wheelchairs, canes, hearing aids, etc. – could even be conceived as "medical model" compatible in the sense that they augment the capabilities of individual bodies. On the other hand, they remain external to the body, and so do not *a priori* constitute corrections on the same order as surgical intervention or rehabilitative efforts. There is a sliding scale: on one end sits the surgically installed pacemaker, on the other sits, perhaps, a pair of eyeglasses. But they both have one feature in common, which is their dependence on a large-scale system of production and distribution. No single person can perform surgery or produce eyeglasses; both activities require substantial institutional organization. Therefore, such technology could also be conceived of in terms of a social model of disability – society has altered itself in order to accommodate the fact that people have varying levels of cardiac as well as visual functioning.

This argument, however, is not as interesting as the question of whether assistive technology belongs to and should primarily be described by medical discourse.

In Norway, a decision was recently made to remove certain types of assistive technology from the roster of items paid for by the national welfare services. The items in question are classified as *ADL*, an abbreviation of "activities of daily living", such as grabbing tools, cutlery, and personal hygiene items. People who require these items are referred to commercial suppliers.

Concurrent with this development, such commercial suppliers have become more numerous and prominent, and they do not employ medical discourse to anything approaching the same degree as those companies that act as suppliers to the welfare services. One supplier is called *Enklere liv*, "Simpler Life", and publishes a mail-order catalogue and website that emphasizes fashionableness, convenience, and simplicity of design. Items that were previously situated mostly in medical or para-medical discourse are now situated squarely in a discourse that can be labelled "convenience" or "utility" – but they are now only available to citizens as consumers, and at market prices.

This shift from one discourse to another – in this case from a non-commercial to a commercial – cannot easily be accounted for in an analytical framework that emphasizes models, whether medical or social ones. The social, economic and political change in the Norwegian disability field which is signified by, and carried out through, the shift in discourse, *could* perhaps be related to a privatization of the responsibility for acquiring assistive technology, a shift which in turn is explicable as the consequence of an individualizing turn in the state's comprehension of disability. But the de-medicalization of ADL items, their integration in consumer discourse, means that this turn is rather difficult to treat in terms of medical and non-medical models. It is perhaps better, therefore, to focus analytical efforts in such cases on the multitude of discourses (medical and non-medical) that influence disability.

Discourses and Pragmatism in the Disability Field: An NGO Example

Medicine presents a certain view of bodies, whether disabled or non-disabled; it emphasizes what is wrong with them. Medicine generates and represents certain forms of knowledge; knowledge about fixing or attempting to fix individual bodily problems. This knowledge is useful to disabled as well as non-disabled people, as practically everyone engages with medical discourse at various points in their lives. Such discourse is necessary in order to provide a precise conceptualization of many aspects of bodily form and function – not to mention a fundamentally intersubjective vocabulary for discussing these things. There is little possibility of engaging with disability without, at some point, discussing medicine, if for no other reason that disabled people do get sick, and have experiences of illness that interact with experiences of impairment and disability.

The question, then, should perhaps not be "Does medical discourse have anything to do with disability?", but rather, "What purposes can medical discourse serve in the context of disability?". I'll provide one example of how things do work, in one particular discourse setting, that of an umbrella organization in the disability field. In this example, medical discourse permeates an organizational framework that is predicated on the semi-permanent coordination of the political interests of a highly diverse population of disabled people. Arguably, medical discourse serves as a more effective way to anchor this population in direct-membership organizations than political discourse could.

The organization in question is The Norwegian Federation of Organizations of Disabled People (hereafter referred to by its Norwegian acronym, FFO). It is the biggest most politically significant Norwegian disability NGO, and it is strongly committed to a socio-political view, defining disability in terms of human rights and discrimination. Its definition of disability is as follows:

> FFO bases its definition of disability on the understanding of disability as a conflict between the capabilities of the individual to function and the demands for function made by the surroundings. […] The conflicts, or matters of discrimination, are experienced differently by different individuals, but are united by the fact that they affect aspects of life taken for granted by most people. […] The relations of conflict faced by disabled people therefore centre on the basic interests of human beings – human rights. (FFO, 2014)

FFO is an umbrella organization, which represents (as of 2014), 75 member organizations and collectively some 350,000 members – approximately seven per cent of the Norwegian population. A major part of its brief is to coordinate the policy interests of these member organizations in negotiations with government agencies. The federation was founded in 1950, as the National League of Organizations of the Partially Employable, with the aim of strengthening the position for disabled people in negotiations with the emerging welfare state. It exemplifies the Nordic tradition of a strong civil sector, where organizations receive state funding in order to coordinate and represent citizens' interests vis-à-vis state agencies and government departments.

Originally, FFO was an umbrella for organizations for people with mobility, hearing and vision impairments, as well as people with tuberculosis. Over the following decades, various other diagnostic groups formed organizations and joined FFO. This trend accelerated considerably throughout the 1980s and early 1990s, as both more precise diagnostic techniques and less expensive technology for organizational work became available (Drejer, 1994). The organizational diversification has continued on multiple levels, as new direct-membership organizations are formed and as existing organizations include new diagnoses as a basis for membership.

The upshot of these developments is that there are many ways to become "a disabled person" in the eyes of the civil sector, which is to say implicitly. One of FFO's biggest member organizations is LHL, the Norwegian Heart and Lung Patient Organization. It is one of several organizations which classifies and addresses its members primarily as *patients* and having a disease; its goals and strategies are framed in terms of *health*. Its members constitute almost one seventh of FFO's membership mass; it is unknown how many of them think of themselves as disabled. In the organization's materiel – this is fairly representative of many patients' rights organizations – "disability" is a term with two main functions: it represents the potential consequences of heart and lung disease, and it refers to people *whose interests are similar to those with chronic illness*.

I stress this latter point because it is a curious one. Even though the members of FFO are manifestly disabled, many of their direct-membership organizations, and in fact FFO itself, take considerable pains to distinguish between "disabled people" and "people with chronic illnesses". In combination with the above usage, in which disability is a possible (though not inevitable) consequence of chronic illness, an implicit hierarchy is created. There are the chronically ill, some of whom may become well, and there are the disabled, which the chronically ill are at risk of joining.

This apparent paradox – the overarching socio-political rhetoric of FFO's "conflict" definition of disability collapsing in its everyday distinctions between the disabled and the sick – is likely a result of two related problems that remain central to the disability field: although approximately one billion people worldwide count as disabled according to the definitions of, for example, the World Health Organization (WHO, 2011), we do not know how many of them explicitly identify as disabled – and if they did, it is highly unlikely that they would use the same definition of disability. Identifying as "disabled" can mean that one identifies with the subject position of disability as laid out in socioeconomic marginalization theory or in minority theory; it can mean that one receives a disability pension, or that one uses a wheelchair, and that one interprets such facts as indicators of disabled status.

The fact that there exists a multitude of disability discourses implies that it is very difficult to describe a single stable phenomenon on which they all converge. The fact that disability carries connotations of permanence, marginality, and stigma, implies that it is an identity that may be played down, or even actively avoided, in any instances. It may, quite simply, be preferable for individuals to identify as ill, preserving the possibility of cure.

One of the communicative challenges inherent in the FFO organizational model is to identify political goals that are shared by at least a majority of its diverse member organizations, and to coordinate their interests. Since the organizations act as representatives for people with specific chronic illnesses and impairments, the challenge consists partly in translating between medical self-perceptions in a local context with an overarching social model strategy directed towards political and economic equality.

FFO therefore has to communicate with readers who use both medical and socio-political language. Analysing its discourse is therefore not necessarily a matter of exposing or unveiling hidden models, but of identifying different communicative purposes. The discourse produced by the federation must serve as a constant reminder that it is a necessary part of Norwegian civil society and the disability field. This function has become particularly important in recent years, as the Norwegian government has redirected a substantial amount of funding towards the individual member organizations, who must be reminded of their common goals and reasons for *staying* members.

Since medical discourse is effectively impossible to avoid, it must be harnessed: FFO is predicated on the assumption that disabled people have certain characteristics in common which make them deserving of special mention as a group. These characteristics are best captured in socio-political discourse: general experiences of exclusion and discrimination are invoked in the definitional document. There is, however, always a need to establish some way of distinguishing the group of disabled people from the able-bodied population, and that distinction inevitably has a medical component.

FFO's uses of socio-political discourse, e.g. in its overarching programmatic documents, are therefore in one sense secondary to its medical definitions (it draws on them and makes use of them), in the same way that its membership base is organized primarily according to impairment. Arguments that construe disabled people as a political minority allow FFO to speak on behalf of a large group of people – as previously mentioned, approximately seven per cent of the Norwegian population. But these arguments in turn rest on a medicalized identification process in which people technically come to count as disabled.

Socio-political discourse has a primary function of keeping FFO together and creating a united front. Representing disability as a conflict emphasizes that the gains made by the disability movement (e.g. in the form of legal rights) or are not *granted* by the state so much as *fought for* by the organizations themselves. Even as the disability movement in Norway remains heavily dependent on welfare state categories, socio-political discourse remains a way to maintain an independent organizational identity.

The existence of a federation such as FFO is partly motivated by the understanding of disabled people as a group that shares common goals. But impairments differ immensely in their impact on people's lives, and allow for different life goals. The opposing forces of the ideal of unity and the reality of diversity manifests itself, for FFO, in the split definitions of disability: 1) as a defining, unitary characteristic of a political minority; and 2) as a pragmatic re-labelling of physiological or mental impairments, as well as chronic illnesses.

At the Limits of Pragmatism: ME and CFS

Disability is often presented as a binary category; this is one of the reasons it forms the basis of a dis-preferred identity. The historical organization of state economies into separate systems for people who earn money based on effort and people who received money based on need (Stone, 1984) creates a basis for considerable stigma. As the *World Report on Disability* points out: the widespread discrimination towards disabled people motivates the need for a nuanced analytical approach towards disability (WHO, 2011: 5–6) – and that approach that does not depend on binary or dichotomous category systems.

The FFO example illustrates the status of disability as, in general, a nuanced phenomenon defined by and situated in multiple discourses; it also provides some reasons for the persistence of medical discourse in particular. Medical knowledge and language, centred on individual bodies, can provide an explanatory bridge to the group-identity of disability. This function is not without its problems, as we'll see from a closer look at some of FFO's member organizations.

Among the newer members of the federation is the Norwegian ME Association, which organizes people who have either been diagnosed with or believe they should have been diagnosed with myalgic encephalopathy (ME). This organization exemplifies particularly well the limits of binary category systems, because it is particularly geared towards the appropriation and subversion of medical discourse. It presents something of a paradox for Disability Studies: how can a community of people who are seemingly quite hostile towards institutional medicine, people who are administratively and for all practical purposes disabled, nevertheless remain detached from socio-political disability discourse? That is the question for the following discussion.

One of the issues identified by the WHO is under-reporting – the fact that many people who technically count as disabled do not identify as such. The myalgic encephalopathy community provides insight into this problem area because they tend to be prolific writers, especially on the internet. According to one Norwegian study, people with ME are eight times as active online as the next comparable diagnostic group. Their texts explore the issue, among many others, of whether they see themselves as disabled – which in turn has implications for how disability is generally comprehended among people with chronic illnesses.

Narratives from people with ME are relevant to the issues of under-reporting and identification, too, because there is considerable controversy as to whether the diagnosis correlates with a distinct medical disorder or group of medical disorders. I will not discuss this controversy extensively, but note that not only the aetiology and symptomatology, but also the history of ME is under severe dispute. Although the diagnostic label "myalgic encephalomyelitis" is attested by the OED as first occurring in *The Lancet* in May 1956, the term "chronic fatigue syndrome" (CFS) has been used to refer to similar sets of symptoms or the same groups of patients for the last several decades; there is no universal agreement on whether ME and CFS refer to the same underlying condition or not. Both diagnostic labels are associated with recurring symptoms that include persistent fatigue that is not improved by rest, as well as weakness, muscle pain, impaired memory and concentration.

Even though there is no definitive aetiology of and no clear course of treatment for either diagnosis, names are important. The level of what is termed "disease prestige" (Album & Westin, 2008) associated with ME is higher in the medical community than that associated with CFS (Jason, Taylor, Plioplys, Stepanek, & Shlaes, 2002). It is therefore not surprising that the ME label is preferred by many patient groups, including the Norwegian association that served as a major source of data for this book. Keeping in mind the multiple connotations of ME and CFS respectively, I will, for the above reasons, use "ME" rather than "ME/

CFS" throughout the text (for a more extensive discussion of different diagnostic criteria, I'll refer to Jason, Fennell, & Taylor (2003)).

For a community that is highly aware of the prestige attached to different classifications and labels, it seems likely that they are also aware of the prestige and stigma related to illness versus disability. People who have received the ME diagnosis often use wheelchairs or are in other ways effectively disabled, but there is considerable variation with regard to how they identify themselves. In this they resemble other indirect members of FFO, their overall disability umbrella organization; they do distinguish themselves from – in this particular comparison – people with neuromuscular diseases and people with multiple sclerosis.

The material referenced here consists of texts that are framed by the NGOs – organizations that belong to the FFO umbrella – as representations of everyday life with the relevant diagnosis/diagnoses. As such, they indicate partly how the NGOs see their members and partly how they wish their members to be seen. They are signals of preferred identities. The disability identification is strongest for the neuromuscular NGO, weakest for the ME association. Since they are all members of FFO, they provide an ambiguous identification space for their members. Individuals may legitimately consider themselves members of a particular diagnostic group without directly identifying as disabled, since disability-themed discourse is more prevalent in those parts of organizational discourse production that are directed at public policy, and less prevalent in member-oriented communication.

These narrative priorities are not only practical, but fraught with moral and social meaning. It is well established that disability has multiple causes, including but not necessarily limited to the cultural, biophysical, social, political, and economic spheres. The issue of whether someone sees himself or herself as disabled may be considered similarly complex – it isn't simply a matter of the kind or degree of bodily impairment, but also of the context in which identity is articulated. From the perspective of discourse analysis, as we'll recall, language as a form of social practice (Fairclough, 1992, 2001 [1989]; van Dijk, 1997). One implication of this approach is that texts have to be analysed with an emphasis on their social conditions of production as well as their specific processes of production (see Figure 3.1, below), and that the narrative form must be considered, in part, a response to those conditions. This perspective must, in turn, inform the process of interpretation. That is to say, the narratives must be considered in terms of their social conditions of interpretation (as well as their social implications).

As mentioned previously, there is a considerable difference between the way disability is discussed at different organizational levels within FFO (J. Grue, 2009, 2011b). As has been shown to be the case elsewhere (Stalker, Baron, Riddell, & Wilkinson, 1999), theoretically informed concepts such as the social model are not always well-understood or perceived as relevant in everyday contexts of language use and communication. Key organizational documents and bylaws adhere to a socio-political conception of disability, using the language of rights and discrimination, while everyday communication directed chiefly at individual members is more often framed in terms of health and illness. This is why it is possible for someone who

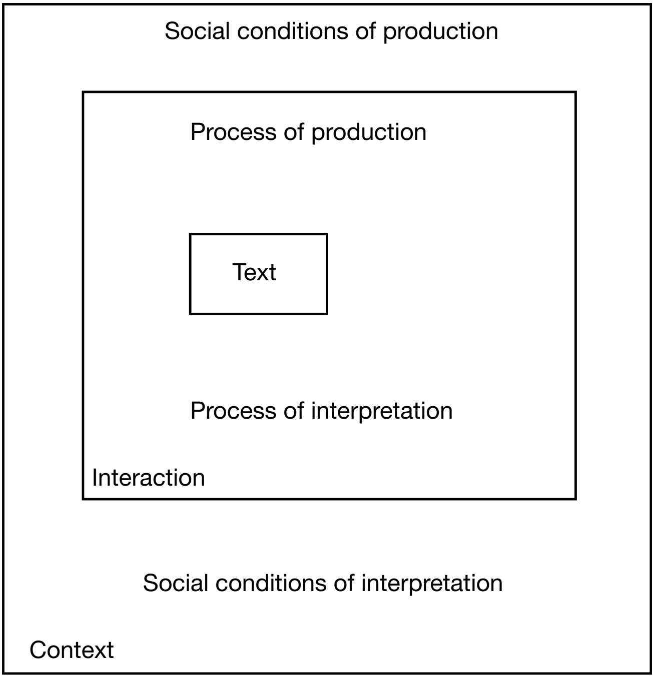

Figure 3.1 Norman Fairclough's (2001 [1989]) model of textual production and interpretation

does not see himself or herself as disabled per se, but rather as having a (temporary) illness, to count as disabled for FFO's political purposes.

This dynamic between illness and disability is familiar from other contexts, in the longer, historical view. To recapitulate: while disability has become an increasingly prominent concept in global policy discussion, not least because of the UN Convention on the Rights of Persons with Disabilities (2007), it carries multiple meanings with it. The construals of disability variously as a medical matter (Zola, 1972), a marker of cultural affiliation (S.E. Brown, 2002), and a form of socioeconomic oppression (Oliver, 1990) by no means exhaust the range of interpretation for the concept. While disability has been extensively theorized, as in the second edition of Davis' *Disability studies reader* and Siebers' *Disability theory*, no dominant or hegemonic way of representing it has emerged. Although approximately one in seven people are estimated to be disabled on a global basis, a far lower proportion have any affiliation with a disability organization. The proportion of people who count as disabled that are aware of socio-political definitions of disability is very low indeed (Shakespeare, 2006a: 73).

Under-reporting of disability persists for many reasons – one of which, according to the WHO report, has to do specifically with language and framing:

> Imprecise or off-putting wording in the questions – such as using the word 'disabled' when asking about difficulty with an activity – can also result in under-reporting (WHO, 2011: 24).

It is indeed plausible that greater stigma attaches to the word "disabled" than to the word "ill", particularly if one assumes on the part of the language user a form of *doxa* in which disability is conceived of as a property of persons rather than relationships. Disability connotes permanence while illnesses may be cured; if, in the much-quoted words of Erving Goffman (1963: 13), stigma is an "attribute that is deeply discrediting", then people would be likely to avoid the appearance of possessing permanent markers of stigma – if they can reasonably do so.

Much of the work done in Disability Studies can be conceived as an attempt to shift definitions of disability from the attributive to the relational. Although Goffman's exploration of stigma is very much focused on the interactional, what has been referred to by Graham Scambler as "the causal input of social structures" (Scambler 2009: 444) is of particular concern to many disability theorists. The fact that disability has historically been a label for the unemployable (Stone, 1984) suggests that "disability" connotes dependence and marginalization to a greater extent than "illness". In a previous, much used WHO definition of disability (1980), it was defined as a condition *resulting from* illness – effectively, an additional mark of stigma imposed on top of the stigma of a medical disorder. It is not surprising, then, that "disability" becomes an undesirable label.

Even today, in the international classification of functioning and disability (WHO, 2001), the conceptual relationship between illness and disability is highly complex. The term "impairment" is reserved for biophysical damage, while "disability" is intended to describe a situation of disadvantage due to multiple causal factors, certainly including social, political and economic ones. Nevertheless, it is difficult to entirely escape the notion that it would be preferable merely to have an illness or an impairment, and not have to "come out" as disabled. The fraught matter of identifying oneself as a disabled person is a common topic in Disability Studies literature, with many authors describing a process – of moving towards an acceptable way of self-identifying as disabled – that takes years, or even decades.

There are very good reasons for this. Disability, although it is part of the permanent life circumstances for many people, is frequently construed as a form of ongoing crisis. A recurring feature of discourse produced by disabled people, as well as much work in Disability Studies, is the argument that life as a disabled person constitutes normal life (see for example Crow, 1996; Davis, 1997b; L. Grue & Heiberg, 2006; Hahn & Belt, 2004; Longmore, 2003; Morris, 1991; Moser, 2000; Zola, 1989).

With this in mind, we can approach the texts that discuss everyday life. Although they represent three different genres, i.e. the portrait interview, the self-portrait, and the blog "about me"-self-presentational note, they share the following features:

- they consist of temporally ordered clauses;
- they detail the onset of symptoms and the designation of a medical diagnosis; and
- they have the discussion of illness as a salient feature.

This qualifies them as illness narratives, a well-known genre both in medical sociology and in Disability Studies. In this case, they serve as a basis for negotiating identities of illness and disability, respectively. Narratives about chronic illness typically involve

> three types of narrative form: 'contingent narratives' which address beliefs about the origins of disease, the proximate causes of an illness episode, and the immediate effects of illness on everyday life; 'moral narratives' that provide accounts of (and help to constitute) changes between the person, the illness and social identity, and which help to (re) establish the moral status of the individual or help maintain social distance; and 'core narratives' that reveal connections between the lay person's experiences and deeper cultural levels of meaning attached to suffering and illness. (Bury, 2001: 265)

The diagnosis narratives' primary readership consists of organization members or potential members, as well as their next of kin, suggesting that all three of Bury's types of narrative form will be relevant. Origins and causes of illness, as well as the moral status of the individuals concerned, are highly relevant to people who have experienced symptoms but have not yet received a diagnosis, as well as to people who are searching for a realistic prognosis and for life trajectories that are comparable to their own.

As for the texts' status as "core narratives", it is here that the relationship between illness and disability will come to the fore. Although the illnesses written about in the material are in many senses quite different, they share many symptoms as well as posing many of the same dilemmas with regard to everyday life management – how and whether to retain a job, whether or not to use a wheelchair, and so on. But a core narrative about falling ill and striving towards recovery is very different from a core narrative about becoming impaired and starting to identify as a disabled person.

Narratives are examples of verbal communication that "[draw] upon the fundamental human capacity to transfer experience from one person to another" (Labov, 2011). The NGOs that have sanctioned the narratives serve, among other things, as conduits for the experience of having particular symptoms and receiving a particular diagnosis; what is of interest is how that experience is framed. According to Bury (2001), narratives that involve chronic illness routinely provide accounts of the changing relationship between the person, the illness, and the available social roles. The NGOs, in turn, have a vested interest in (re-)producing social roles that are amenable to their organizational purposes, including recruitment of new members.

Five narrative elements were originally proposed by Labov and Waletzky (1967): *orientation, complication, evaluation, resolution*, and *coda*. Though originally intended for the purpose of analysing oral narratives, they've subsequently proved applicable to written texts – not least due to the debt they owe to older, Aristotelian categories (Bruner, 1997). In the analysis of personal narratives, different category systems serve different purposes. Here, the Labov and Waletzky schema is useful primarily because it marks and emphasizes the narratives' explanatory and communicative aspects. The analysis focuses on interpreting narrative functions. Different parts of the texts may of course be assigned different or multiple category labels. Depending on the reader's stance, the most salient element of a narrative may be reconsidered – a story about receiving a diagnosis may also be a story about coping with a diagnosis.

Nevertheless, most texts include biographical facts, which may be considered part of the *orientation*. The *complication* may be one or more health related events, including but not limited to the appearance of symptoms and the arrival of diagnostic results. The *resolution* tends to be either the moment of diagnosis or the moment when a course of action is established. Although fundamentally ambiguous – no story about chronic illness can be entirely resolved – the moment of resolution is tied to the establishment of a new form of identity. The interesting part is what informs this identity. The coda is a variable element, usually focused on everyday details that elaborate the biographical facts presented in the orientation.

It is difficult to present the data in a way that preserves the individual narratives while highlighting the common or shared elements. At earlier stages in the analysis, tables organized according to Labov and Waletzky's categories were employed, but these eventually proved too schematic, obscuring the individual features. It should therefore be emphasized that the narratives excerpted here are only examples of ways in which diagnosis can be represented. The examples are broadly representative, though they do not, of course, give a comprehensive picture of the individual variations.

Two major arcs can be discerned in the material as a whole. One represents diagnosis as a complicating action, a problem that has to be resolved into treatment and/or cure. The other represents diagnosis as a form of resolution in itself. This is another way of saying, perhaps unsurprisingly, that a diagnosis can be a source both of relief and anxiety, of confidence and uncertainty. An example of the second arc is given below, from the neuromuscular narratives:

> *Narrative 1: Woman, 54 years old, neuromuscular disease:*
>
> Already as a young girl, I went to see doctors in order to discover why my arms and legs kept falling asleep. […] After several years, I was given a neurological exam and diagnosed with potential polyneuropathy. […] A blood sample provided the answer: Hereditary Neuropathy Pulsar Pressure. […] Today, I'm very happy that I was stubborn enough to get to the bottom of my own diagnosis.

Here, the narrative is motivated by the appearance of symptoms. They are mysterious but problematic, and remain so until the diagnosis is made. After that, a new sense of normality and/or equilibrium is established. Subsequent information is provided on the author's coping and life management strategies, particularly relative to work.

In Bury's (2001) terms, the text is both a "contingent narrative" (event-focused, about the causes and effects of illness) as well as a "moral narrative" (providing a justification of the narrator's new social role as a person with a significant impairment and a correspondingly reduced activity level). It emphasizes the author's choice of living equably with her diagnosis. A similar pattern is displayed in the MS narratives:

> *Narrative 2: Woman, 44 years old, MS:*
>
> [She] has had MS for 18 years. […] Eventually, [she] entered a progressive phase. […] [Now] there was nothing further that medical science had to offer. […] [She] does what she can with the situation. […] 'I try not to bury myself in this, try to see opportunities and focus on what I can manage. I think I'm pretty good at that.' […] 'For now, I'm going to live as well as I can, and not think about MS.'

The texts become culturally significant core narratives partly by dint of their publication context. There are no direct mentions of the terms "disabled" or "disability" (i.e. the Norwegian words *funksjonshemmet* and *funksjonshemning*) in either the neuromuscular or MS narratives, but they are available for reading on websites that embed them within a context saturated by disability discourse. Their narrative structure enables the normalization of disability by having the resolution of diagnosis lead into codas centred on everyday life management.

Narratives presented by NGOs are, of course, exemplary texts, chosen partly because they present a view that is acceptable to the NGO in question. But precisely for this reason it is interesting to consider the ME narratives. They are similar to the above narratives in many respects, particularly as regards coping and overall life management, but place a stronger emphasis on and are in two cases structured around the possibility of cure.

> *Narrative 3: Woman, ME:*
>
> A long time ago I got a viral infection that I didn't recover from. […] [Eventually I] found answers on how to get well. Now I'm on my way back. […] Problems are there to be solved, at least in my head. […] [Web link embedded in original text:] Here you can read more on the kind of treatment I follow.
>
> *Narrative 4: Woman, ME:*

> I'm mostly to be found at home with my husband and two children. […] I've tested positive for the HIV-like XMRV virus, and intend to start treatment for this in September. […] I still follow Professor De Meirleir's treatment, it costs all my savings and then some, but it slowly but surely gives me my life back so it's worth every penny.

> *Narrative 5: Woman, ME:*

> On this blog I […] share things from my own life, amongst other things what it is like to live with ME/chronic fatigue syndrome. […] Besides this I'm 33, originally from Trondheim, currently living in Oslo with husband and part time bonus children. […] The blog was meant to be a place for professional reflection and travel, but when illness entered the picture, the blog took a different direction too. […] Where this blog will end up in the future, nobody knows! ☺

The ME narratives serve many of the same purposes as the other narratives. They are acts of self-presentation performed by people with a particular diagnosis, directed to some extent at people with the same or a similar diagnosis. Recurring features include: a) confusion and worry connected with the display of symptoms; b) relief tied to diagnosis; and c) orientations, evaluations and codas that deal with overall life trajectories and situations. The texts do not deal exclusively with health, although they include a considerable amount of medical detail, and consistently refer to the health and bodily aspects of their experience in a life-world context. They are about noticing a set of symptoms, seeking a diagnosis, finding a diagnosis, and restoring a form life that was there previously ("gives me my life back"). The salient differences have to do with this return to a previously established identity and with the foregrounding of treatment: the narrators are themselves agents that seek out potential cures, and their quest is not just for a diagnosis but for restored health. In the cases of narratives 3 and 4, normal life is deferred, to a much greater extent than in any of the neuromuscular and MS texts.

The ME narratives are much like the MS and neuromuscular texts when considered as contingent and moral narratives. They give case histories, represent the diagnostic moment as a narrative crux, and legitimize the life the author is currently leading. But in the case of ME, the new social role being legitimized is also that of the cure-seeker. This in turn impacts the texts' status as core narratives, particularly when they are considered in their publication context. Unlike the neuromuscular and MS associations, the ME association does not use the terms "disability" and "disabled" at all. For this reason the narratives become substantially different – while broadly similar in their content, they have radically different orientations.

What Does it Mean to be Both Chronically Ill and Disabled?

What is medicalization? Peter Conrad has defined it as "a process by which nonmedical problems become defined and treated as medical problems, usually in terms of illness and disorders” (Conrad, 2007: 4). At the beginning of this chapter, Susan Wendell described a moral corollary to this process, in which “disability is regarded as an individual misfortune, and people with disabilities are assumed to suffer primarily from physical and/or mental abnormalities that medicine can and should treat, cure, or at least prevent”. Conrad points out that medicalization tends to remove moral responsibility from individuals for their condition, but it does so partly by shifting the burden of responsibility (and agency) to others – primarily medical professionals and institutions.

This perspective is hard to reconcile with at least some political and social goals that are absolutely central to the disability movement, i.e. those goals that necessitate the most thoroughgoing changes to social structures that have little or nothing to do with medicine. If disability is suffering that can *and should* chiefly be alleviated by medicine, what is the purpose of social change? Medicalization is a rhetorical phenomenon in that it presents disability as a particular kind of problem, which entails a particular kind of solution.

But as we’ve seen, “medicalization” is hard to identify and even harder to isolate. Even within the context on highly socio-political organizations “by and for” disabled people, medical *discourse* proliferates and is a crucial tool for maintaining organizational integrity and purpose – certainly this is the case in FFO. The problem, in such a context, is more to do with how disability grafts on to and gives direction to medical discourse. It is a problem of identification and solidarity.

Narratives from all three diagnostic categories/organizations situate the experience of diagnosis within the discourse of normal life. From an organizational point of view, they substantiate the claim that normal life is possible for people who have received that organization’s diagnosis. The emergence of symptoms followed (eventually) by diagnosis constitutes an identity crisis, which can nevertheless be resolved by adaptations, whether new medical regimes, the use of technical aids, and/or a new relationship with government agencies. Equilibrium and normalcy is reasserted, even in cases where further decline is expected and the future is uncertain. This is unsurprising, as there is likely to be a strong selection bias on the part of the NGOs that publish or recommend the text.

Within that framework, the narratives display the very different organizational attitudes to disability. The ME narratives do not mention the words “disabled” and “disability” (*funksjonshemmet* and *funksjonshemning* in the Norwegian). They are more prominently featured in the MS and neuromuscular narratives – while they do not fundamentally change their content and communicative function, they effectively add another dimension. It is possible, in many cases, to reconcile illness narratives and disability narratives – in effect, to apply the word “disability” to certain life areas.

The ME narratives strongly emphasize treatment and potential cure, but they do, as do all the texts, deal to some extent with the key areas of everyday life: family, relationships, work and hobbies/interests. The MS and neuromuscular narratives differ in that they describe medical and surgical interventions in terms of coping, not cure. It is in this respect that the ME texts are different – they all focus on curative possibilities. This coincides with the absence of any explicit mention of disability on the website of the ME association (which is nevertheless a member of FFO, the disability umbrella). The implication is that disabled identity is played down or avoided when the provenance of a condition is uncertain, as with ME, or when a cure is posited as a short-term possibility (as opposed to MS and the neuromuscular diseases).

There is no known cure for ME, and the Norwegian ME association explicitly does not endorse specific courses of treatment. The single most important distinguishing feature between the ME narratives and the other narratives is the *degree of uncertainty* with regard to cure. And this presents a considerable dilemma for disability advocates. If the absence of evidence is enough to eliminate disability identification, then disability identification must not be a very enticing strategy for many people.

The above point is perhaps not too surprising. It supports the case made by the World Health Organization that disability is under-reported because of stigma associated with the word and/or the category. There is probably a greater willingness on the part of people with MS and neuromuscular disorders to identify themselves as disabled than on the part people with ME because people with ME can plausibly claim the identity of being (temporarily) ill. What is interesting is that 1) the ME narratives and the MS/neuromuscular narratives share a number of features as well as the normalizing impulse; and 2) the ME organization is, in fact, a member of the disability umbrella organization FFO.

There is, perhaps, a political space that is more comfortably occupied by an umbrella organization such as FFO – a space that bridges the gap between the biographical disruption of chronic illness and the permanent predicament of disability. Tom Shakespeare quotes Kathy Charmaz's suggestion that "[c]hronic illness assaults the body and threatens the integrity of self. Having a serious chronic illness shakes earlier taken-for-granted assumptions about possessing a smoothly functioning body" (Charmaz, 1995: 657). This encapsulates one of the primary distinctions between the perspective of Disability Studies and the perspective of many other approaches to health and illness. To state that there *is* a taken-for-granted assumption about a smoothly functioning body is to elide the perspective and experience of a significant number of people who have been born not only with a range of different impairments, but with illnesses. That this perspective nevertheless appears present and indeed prominent in the organizational structures in the disability field suggests that there is ample work to be done in analysing chronic illness, particularly acquired chronic illness, in its relation to disability.

Disability Prototypes and the Problem of Identification

The history of FFO is one of expanding membership. Originally, its members were associations for people with hearing impairments, mobility impairments, and pulmonary diseases. Today's membership of 75 associations numbers far more (and more specific) diagnostic categories than ever before. These categories are all part of the discourse of disability, but some categories have stronger connections than others. Disability identity is more symbolically prominent in organizations that match what the WHO has termed "classical types" of disability: organizations that represent people with mobility impairments, preferably wheelchair users, people with hearing impairment, and so on. They suggest a prototypical category system of disability – one that is perhaps tied to recognizable visual identifiers: wheelchairs, hearing aids, walking canes.

The global visual shorthand for disability is a wheelchair or wheelchair user, as represented on innumerable accessible entrances, lavatories, parking spaces, and service counters. The symbol is often supplemented by other symbols, and in any case it is not meant to be exclusive. And yet, the suspicion of simulation is a familiar topic in Disability Studies, known to be directed at anyone who does not fit the disability prototype. Unless a person with, say, ME, does in fact use a wheelchair, he or she is likely to be at the categorical periphery – far from the prototype. He or she has a double incentive not to identify as disabled: a greater risk of sanctions – of suspicion – and a better chance of passing, that is, to avoid projecting a stigmatized identity.

Disability is defined relative to able-bodiedness even more than illness is defined relative to health. Impairment is deviation from a statistically or otherwise defined bodily norm. Some of the most famous motifs in Disability Studies are attempts to demonstrate and subvert this fact. One counterfactual example is Vic Finkelstein's fable in which a local community physically adapted to the needs of wheelchair users, leaving walkers to bang into doorways and develop back problems from constantly stooping to low counters and tables. Anthropological examples tend to focus on communities in which sign language is a majority rather than a minority language, whether on Martha's Vineyard or in Mexico.

In conjunction with the industrial and post-industrial connection between disability and unemployment, the norm-and-deviation-frame implies that "disabled people" will always be in the minority, usually a quite small minority, if for no other reason than that the category is predicated on the kind of socio-political marginalization that cannot be sustainably applied to a very large segment of the population. It is very difficult to conceive of a sustainable society in which a majority, or even a large minority of the population were disabled in the current sense of the word.

The purpose of disability activism, of course, has been both to change the meaning of the word *and* the conditions of disabled people. This book focuses primarily on the meaning of words; in this particular case, on the reasons why the word "disabled" seems irrelevant or threatening to so many people with chronic illnesses. In the above example, it appears that multiple incentives (and the lack of same) are in play. First, the category of "illness" covers one's needs to tell a meaningful, recovery-oriented story about one's situation, while the word "disability" implies an augmented level of debility. Second, the concept of "disability" relates mainly to bureaucratic and political issues that do not impinge directly on individuals' life-worlds. Third, "disability" relates to a marginal identity, while "illness" describes a more universally accessible form of experience.

A major purpose of narrative structure is the extraction of meaning from events. The experience of serious illness or bodily impairment is often accompanied by a loss of meaning; narrative structure is a strategy for re-imposing it. This is of considerable significance for Disability Studies. Much of the effort spent on theorizing disability centres on the ways in which social, cultural, economic, and political factors interact with biophysical factors – and on how people come to consider themselves "disabled" in a social, cultural, economic, and/or political sense, rather than simply "ill". That question is in itself significant because of its presupposition – that illness precedes disability. Even in disability NGOs, and even in such organizations' text and talk directed at their own members, disability remains a secondary category, and represents an additional level of analysis.

This chapter is largely about medical discourses of disability, and the tentative conclusion is that medical discourse remains hegemonic, or very nearly hegemonic, even in a context where socio-political thought on and language about disability is ostensibly dominant. What does this tell us? It is not *a priori* desirable that as many people as possible come to understand themselves as being disabled. But it is presumably a good thing if concepts of disability and disablement, as developed and theorized in Disability Studies, are seen to hold some relevance for the life experiences of the population in general.

Disability Studies has made major contributions to the understanding of how bodily difference and social marginalization are intertwined. The story of how disability has become a meaningful part of social discourse is also the story of the emergence of a new perspective on social inequality. And that story cannot, ultimately, be told without a significant number of people identifying as disabled. The number must be high enough that disability can be shown not to be tied *essentially* to any bodily or medically defined feature or characteristic. In a sense, the question is how to harness medical discourse: how to find ways to organically integrate a socio-political concept of disability into a medical discourse, and vice versa.

A version of this dilemma is integral to the previously mentioned attempts to revise the British social model of disability. These efforts have often focused on the analytical division between socially imposed disablement and biophysical impairments; from the mid-1990s onwards, revisionists have attempted to include impairments, and embodiment, as integral parts of the social model (Crow, 1996; Thomas, 1999). Those efforts targeted – and continue to target – the aspects of disabled experience that are the most susceptible to framing in medical terms. In order to succeed, they must find some way to include, adapt and relate to medical discourse, which cannot be ignored, but can, perhaps, be accommodated and dealt with on a constructive basis.

This "constructive" framing is, in a sense, both normative and problematic. The texts analysed in this chapter are ostensibly positive framings of the process of receiving a diagnosis. All of the texts have either been edited or endorsed by a disability NGO that is engaged in community building and the development of positive identities for disabled people. That, in itself, isn't an obvious goal for academic work. Moreover, even if the goal is accepted as legitimate, it is notoriously difficult to find a robustly positive definition of disability. Unlike definitions of ethnicity, gender and sexual orientation, all of which categories are frequent bases for comparison in Disability Studies literature, any definition of disability invariably includes an element of inherent disadvantage.

But the discussion of positively inflected identities is in fact at the heart of even critical Disability Studies, which aims at least in part at subverting the value hierarchies expressed through and embedded in culturally hegemonic ableism. Nevertheless, the category of disability remains negatively inflected. Even definitions that play down the role of individual bodies and impairments in the production of disability – e.g. the "Fundamental Principles of Disability" (UPIAS, 1976), or versions of the British social model as articulated by Oliver and others (Barnes et al., 1999; Oliver, 1990) – depend on social, economic, and political marginalization as a way to delimit the class of disabled people.

Disadvantage is, almost tautologically, at the centre of most definitions of disability. The disadvantage can be framed as oppression (Oliver, 1990), as crimes (Thomas, 2007), and as the negative impact, psycho-emotional and otherwise, of the ideology of ableism and concordant exclusionary disablism (Goodley, 2010).

Compared with other definitions, such as the Nordic conception of an agency-free "gap", such definitions serve mainly to allocate the responsibility for the unfairly distributed disadvantage. This difference is mainly important for the setting of political goals and strategies (and tells us something about the expectations that Disability Studies have of their respective states and societies). But it also tells us something about the profound difficulty of articulating a category of disability that is not profoundly alienating to the people who might be expected to identify with it.

Given a range of symptoms and impairment effects, an individual faced with the question of identifying as ill *or* as disabled will choose illness nine times out of ten: identifying as ill has the sometime advantage of carrying a smaller and potentially temporary stigma, while identifying as disabled has the disadvantageous connotations of both permanence and a more heavily stigmatized social role. If disability entails the acknowledgement of further and more permanent disadvantage – whether of psycho-emotional harm or of a wider "gap" between one's actual and desired life situation – it should be accompanied by some form of benefit, whether in material or immaterial form.

The formal or technical acknowledgement of disability is, particularly in a welfare state, a precondition for many services and goods. Those benefits are quite tangible, but they are not strongly linked to a self-identification as a disabled person, or a subject of disablement. To a great extent, this problem is expressed in the Norwegian NGO system itself. All three organizations discussed in this chapter are members of an umbrella organization that emphasizes disability to a greater extent than do the member organizations.

It is quite possible, in other words, to self-identify as ill, not disabled, and nevertheless be an indirect member of a disability rights umbrella organization and receive what are effectively provisions for disabled people. This presents the possibility that a significant number of people – of which people with ME are representative – are so uncomfortable with the idea of being disabled that they would *only* accept indirect membership in a disability NGO. But this situation may be temporary, since people whose diagnoses have a longer history have an easier time describing themselves as being disabled.

The problem is also expressed, in different ways, in many other political systems – and that is the topic of the next chapter. The narratives analysed in this chapter suggest that stories about illness can, under certain circumstances, become stories about disability. This implies that disability is a category whose edges are less sharp than is sometimes suggested. The question, which is essentially a political question, is what circumstances create permeable category boundaries, i.e., allow for disability as a politically, economically and socially progressive concept and category system.

Chapter 4

Political and Economic Discourses and the Limits of Language

The concept and category of disability is of course embedded not only in medical but also in political and economic discourses. These frequently break down along national lines, as does much of the body of research that deals with them. In one country alone, from the pioneering studies of the early-industrial origin of the "unemployable individual" conception of disability to recent analyses of "morally deficient scrounger" characterizations of disabled people, the range of discourses potentially match every significant historical trend in the organization of the state as well as the labour market.

This chapter will attempt to isolate and discuss one particular line of argument – one where disability is seen as a concept which, however cleanly and programmatically it is defined, inevitably and immediately becomes enmeshed in local power structures, bureaucracies, and procedural regulations.

That argument mirrors the one made in the previous chapter, in which disability was situated with regards to medical discourse. A story about chronic illness, told in medical discourse, can be a story about the permanent search for a cure, or a story about the new life situation of disability. This depends greatly on the context in which the story is told, by whom and to what kind of audience. Similarly, political and economic discourses of disability can present the concept as a marker of stigma or privilege, and they can embed disability rights in a framework of autonomy, dependency, or for that matter even medicalization.

This chapter has two sections. The first section discusses two different frames of political/economic discourses of disability, namely the Anglo-American and the Scandinavian frames. Both frames are, of course, analytical constructs, but I will argue that it is possible and productive to maintain a distinction between the two – even if my subsequent act is to examine how the distinction becomes blurred in practice.

That blurring is the topic of the second section, in which I look at a Norwegian piece of disability rights legislation from 2009. On paper, the law in question represents a dual watershed in disability politics in Norway – the first implementation of formal anti-discrimination measures, and the culmination of a long tendency in Norwegian disability discourse towards the language of rights rather than the language of special accommodations and compensations. In practice, the law represents a somewhat less seminal moment in time, for reasons that have everything to do with the way in which disability is embedded in the fabric of the state.

A Tale of Two Discourses: Scandinavia and the Anglo-American World

Let us assume that there are Scandinavian and Anglo-American discourses of disability, and that they differ in a number of aspects. The most salient difference, for the moment, lies in the essential conception of the concept of disablement. In the Scandinavian discourse, disablement is conceptualized as a gap between the demands made by an essentially benevolent society and state, and the capabilities of a person with impairments who can nevertheless become a fully integrated – and *normal* – member of society. Disability is the predicament that results from that gap.

In the Anglo-American discourse, disablement is conceptualized not as a gap, but as a form of oppression or imposition. Disability results from active or passive discrimination and the abrogation of rights, or alternatively from the insufficient interpretation of rights as they apply to people with impairments. The predicament of disability is, to a much greater extent than in Scandinavian discourse, a consequence of neglect or open hostility on the part of the state.

These discourses, such as they are, stem primarily from disability research about the Scandinavian countries, the US, and the UK. They are centred on, respectively, the so-called gap model, the minority model, and the social model of disability; the models are, in their turn, attempts to capture the essential dynamic of disability in a given society. As I've discussed previously, I prefer to talk about discourses rather than models, because the discourse perspective allows for more variation – a person or text does not have to adhere very closely to a particular model in order to be counted as part of a discourse. Moreover, there is a feedback loop built into the discourse perspective: The Scandinavian discourse of disability changes over time, as the documents, individuals and institutions that make it up change themselves.

Even so, the models mentioned above can be treated as key topoi of the discourses in question. In Anglo-American discourse, the British social model and the American minority model are absolutely central topoi, in that they form the basis for specific arguments about disability in various social and political contexts. They can legitimize state intervention and services, anti-discrimination efforts, legal provisions, and so on – just as the Scandinavian gap model can serve as a multi-purpose legitimation strategy for such efforts, in conjunction with even more general and abstract precepts of social justice and economic redistribution. As long as "disability" is in some way construed as a political or social problem, models of disability such as the three referred to here will effectively serve as bridges in argumentation, providing blueprints for how to approach the problem in specific contexts.

This first part of the chapter is a look at the two sets of blueprints. As I've pointed out, US, UK, and Scandinavian discourses on disability differ considerably, and partly in keeping with national political traditions. Scandinavia in particular provides a laboratory for observing the mixture of discourses, as American-inspired language on anti-discrimination is implemented without the requisite legal safeguards. Effectively, different blueprints are being adopted – with varying degrees of success.

This is, in a sense, a discussion of the limits of textual analysis and discourse analysis, and a discussion of the limits of the importance of language in general. In this book on disability and discourse analysis, part of my intended message is, paradoxically, that words are not *that* important. Rather, their importance rests in their context of usage, and in the people who use them. Discourse analysis, as discussed in Chapter 2, is not reducible to textual analysis – its remit includes situational and comprehensive contexts. This means that it must be very aware of, must respect, the limits of language. For example, it must be aware that formulations from the United Nation's *Convention on the Rights of Persons with Disabilities* can and necessarily must have vastly different implications in different countries, in accordance with those countries' political priorities and economic resources. That point is directly related to my previous argument about not taking either the "medical model" or the "social model" as unitary entities.

Ostensibly Universal Concepts: The WHO and "Disability"

Discourse analysis teaches caution in taking language at face value, and stresses the necessity of following the textual trail as far as possible, i.e. from "top level" declarations of intent to bureaucratic implementation in everyday, run-of-the-mill texts, as well as interactions that involve such texts. That makes it difficult and time-consuming to conduct; under ideal conditions, it works from much greater quantities of material than what forms the basis of this book. Under real-word conditions, the closest compensation at hand is field-specific literature, i.e. histories of and investigations into disability as it is construed in different countries.

To wit: what are disability rights? The modern state has traditionally viewed disabled people as passive victims of personal tragedies, fit mainly for medical intervention or institutionalization (Oliver, 1990). This is true in many countries, in many historical phases. Moreover, there are many ways to challenge that view. In North America and Western Europe, the challenge has come from activists, scholars and organizations with indirect or tenuous connections to the state, but also from politicians and bureaucrats directly in state employment. Disability rights can be viewed as concessions wrested *from* the state, or as adjustments made *by* the state – in the interest of the general public good, or in the interest of a minority of citizens.

The differences between such perspectives can turn out to be quite important, as the consequences of the transformation we are currently experiencing are not yet fully known. We – the big we – haven't yet decided what disability rights are. The discourse in which such rights can be justified, established, clarified and elaborated is still taking shape. It is discourse that touches on fundamental, philosophical concepts: one of the key challenges that faces the disability rights advocates, lawyers and policy makers who produce such discourse is that of defining what "equality" means for people with very different abilities and potential. People with very different impairments are discriminated against in very different ways by social, physical and economic arrangements, and ensuring equality is not simply a matter of removing barriers or eliminating prejudice.

There are benefits, in this situation, to employing universalist discourse. There are, according to the World Health Organization's estimate, roughly one billion disabled people, all told. Its definition of disability in the *World Report on Disability* is staunchly universalist:

> Disability is a part of the human condition. Almost everyone will be temporarily or permanently impaired at some point in life, and those who survive to old age will experience increasing difficulties in functioning. Most extended families have a disabled member, and many non-disabled people take responsibility for supporting and caring for their relatives and friends with disabilities. Every epoch has faced the moral and political issue of how best to include and support people with disabilities. This issue will become more acute as the demographics of societies change and more people live to an old age. (WHO, 2011: 3)

"The human condition", "almost everyone", "every epoch": this is a strong universalist definition, which puts disability simply in the context of "life" and common human vulnerability. It makes sense as the lead-in to a report that is, in principle, about and for a universal readership. Of course, the universalist principle is not uncontroversial – it can, for example, blur the difference between significant impairments and smaller, less important variations in human characteristics and capabilities. If the starting assumption is that we are all either disabled or potentially disabled, then what exactly is the category *for*?

Consequently, the *World Report* very quickly moves to anchor its discussion in a reference to specific groups of disabled people, namely blind people, deaf people, and wheelchair users. The rhetorical move in question is actually quite sophisticated – the groups in question are used as cognitive anchors, even as the report emphasizes that disability is *not* restricted to people with "classical" visual, hearing, and mobility impairment, but affects a great variety of people with, for instance, chronic illnesses. Disability is defined as influenced by public health conditions, by political conditions, by cultural conditions, and so on.

So the answer to the question "how can you provide a general definition of disability?" is, for the moment: you can't. You can, as the *World Report* does, provide approximate definitions and aim at a plausible picture of the situation in many countries, while acknowledging the lack of adequate information and statistics. You can acknowledge that there is no objectively available line to be drawn between short-term and long-term illness, and that it is not clear when potentially curable chronic illnesses should be distinguished from ostensibly permanent impairments. You can acknowledge the limitations, and move on to specific examples, as the report does.

Disability as Gap

The Scandinavian gap model is anchored in and made possible by the Scandinavian welfare state. Certainly, without general acceptance of the underlying moral and political principle that the state should safeguard the wellbeing of its citizens whatever their life circumstances, the "gap" must be conceptually reconfigured. As it is currently understood, it refers to the differential between "full participation" in different spheres of life, and less-than-full participation in same. What exactly "full participation" means tends to be unclear; it may be a paraphrase of the *normal range* of participation.

The notions of normality and normal life is obviously tied to the different life stages. The welfare state's safeguards are predicated on the normal level and range of activity at various stages, from free education in childhood and early adulthood through unemployment benefits throughout adult life to pensions following the age of retirement. Citizens are to be provided for in different ways according to their changing circumstances; this includes child benefits for those who become parents, and health insurance in order to support people who become ill. The schemes have multiple interconnected purposes: to ensure a certain amount of redistribution of wealth, which in turn ensures a minimum standard of living, which in turn provides the baseline conditions for people to have a minimum quality of life.

The safeguards help to reduce socioeconomic inequality; they compensate for different conditions and states of being which would – without compensatory efforts – result in acute inequalities. The reasoning is based on a hypothetical: impairments, in this view, are latent causes of inequality. Having unusual bodies, negatively anomalous bodies, place people at a disadvantage in terms of capabilities, creating a gap between the level of participation they *could* have achieved, had they not been born with or acquired their impairments.

This social justice perspective places rights, to an extent, behind desired policy outcomes. Disability is in conceived of as a negative space or absence, to be minimized by the most effective available means, which can target either the capabilities of the individual or the demands of society. The distance between these two entities can be decremented through both individual-oriented and community-oriented efforts, and it is not always easy to draw a line between the two. Technical aids, as mentioned previously, sometimes blur the line. If wheelchairs (and wheelchair repair) is made universally available through a publicly funded and administered distribution system, as is the case in Norway, does that count as an individual-oriented effort or as a form of social?

This brief sketch does not account for the minutiae of definitions, procedures and operational documents that are necessary for the gap model to be implemented. And in recent years, starting with the white paper entitled *From User to Citizen* (NOU, 2001), efforts have been made to specifically identify the group of people subject to the disablement gap as *people with impairments* ("funksjonsnedsettelser") who should have *rights*, in the anti-discrimination sense of the word.

The gap model is in principle quite open and flexible, as well as ambiguous. The demands or requirements made by society can be interpreted in terms of physical strength and stamina (as required for physical labour), but also in terms of qualifications such as education level. In some cases, then, adjusting the level of demands will be a matter of changing the physical environment, in some cases of providing adequate levels of technological assistance, but in many cases a much more complicated matter. “Demands” on education levels can’t very easily be altered by individual industries or even individual nations. Even in the relatively specific case of using the gap model to analyse the job market, therefore, the relationship between individual capabilities and systemic demands is difficult to delineate. If individuals are provided with income support in one form or another – if their employment is subsidized – does this in any way alter the structural demands in the job market?

In a sense, the gap model is utopian, envisaging a world in which disablement can be fully eliminated. If people are not presented with unreasonable demands, if they are built up by the state and society in which they live, they can, regardless of their impairments, come to live lives that are fully integrated with the societal mainstream. And this perspective is valuable, partly because it preserves a sense of universalism. Disability becomes a social ill that is not causally restricted to individual impairments, but rather to the universal *risk* of impairment. The gap model, then, approaches a Rawlsian idea of ideal social arrangements, where the labour market and welfare arrangements, among many other things, are laid out so as to provide justice whatever one’s bodily circumstances. In that, this ideal goes well beyond Rawls himself, who did not, ultimately, present inequality of physiology as a matter that could be taken into account in the provision of social justice.

Disablement is neither natural nor unchangeable in the gap model, but an aspect of its flexible and dynamic definition is that it makes it hard, in some cases, to clearly account for what constitutes an impairment (as opposed to insignificant variation in human capability). This leads to some interesting questions, partly familiar from the discussion of universalism. First, it appears to entail a highly relativist definition of impairment. If there is some slight disadvantage to an individual’s physiological characteristics (red-headedness, say), a disadvantage which *in combination with societal norms* leads to lower employment rates and social marginalization, who is to say that this characteristic is not tied to disablement? Conversely, if there are no or few mechanisms of social disablement linked to a particular form of impairment, as could conceivably be the case with slight muscular weakness in a highly developed, highly mechanized society, must the definition of “impairment” be restricted to ever more severe forms of negatively valued physiological difference?

In practice, of course, the gap model appeals to medical judgement and medical discourse. Disablement is administratively restricted only to people with medically certified impairments, partly for fear that someone might exploit the scarce goods that are distributed in order to compensate for impairment. The mechanisms are plainly laid out by Deborah Stone:

> The link between the formation of disability and its definition as a medical phenomenon is the concept of deception. The other two major categories of

> modern social welfare policy, old age and childhood, were always assumed to represent authentic states of being, totally independent of the will of individuals. Disability, on the other hand, even in its early incarnations as more specific conditions, was seen to exist in both genuine and artificial forms. People could either be truly injured or feign injury. In the modern understanding of disability, deception has become part and parcel of the concept itself, and the nature of this deception is tied to the particular form of validation used to detect it. The definition of disability and the means to determining it became critically linked. (Stone, 1984: 28)

The gap model, as administered by the welfare state bureaucracy, becomes a system of privileges, distributional procedures, and validation procedures. One practical consequence of this fact is that the gap will never be fully closed. Given the limitations imposed on compensatory measures, they also tend to be clearly marked as such, and their recipients as also belonging to a special category of citizens. An obvious example is the implementation of para-transit systems, i.e. transportation services that are intended to allow people with impairments to enjoy the same level of mobility as the general population.

A common way to provide this service is through designated shuttles or vans, capable of carrying wheelchairs and owned by companies that specialize in providing such services. Effectively, a separate fleet of cars is put on the roads, usually marked with wheelchair symbols, in order to integrate people with impairments. Is the disablement gap removed in this case? It would only be possible to argue the case if para-transit services were consistently equal to public transportation in general – and this is unlikely to happen as long as such services are (as their name suggests) approximations of general-purpose transit systems.

One (general) service or activity serves as the baseline and point of comparison; another tries to approximate. Even in utopian terms, in this perspective people with impairments can only close the gap. They can only remove the negative space. It is difficult to conceive, in this model, a way for people with impairments to achieve anything beyond the average, anything beyond the normal – whatever that is.

Vanishing Impairments? Implicit Standards and Points of Reference in Models of Disability

The gap model and the welfare state have depended upon routines and standards for implementing compensatory measures. Even if disability and disablement are construed as socio-political entities, they must at some point encounter individual bodies in order to become meaningful. This is also true of the British social model, however one wishes to define it. *The Politics of Disablement* (Oliver, 1990), for example, was an attempt to introduce hitherto unacknowledged social, political and economic causes of disablement; not to ignore physiological causes. Its conception of disablement is similar in many respects to the gap model, but with a greater emphasis on the unreasonable demands made by society.

Oliver's analysis of industrial capitalism focuses, as do analyses by Brendan Gleeson and other scholars, on the lack of competitive ability that people with impairments have in certain contexts, under certain conditions, compared with other people. There is nothing principally in the way of combining such an analysis with a capabilities/demands-type political agenda; the main analytical difference lies in the conception of the state, as well as most capitalist employers, as essentially hostile.

Once an adversarial interpretation is used to explain the marginalization of people with impairments, disablement becomes not an agentless "gap", but a form of active oppression. Outside of that, the people who become marginalized must still be identified with some reference to physiological capability. Whether disablement is then described either as politically rational or as politically unacceptable depends rather more on what kind of political discourse is at work – and, for example, on whether it is economically and morally inflected.

Oliver argues that people with impairments bodies become disabled mainly because it is considered economically rational. That is to say – the very idea that there is a clear distinction between the disabled and the non-disabled only comes into being in its modern sense because people play certain roles and society is organized in a certain way. A "disabled person" really *is* one who cannot compete with the broad field of workers under certain conditions, *not* a person with impairments placed in a certain context.

This analysis is in many ways identical to the social understanding underlying the gap model. There, disability arises in the mismatch between the requirements that come with a social role, and neither the role nor the requirements exist independently:

> The idea of disability as an individual pathology only becomes possible when we have an idea of individual able-bodiedness, which is itself related to the rise of capitalism and the development of wage labor. [… Disabled] people could not meet the demands of wage labor and so became controlled through exclusion. (Oliver, 1990: 47)

In this example, the "social model" is an analytical tool designed for the identification of these control mechanisms – these instruments of oppression – whereas the gap model is a tool for the identification of the agentless phenomenon of disablement. Research in the tradition of which Oliver is a central member is fundamentally oriented towards identifying disabling processes and conceptualizing disability as oppression, and the more hostile the society under analysis is towards people with impairments, the better the analysis fits. A relatively benign welfare state, where many actors see the benefit and value of the thorough integration of people with impairments, does not fit as well with this understanding.

It is in this light – that of analytical purpose – that the models and their accompanying discourses should be viewed. That light can become relevant, too, to the much-criticized inattention to impairment in the social model tradition.

The social model has been held to play up the distinction between impairment and disability to an untenable degree, and to unreasonably reserve disabling mechanisms for social, political and economic arrangements. A case in point is Vic Finkelstein's utopian fable (Finkelstein, 1975) about a village or small community built *primarily* for the needs of wheelchair users rather than walkers. His argument was partly that a majority population of wheelchair users would dictate an environment adapted to *their* needs, necessarily an environment without stairs, steps, and so on – and possibly also with lower ceilings, fixtures, and so on.

The point of that fable was emphatically not to deny the problematic aspects of impairments that some wheelchair users have; to read it as such is to deny its context and function as a political argument. It is a form of discourse which is aimed at identifying certain causes of disablement, not to obscure others. That it may be interpreted as doing so probably has more to do with the limited attention any of us can pay to complex causal relationships; talking about one thing inevitably means not talking about something else, for the moment.

Social model analysis obviously involves much more than the physical environment. It is a kind of analysis well-suited for dissecting certain institutional arrangements, perhaps primarily those of the labour market. It is embedded in socio-political discourse, which is apt for posing questions such as: what are the prerequisites for being able to work, and why?

Deborah Stone, in *The Disabled State*, sketched out parallel economic systems for the industrial and post-industrial era: a primary system which rewards performance, and a secondary system that caters to medically certified needs. A key observation of this system is that it can be very benign or very draconian, depending entirely on the political tendency of the state in which it is implemented. Furthermore, independent of its implementation, it can be conceived of as a form of collaboration (gap model) or as a form of political *agon* (British social model). It is probably not accidental that Stone is just as much of a canonical reference in Scandinavian as in British and US Disability Studies.

My (recurring) point is that the models are very, very flexible. Carol Thomas demonstrated as much when revising the social model as follows:

> **A social relational definition of disability**
>
> Disability is a form of social oppression involving the social imposition of restrictions of activity on people with impairments and the socially engendered undermining of their psycho-emotional well-being.
>
> **Disability and impairment effects**
>
> The lived experience of many people with impairment in society is shaped in fundamental ways by the interaction between, and the accumulative impact of, disability (or disablism) and impairment effects. However, a careful *analytical* distinction needs to be made between the consequences of disability and

> impairment effects. The most fruitful way forward is to develop an approach which understands disability as a form of social oppression, but which finds room for the examination of impairment effects. (Thomas, 1999: 156)

Here, the "oppression" frame is preserved, and even extended. In other ways the "social model" is very different from earlier incarnations, but the differences appear primarily through its extension into other forms of discourse. It becomes different (and, generally speaking, more nuanced) by being applied to new examples and being made to do new work. As models, and theories, should:

> Theory should do something in the social world: enhance our awareness of inequality and, wherever possible, permit new ways of thinking about disability affirmatively. Theory can shift our focus away from the perceived pathologies of disabled people on to the deficiencies of a disabling society and an [ableist] culture. (Goodley, Hughes, & Davis, 2012: 4)

Doing the Work: Models in the World

The British social model is in use, in various forms, far beyond the borders of Britain. It has a broad appeal, but not a universal one. The last piece of this particular puzzle is the relative lack of US interest in a class-based approach to disablement, which coexists with arguments about social justice that are familiar not only from the British, but also from the Scandinavian contexts.

The British social model and the gap model alike are embedded in forms of discourse that chiefly explicate and are oriented towards matters of economics and resource allocation; this is their frame of reference for discussing the relationship between individuals and structures. Although US research on disability is highly diverse and extensive, from a European perspective, whether anchored in Britain or Scandinavia, it is remarkably grounded in the humanities and soft social sciences – concerned with identity and culture, and practiced by literary and film scholars, philosophers, and anthropologists.

The American tradition defines itself partly by its strong interest in cultural expressions and representations of individuals' experiences. Among the most prominent texts in US Disability Studies are memoirs with a scholarly or political bent, or, conversely, scholarly texts suffused by memoir. The tendency to intertwine historiography and autobiography is not uniquely American, but it does have some very prominent American exponents (Bérubé, 1996; Linton, 2006; Siebers, 2008).

I do not intend to summarize or even engage extensively with identity politics and its academic corollaries here, merely to point out the following: many American movements connected with various forms of marginalized identity politics, including post-war feminism, the civil rights movement, groups representing indigenous people, as well as gays, lesbians and other sexual minorities, have talked about politics without talking primarily about class or economics. This is partly the case in the disability movement as well. The US "minority model" of disability is embedded in a discourse of identity and cultural community in a way that the gap model emphatically is not. This reflects, too, the minimal character of the American welfare system.

Each model has different analytical and pragmatic goals. Arguments directed at the state, whether the state is ostensibly obligated to listen or not, are necessarily different than arguments aimed at recruiting individuals. Arguments aimed at constructing or legitimizing the existence of a culturally distinct minority are different from arguments aimed at explicating the compensatory measures required by individuals.

There is, of course, plenty of political discourse in the US disability field with very direct economic consequences for individuals, including the two landmark pieces of legislation – the Rehabilitation Act of 1973 and the Americans with Disabilities Act of 1990. Both have been framed, however, as recognizing the disabled *as an American minority*. While each law included many provisions affecting the allocation of funds, the provisions of services, etc., disability activists and many disability researchers have consistently framed the laws as landmarks because of their implications for identity politics.

There are many unresolved questions about what it means to be part of a minority and to have a minority identity, and what it means for a minority to be defined as a group that must be recognized and protected by legal safeguards. The overall topic of the next section of this chapter belongs to this area: what happens when minority rights discourse is introduced into a new and relatively unfamiliar legal context.

Mixing Discourses: The Norwegian Discrimination and Accessibility Act

Over the last few decades, as we know, comprehensive bills that define disability as a matter of universal human (or civil) rights and thus as a suitable target for anti-discrimination measures have nevertheless been introduced in a number of countries and territories. These include, but are not limited to, the United States (1990), Australia (1992), the United Kingdom (1995), and Ontario in Canada (2002). Quite recently, the Norwegian Department of Children and Equality introduced a legislative proposal entitled the *Discrimination and Accessibility Act*, (hereafter, the DAA), which entered into law on 1 January 2009.

One way of rephrasing this question is how the provision of equal opportunity for people with impairments in Norwegian society is tied to discourses that originate outside the disability field – in architecture, in public works, in the health professions, etc. From this it follows that we need to talk about what is still, according to Tobin Siebers, the "emerging field of Disability Studies" (2008). This field, emerging though it may be, is in constant danger of turning in on itself – of "producing the illness it seeks to cure", in the words of one reviewer of Siebers' book (Davidson, 2008).

One such illness, to go with the reviewer's metaphor, is the overindulgence in reductive theoretical models and the dichotomies between such models. I'll begin this section with an overview of the DAA, which is a six-page law supported by a 270-page advisory statement (hereafter, the AS). Thematically, it ranges over a wide variety of topics. This range follows from its central concern with equality.

> The purpose of the law is to promote equality and equal worth, to ensure equal opportunity and equal rights, and to prevent discrimination due to impairment. (Barne- og likestillingsdepartementet, 2009: 12)[1]

The range of the DAA follows from how the concept of equality gets translated into anti-discrimination measures that are specific to the disability field. As Tom Shakespeare has pointed out, preventing discrimination against people with impairment presents challenges that are unique, and very different from those that relate to anti-discrimination measures in the fields of gender and ethnicity:

> Women and men may be physiologically and physically different, but it is no longer possible to argue that women are made less capable by their biology. […] Similarly, only racists would see the biological differences between ethnic communities as the explanation for their social differences. Nor is it clear why being lesbian or gay would put any individual at a disadvantage, in the absence of prejudice and discrimination. But even in the absence of social barriers or oppression, it would still be problematic to have an impairment, because many impairments are limiting or difficult, not neutral. (Shakespeare, 2006a: 41)

Discrimination on the basis of gender (or ethnicity) may frequently be described as a form of negative intervention – an imposition of social barriers or oppression, in Shakespeare's terms. Discrimination on the basis of impairment, in contrast, is frequently a lack of positive intervention. Hence there is a need not only to claim that discrimination has taken place, but to explain precisely what the act of "discrimination due to impairment" consists of.

§2 of the DAA states that the act will apply in "every area of society, excepting family life and other relationships of a personal nature", prohibiting discrimination on the basis of impairment in all such areas. Specifically, it contains provisions that relate to:

- employment, education and social services (§3 and §12);
- harassment (§6);
- universal design standards for publicly accessible buildings and concerns (including public transport) as well as information technology (§9, §10, and §11);
- housing and rental regulations.

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[1] All translations from the Norwegian are mine, unless otherwise noted.

Trying to fix, in Mike Oliver's self-consciously general phrase, "what is wrong with society", leads to the question of how the particular problems that need fixing are going to be identified. In some of the areas, the responsibility clearly lies with public authorities, corporations, and other institutional agents to both conform to the DAA by changing their structures or procedures. Universal design is the most relevant case. In other areas, however, it is disabled people themselves (or other outside agents) who will have to report violations of the law, as with harassment or the lack of provisions in education. This means that the anti-discrimination measures in the DAA are sites of complex negotiations between parties with different interests. The space in which the sites are distributed can be described with dimensions of directness and indirectness, as well as individual protection or structural change, as shown in Table 4.1.

Table 4.1 Policy measures in the DAA

Measures of individual protection					Anti-harassment measures
		Workplace adaptation (in general)			
		Adjustments to social services etc.			
			Adjustments to educational programmes		
		Workplace adaptation w/ mandatory reporting (50+ employees)		Equal opportunity hiring practices	
Measures of structural change	Universal design				
	Indirect discrimination				**Direct discrimination**

The table illustrates firstly that discrimination due to impairment is represented as a complex phenomenon in the DAA. The general goal leads to the multiplicity of particular changes in the social fabric. I've placed universal design in the lower left corner because the rules and regulations intended to implement it are aimed at institutional practices that discriminate indirectly; it is the architects and builders that are required to comply with the standards. Anti-harassment measures in the upper right corner, on the other hand, will require direct action from disabled people themselves in order to be effective, and may or may not address the underlying causes of harassment.

The diagram illustrates secondly that most of the DAA measures cluster in the centre of the diagram. They are neither blanket requirements directed at institutions, nor are they primarily directed at overt forms of discrimination. They are justified as means of compensation for inherent or pre-existing disadvantage, and their extent is qualified or limited to the scope of reasonable individual accommodations. They largely avoid matters of structural change, but propose adjustments to established institutional practices that disadvantage people with various impairments. As such they will enter into a web of pre-existing power relations. Their justifications are frequently of the form "if people with impairments are disadvantaged in situation X, individual accommodations must be made". Changing what is wrong with society, in other words, implies finding out what is "wrong" with the people in it. This, of course, means that people will have to admit that something is wrong in order for society to change. What are the requirements for *this* to happen?

What is Wrong with You? Disability, Discourse and Identity

Who counts themselves as being disabled? Who will (no pun intended) stand up to be counted? It has been repeatedly established that being "a disabled person" is something that varies with historical epochs, cultural environments and situational factors (Snyder & Mitchell, 2006; Stiker, 1999 [1982]). It is also well known that the proportion of any population that counts as disabled varies greatly according to definitional criteria and measurement techniques, as well as context. In recent decades, many attempts have been made at minimizing or marginalizing the medical aspects of disability definitions, in order to link the goal of equality to political and legal discourse.

Some sort of division between impairments and disabilities nevertheless seems essential to any definition; legally and politically because it separates medically defined diagnoses from social or economic disadvantage, practically because people with vastly different impairments frequently share experiences of oppression and exclusion. The recent United Nations *Convention on the Rights of Persons with Disabilities* states that:

> Persons with disabilities include those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others. (United Nations, 2007)

Such a definition is problematic on (at least) two main counts:

a. *Duration* and *severity* of the impairment, which is sometimes presupposed as a stable factor. But what counts as "long-term"? And when, precisely, is a body impaired? Labour market research from Statistics Norway suggests that approximately 15 per cent of the Norwegian population consider themselves to be impaired (Olsen & Van, 2007), but the researchers note that fully 35 per cent of respondents provide different answers in different studies.

b. *Causality*. Is "full and effective participation" hindered by the impairment or by the barriers? This has been a point of contention for most, if not all, modern writers on disability, because it carries strong implications for the direction of political efforts. At one extreme, being unable to walk is the reason why citizen A cannot get a university degree – not the fact that all the university buildings have steps. At the other, "disablement has nothing to do with the body" (Oliver, 1996a). The UN definition places itself somewhere in the middle, where impairments and barriers share causality.

Finding out who is disabled isn't a matter of counting broken limbs *or* counting the marginalized part of the population. From the complex interactions between people with impairments and various social institutions, different discourses of disability arise. In the pre-modern age, religion played a crucial role (Stiker, 1999 [1982]), as in the social interpretation and construction of mental illness (Foucault, 1973b), but for the last few centuries, medical science has provided the singularly most important source of disability discourses. Given that there is a statistically average or normal human body, and given that some people display significant negative deviations from the norms of bodily function, society may classify these deviations as impairments and react in a number of different ways. But disability has relatively rarely been a positive identity championed from within, compared to how frequently it has been a negative identity imposed from without.

The question isn't clear-cut. Public or private charitable institutions may use impairments as the basis for morally legitimate needs, making disability a superior alternative to delinquency – for some people. Institutions of state welfare may define impairment as the threshold beyond which an individual is unable to work, and may be relegated from the wage economy to the needs-based economy (Gleeson, 1999a, 1999b, 2001b; Stone, 1984), and this may be desirable – for some people.

A medical bureaucracy may certify this inability, and subsequently provide people with impairments with identities that make them legitimate objects for intervention and rehabilitation,[2] viz. techniques of normalization. Identity-defining discourses of charity, welfare and rehabilitation, then, all have origins in the medical model, in part because of the crucial function of the medical bureaucracy as a presumptively objective gatekeeper (Stone, 1984). And these discourses remain alive, even in a document as progressive as the DAA.

Marginalizing Medical Knowledge

Another way of talking about the above discourses is to say that they are grounded in medical topoi – as noted earlier: "parts of argumentation which belong to the

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[2] Note that all three of these examples present institutions that legitimize *themselves* by means of impairments as well as providing legitimate social roles for impaired individuals.

obligatory, either explicit or inferable premises" (Wodak, 2001b: 74). Topoi are particularly salient in grounding key concepts, because they provide the link to the more specific arguments in which those concepts will be employed. As such, they have direct bearing on identity construction. Medical topoi may be conclusion rules such as "because disability describes a medical property of individuals, the consequences of disability should be addressed on an individual basis" and "because disability is caused by bodily impairment, attention should be directed towards remedying or ameliorating the effects of these impairments". Such rules of thought connect a host of particular facts about the socioeconomic marginalization of disabled people with impairments to conclusions about the necessity of charity, welfare and rehabilitation in order to improve their situation.

On the other hand, there are social topoi such as "because disability is a property of social situations, attention should be paid to how these situations arise from the organization of society" and "because disabling situations are caused by barriers and institutions, the barriers should be removed and the institutions reformed". These topoi are grounds for connecting the same observations about the socioeconomic marginalization of people with impairments to conclusions about the necessity of socio-political change.

The facts themselves can be integrated with either discourse – the situation of the people in question is identical – but the drive towards political action will run in very different directions. Similarly, recurring medical or social topoi will sustain an identity framework in which disabled people are, respectively, marked primarily by their impairment or primarily by their social exclusion.

Which topoi are employed in the DAA? We've already seen that the law is presented, in its most programmatic sections, as a weapon for securing equality and preventing discrimination – for fixing what is wrong with society:

> The purpose of the law is to promote equality and equal worth, to ensure equal opportunity and equal rights, and to prevent discrimination due to impairment. (Barne- og likestillingsdepartementet, 2009: 12)

In fact, talking about what is wrong with people is explicitly marked as undesirable. From the advisory statement:

> The Department does not support the ranking of different impairments. The safeguards against discrimination will not be reserved for a particular group of people with impairments. The decisive factor is whether discrimination due to impairment has taken place. (Barne- og likestillingsdepartementet, 2009: 91)

Elsewhere, the AS argues that disabilities arise when there is a gap between the abilities of the individual and the demands for functional ability in a specific situation (Barne- og likestillingsdepartementet, 2009: 90). This is essentially a variant of the Scandinavian relational model, which incorporates both medical impairments and social arrangements. On the whole, however, there has been a shift of attention away from the properties of individuals when definitions of disability are being attempted.

This reflects recent developments, in which the relational model is being increasingly influenced by more strictly social model elements. By way of comparison: in the late 1970s the relational model still contained strong elements of “personal tragedy”. The following quote is from a white paper titled *On Disabled People in Society*:

> A person is disabled when he, because of chronic illness, injury or impairment, or deviations of a social nature, is significantly restrained in his practical way of living, relative to the society that surrounds him. This may apply to education and work, as well as physical or cultural activity. (St.mld., 1977–1978)

By 1983, however, following the United Nations’ International Year of Disabled Persons in 1981, disabling environmental factors were being taken more strongly into account. The relational model is compatible with both medical and social topoi (because it acknowledges both individual/bodily and social causes of disability) and over the course of the next two decades, it became more explicit about the role of society’s demands in producing the disability gap (Tøssebro, 2004).

Eventually, social factors get prioritized in more prominent and visible sections of public discourse. The DAA intertwines definitions from the gap model with markers of Anglo-American socio-legal discourse, and employs formulations such as these:

> It is unacceptable that certain groups have their opportunities and rights in Norwegian society curtailed because they are exposed to discrimination, e.g. in the form of direct and indirect discrimination, harassment, etc., or in the form of discrimination due to lack of accessibility. (Barne- og likestillingsdepartementet, 2009: 11)

The pan-disabled experience of discrimination and exclusion is privileged over impairment-specific experiences (for criticism of this privileging, see Thomas, 1999; Wendell, 1996).

Building New Arenas for Negotiation

What does the absence of medical topoi in the programmatic sections of the DAA mean in policy terms? The act makes clear that the absence of a strict definition of what constitutes an impairment and a list of recognized impairments is a deliberate choice – a choice motivated by data from other countries. The American and British anti-discrimination laws, in particular, were interpreted in the courts as having established a relatively narrow class of people to be protected from discrimination, and wound up being significantly less effective in socioeconomic terms than their framers intended (Colker, 2005; Krieger, 2003). They are cited as examples to be avoided.

The Department, in its attempt to shift focus towards the *act* of discrimination rather than the *subjects* of discrimination, cites gender as a category that is comparable to impairment. The implied topoi are ones of *social justice* or *equal treatment before the law*, as in "if different treatment takes places on the basis of social or biological difference, it counts as discrimination". The purpose of the Norwegian gender provisions is not to protect the category of women or men, but to prevent discrimination because of gender.

In theory, therefore, the DAA represented a decisive victory for social topoi. It suggests that disability is a neutral identity marker, and that making use of the law does not entail declaring membership of a particularly stigmatized group. But this is clearly an illusion. Let me return to Tom Shakespeare's point:

> But even in the absence of social barriers or oppression, it would still be problematic to have an impairment, because many impairments are limiting or difficult, not neutral. (Shakespeare, 2006a: 41)

If real equality is to be achieved – if the full spectrum of provisions in the DAA, both direct and indirect, both individual and systemic, are to be employed – then there is no way to avoid a discussion of specific impairments. There is still a need for medical knowledge and medical topoi.

The social model of disability has been criticized elsewhere for lacking clear policy implications (Samaha, 2007). That lack is conceptually related to the absence of impairment-specific discussions. Policy recommendations are frequently a matter of making provisions for people with specific impairments. Almost all positive interventions, and even several negative interventions, differ vastly according to different conditions.

In terms of topoi, it is very difficult to articulate justifications such as "because disability correlates with disadvantage X, policy intervention Y is needed". The problem is that the number of general or blanket disability policy interventions is relatively small. There is always a need for negotiation: the DAA text uses modifiers like "reasonable" in order to qualify measures in every area except harassment. §4 states that "different treatment which is necessary in order to achieve a valid purpose and which is not a disproportionate intervention for the person or persons being treated differently, will not be considered discrimination under the law".

The organs made responsible for the adjudication of conflicts covered by the DAA will have considerable influence in their interpretations of grounds for discrimination as well as reasonable accommodation. Chapter 14 of the proposal discusses the institutions that are charged with enforcing the law. These are the Equality and Anti-Discrimination Ombud (a 37-person division within the Ministry of Children and Equality, offering fact-finding, mediation and non-binding rulings), the Norwegian Equality Tribunal (an eight-person body capable of ordering fines), and ultimately the courts. The lack of precedents in the area is openly acknowledged: the Anti-Discrimination Ombud itself (on its web page, under the heading "What is a disability?") notes that "it is difficult to define what constitutes a disability until the courts have decided what the term is meant to cover". This means that the consequences of the DAA will depend on a process of negotiation in which people must come before the courts *as disabled people*. That is, the law will both shape and be shaped by the public identities of disabled people as they make use of its provisions.

Aside from the courts and public agencies, who will be in a position to negotiate the definitions of disability under the provisions of the DAA? Chapter 12 of the AS discusses provisions under which particular organizations may be provided with the power of attorney on behalf on individuals who want to bring a civil suit. The organization should, according to §15 of the DAA, be one which "in full or in part works to counter discrimination based on disability". This constitutes a circular definition, but also allows for a structure in which any organization that can convincingly argue that it represents disabled people will be in a position to argue cases. However, in the Norwegian system, §15 will de facto place a significant amount of both agency and responsibility with disability NGOs such as the FFO and its constituent members.

These organizations will be in a position to demonstrate actual disadvantage. This will require the judicious display and framing of impairment-specific knowledge, and will make the organizations in question key sites for the production of disability-defining discourse. There is, however, already a model of sorts for the connections between impairment-specific and socio-political knowledge, because the NGOs that will participate in negotiating the provisions DAA are already obliged to embody such connections. This applies to multiple organizations in the Norwegian civil sector. Because of its size and prominence, and because it is an umbrella organization which organizes 75 impairment-specific organizations, FFO will serve as the best exemplar.

FFO states, in its general policy documents, that it has an anti-discrimination brief:

> FFO bases its definition of disability on the understanding of disability as a conflict between the capabilities of the individual to function and the demands for function made by the surroundings. […] The conflicts, or matters of discrimination, are experienced differently by different individuals, but are united by the fact that they affect aspects of life taken for granted by most people. […] The relations of conflict faced by disabled people therefore centre on the basic interests of human beings – human rights. (FFO, 2014)

The federation has traditionally assumed a coordinating role for its member organizations. It has assumed coordination and top-level communication responsibilities, and deals directly with government representatives in negotiating the level of welfare benefits. Many of the individual people that belong to its member organizations, however, do not necessarily consider themselves disabled in a social or even technical-legal sense. They belong to organizations that represent particular medical diagnoses.

The DAA, through its language and its provisions, is establishing a corresponding arena in which socio-legal and medical discourse will be more closely intertwined than before. It is arguably part of an ongoing process in which a new disabled public identity is developed, one that will allow individuals to construe their impairments as socio-politically relevant and strategically functional, but not dominant. In a sense, this is a logical development from the increased public visibility of disabled people across the world over the course of the last decades (or, for that matter, century). It also means that the disability NGOs are partly responsible for bridging the gap between medical and socio-political identities.

The Public Disabled Identity

What does it mean to talk about a public disabled identity? In Norway, as in many other countries, it is certainly a *hybrid* identity that implies both demanding one's rights and claiming welfare state provisions. It contains elements of stigma and pride, depending on the context. By declaring oneself to be disabled, a person will effectively, at the very least, do one or more of the following:

a. Identify as a member of a class that is deemed vulnerable (under welfare state regulations).
b. Identify as a member of a class that suffers from discrimination (under the DAA).
c. Identify as a member of a class that suffers stigma and prejudice (under the DAA, where "discrimination due to presumption of impairment" is deemed grounds for action).

Awareness of the effects of c) is of course fully established with disabled people, along with the knowledge that the public disabled identity is a deeply problematic one. Generally speaking, disability correlates with disadvantage, because it is by any definition linked to a *negative deviation from a norm or standard of functions of the body*. In this way, it is fundamentally different from other identity categories associated with stigma and prejudice, e.g. gender and ethnicity.

The link between disability and negative deviation is problematic, i.e. identity-threatening for many individuals. Some data suggest that there is a threshold of *declaring one's disability*, of admitting that something is wrong, which has to do with being sufficiently inconvenienced by one's impairment (see Shakespeare, 2006a).[3] People who are able to 'pass', that is, who see themselves as capable of avoiding the imposition of a disabled identity, may choose to do so as long as the

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[3] Although Shakespeare discusses the issue to some extent, the issue is notably tricky. I am currently analysing interview data from several Norwegian impairment-based organizations, which suggests that the people most susceptible to disability activism and organizational activity are those whose impairments fall into a middle range – not severely impaired, but too impaired to pass.

benefits of avoiding stigma outweigh the benefits that would be gained through a disabled identity.

The threshold of declaration will obviously vary in height in different societies. The factors that influence that decision lie outside the scope of this chapter, but let me suggest a few candidates:

a. stigma;
b. the visibility of impairments or inability to "pass" as non-impaired;
c. direct or indirect discrimination;
d. impairment effects such as pain and fatigue;
e. degree of adaptation in the physical environment in general, including access to public transportation;
f. welfare benefits;
g. anti-discrimination measures; and
h. the right to individual accommodation in education and employment situations.

While the confluence of significant impairment effects, strong welfare provisions and a low level of public stigma might encourage "coming out" as disabled, the confluence of a high level of stigma, weak anti-discrimination measures and manageable impairment effects would encourage trying to pass, alternatively invoking the category of temporary *illness* rather than permanent *impairment* (cf. Goffman, 1963). Passing remains a legitimate goal for many disabled people, and it is probably no accident that the most strident activists for disability rights are frequently people who have a minimal, if any, chance of passing whatsoever.

The above holds particularly true when disability is conceived as a global or dominant identity. However, there is another way to think about the threshold at which people will decide to pursue a disabled identity, a way that a) views that identity primarily as a situational, strategic asset; and b) supports that view by embedding disability knowledge deeply in various social fields. The inherent negative connotations of disability and its synonyms – the connotations of negative deviation – may, perhaps, be countered through the strengthening of sites in which specific impairments may be made temporarily relevant.

An example: some airlines, concert venues, cinemas etc. allow their customers to specify that they have impairments. Some provide only for a general declaration of disability. The first option is often unsatisfactory because there is insufficient information about the facilities in question, while the second is all but useless, since it inevitably requires additional information from the patron or passenger. However, when the company in question chooses to embed impairment knowledge in its booking systems, allowing people to specify whether they wanted a seat or a wheelchair parking spot, whether the venue has telecoil capacity, and so on, a number of problems go away.

The above example can be extended, *mutatis mutandi*, to most of the areas in which laws such as the DAA are intended to effect changes. The implementation of the goals of the DAA will hinge on the willingness of people with impairments to pursue their means of legal recourse. This in turn depends on their assuming the law's notion of a disabled identity. This identity must be equipped with provisions that constitute a real form of protection for those who need it the most, but it cannot be constructed in such a way as to de-motivate or exclude people who might gain comparatively minor but nevertheless significant benefits.

The advisory statement of the DAA consistently frames disability as a *consequence of* direct or indirect discrimination. Its express purpose is to strengthen the legal safeguards against such discrimination. At the same time, the people who are to benefit from these safeguards are identified as those who suffer discrimination *because of* having (or being presumed to have) medically diagnosed impairments or chronic illness. In other words, the cause of the problem of discrimination is framed in terms of medical discourse, while the solution is framed in terms of socio-legal discourse.

Chapter 5

Counting as Disabled: Discourses of Identity

The last two chapters dealt with some of the ways in which people are, respectively, directed towards and diverted from the category of disability and the corresponding label, as they are defined in formal and institutional contexts. Part of the point of those chapters was to show that there are many ways of being disabled in a bureaucratic and technical sense, including to be counted as disabled by the state, to qualify as disabled according to functional classification systems, and even to be disabled according to legal guidelines, without in fact identifying as *a disabled person* in a social and interactional sense of the term.

That latter part is the topic of this chapter, which is in many ways at the heart of this book. The discourse approach to disability is in some ways an attempt to ask the following questions: why aren't there more discussions about disability in public life? Why aren't there more people who identify as disabled? And a corollary to these two questions must be: *what is it we talk about when we* don't *talk about disability*?

Different answers arise in different contexts. Within classical medical discourse, it is preferable not to talk about disability, because disability is in many cases synonymous with debility. For many people with ME and CFS, for instance, it is the thing at the end of the road, the thing that is defined by the lack of a cure. Very likely this is the case for many other people with chronic illnesses, people who haven't found a language – a discourse – which accounts both for their embodied experience and for their relationship with society.

As Irving Zola pointed out in 1982, there is something potentially grotesque about the notion of disability pride. His reasons had to do with the central characteristics of diseases and impairments, which, to him, did not hold up well in comparison with other bases of pride movements:

> A mundane but dramatic way of characterising this phenomenon can be seen by looking at the rallying cries of current liberation movements. As the 'melting pot' theory of America was finally buried, people could once again say, even though they were three generations removed from immigrants, that they were proud to be Greek, Italian, Hungarian, or Polish. With the rise of black power, a derogatory label became a rallying cry: 'Black is beautiful!'. And when female liberation saw their strength in numbers, they shouted: 'Sisterhood is powerful!' But what about those with a chronic illness or disability. Could we yell: 'Long live cancer!' 'Up with multiple sclerosis!' 'I'm glad I had polio?' 'Don't you

> wish you were blind?'. Thus the traditional reversing of the stigmata will not so easily provide a basis for a common positive identity. (Zola, 1982: 204)

And yet, in the following decades, disability pride *has* caught on – for a minority of disabled people, a minority within a minority. There are affirmational or affirmative approaches within Disability Studies, i.e. theoretically informed works that try, in one way or another, to yell "Up with multiple sclerosis!" and "I'm glad I had polio!" and see what happens. The work of Steven Brown, for instance, explores the formation of positive disability identity as tied to culture and cultural expression (S.E. Brown, 1997, 2002, 2003).

In some cases, as I will explore in greater detail in the following chapter, what happens is that a new kind of restriction is imposed on the majority of disabled people. The discourse of empowerment, affirmation, and achievement is a problematic basis for identity construction. This is the case as regards ethnicity, gender, or skin colour as well, but even more so when it comes to disability and impairment, the latter of which cannot, ultimately, be defined without some reference to formal or functional disadvantage.

The questions of how to talk about and theorize disabled identity is, nevertheless, just as important as they were in 1982, partly because they affect so many issues in political, economic, and medical discourse. They contribute to setting the terms for group membership, for defining audiences, and to the basic denotation of words. If "the disabled" are perceived as being a marginal minority, effectively a synonym for "wheelchair users" or even "wheelchair users with few or no significant impairment effects", then it becomes difficult if not impossible to argue in favour of many key societal advances and adaptations.

Disability, Identity, and Difference

Zola's appraisal of the basis for a disability liberation movement focuses on the insider perspective – it is difficult to identify the-thing-to-do-with disability that can also serve as a rallying cry. Another aspect of the problem is provided by Tom Shakespeare in his 1996 article "Disability, Identity and Difference", which advocates an intersectional, pluralist approach to disability identity. Here, he points out two other fundamental (and still unresolved) problems in disability identity politics:

> [1:] the fact that people with impairments associated with ageing are not fully represented within the disability movement
>
> [2:] there is an inherent essentialism within disability politics, and indeed in the idea of disability identity. The celebration of disability pride is the celebration of difference, and the acceptance of difference: it is about subverting negative valuation and reclaiming disability. (Shakespeare, 1996: 105–106)

Not only is it difficult to phrase a rallying cry for the disability movement. Even if one is found, the great inherent diversity in the range of impairments that may be associated with disability is such that almost any cry risks being either too specific or too general. The disability movement is in many cases based around what the WHO termed "classical" impairment groups: visual, hearing, and mobility impairments. But these are far from the only relevant impairment types. Moreover, while all three "classical" types of impairment are intrinsically associated with ageing, they are also associated with ideal types or stereotypes of disabled people who are usually not portrayed as elderly: the blind person with dark sunglasses and white cane, the signing Deaf person, the wheelchair user with lower limb paralysis. Those are the types evoked by the signage of accessibility; those types refer to the kind of difference that is negatively valuated and must be reclaimed. When they *are* reclaimed, it is often with an emphasis on abilities or capabilities that aren't necessarily compatible with ageing, or for that matter with chronic illness – the wheelchair user with a strong upper body, the Deaf person embedded in a vibrant and predominantly young signing community.

Differences that are reclaimed are often conceptualized as binary and singular, so that they can be more effectively isolated and negated. The implicit argument, the recurring topos, is "like everyone else, *except for this single thing*". Being disabled becomes a matter of switching off a certain capacity, which can plausibly be viewed as unitary and distinct: seeing, hearing, walking. This elides the fact that loss of such capacities may be tied to, for example, brain injury, and far from discrete (Sherry, 2006).

Absolute and consistent dichotomies are rare occurrences in the real world. A wheelchair user is no more guaranteed to be completely unable to walk than a legally blind person is to have absolutely no vision. From such confusions stem the suspicion of fakery and malingering that many disabled people regularly encounter. Another problem is that the topos of dichotomous, unitary exceptions to general ability or able-bodiedness is highly conducive to a *compensatory* approach to valuation. If a positive disabled identity is predicated on being "like everyone else, except for this single thing", then, in practice, considerable pressure is put on disabled people to be *better* in order for a positive image to be sustained.

The Valuation of Difference: What is Being Valued?

The main topic here is *valuation of difference*. Disability is sometimes included on a list of identity markers that includes gender, ethnicity or race, and sexual orientation; these are all identity markers that are central to social movements, and these social movements include valuation of difference as both analytical and strategic goals. Disability is, perhaps inevitably, compared to other social categories that have connoted, and in many cases continue to connote, marginality, oppression, and resistance.

That comparison is sometimes put to effective rhetorical use, though it sometimes leads only to an *aporia*: what is so good about disability? How, exactly, can it be valued? As Zola points out, all of the other social movements linked to the above categories have, to varying degrees, emphasized positive values that are connected to some form of essentialist difference, whether in the slogan-form of "female strength", "gay pride" or "black beauty".

This is problematic in itself, to the extent that it creates ideals and norms that are difficult for many people to live up to. It is even more problematic when it forms the basis for reasoning by analogy. Essentialist differences connected with the category of "disability" are invariably negative, and essentialist differences connected with various types of impairment are overwhelmingly negative – that is why they are impairments in the first place. Exceptions do exist, such as the attempts by parts of the Deaf community to emphasize the very real cultural-linguistic difference that is coded, in part, in sign languages, and the efforts to re-describe various forms of neurological impairment as neurological *difference*. In the latter case, cognitive variation which is traditionally categorized as impairment is, as compensation, associated with heightened ability in some areas.

Ultimately, such attempts succeed only to the extent to which impairments can be shown *not* to entail overall diminished ability; in this, they effectively lead to a return to the ICIDH causal chain of social handicap caused by functional disability caused by biomedical impairment. If the functional disability is in reality only a *different* form of functioning, the implicit argument goes, then there can be no underlying biomedical impairment, as such, and if there is a persistent social handicap, this becomes somehow more unjust or unreasonable than the handicaps experienced by people with "real" impairments.

Positive valuations tied to the category of disability can always and only be associated with emergent properties of the disability experience or disability community. Cultural and artistic forms of expression, solidarity, social connectedness, a deeper or broader understanding of human life and the human condition – *all* of these are emergent phenomena that have disability as a potential, but neither necessary nor sufficient antecedent. This leads to the question not only of what disability identity is "for", politically speaking, but for whom it is relevant and under what circumstances. In what kind of situations do people identify as disabled, and to what end? Where is the discourse of disability identity situated, and to purpose is it deployed? As Shakespeare puts it:

> [Previously,] there was a limited range of narrative devices and themes available to people with impairment: now, new stories are being told, and we are creating ourselves for ourselves, rather than relying on the traditional narratives of biomedical intervention or rehabilitation, of misery, decline and death. (Shakespeare, 1996: 95)

In Chapter 3, we saw that there is not necessarily a contradiction between telling a story of impairment in biomedical terms, while simultaneously telling a story of one's social and political experiences as a disabled person. To the extent that "disabled identity" has positive valuation in these circumstances, it is quite possibly for its *mimetic* potential: it draws on a form of discourse that is capable of articulating or signifying certain aspects of the world that simply cannot be captured in biomedical language, that are alien to medical discourse.

Disability identity discourse, in this perspective, is a linguistic tool for building alliances across the impairment divide. It is a marker of actual or potential solidarity. It cannot be positively valuated essentially and in itself, because it refers to a form of experience that is, by definition, negative. An analogy might be a strict definition of social class according to access to economic capital: if being working class is defined strictly as being in the lower income range in a given society, then there is nothing inherently positive about being working class. The positive valuation belongs, rather, to the mutual affirmation of shared experience, and to the social and political potential that *can* be unleashed through such affirmation and consequent collective action. To put it another way: there is nothing positive about the form of bodily difference known as impairment, but there is something positive in having the analytical tools to point out not just this problem, but what can be done about it. To put it yet another way: the concept of disability can function as a call to action. This, of course, is a shared goal of most if not all social, interactional, gap, and cultural models of disability: they do not seek affirmation only for descriptive, but also for normative purposes.

Disability can, of course, just as easily become an alienating concept, particularly as it connotes stigma, social marginalization, and permanence. What is interesting is that it can simultaneously function as a tool for activism. Close attention should be paid to the difference between these two interpretations and forms of usage, because they make apparent the process of self-education and, usually, politicization that is necessary for most people to move from one category to another. The disability field – peopled by activists, organizers, researchers, and so on – is replete with stories of steadily increasing awareness: awareness of the structures which produce disability, awareness of the situation of disabled people, awareness of the subtle nuances of disabled experience. It is a kind of awareness that does not often come easily, and one that, as pointed out in Chapters 3 and 4, is more likely to have been achieved by people who have considerable familiarity with disability politics, disability activism and/or disability theory.

I recently participated in the writing of a report on media coverage of disabled people. During the press conference where the report was launched, various media representatives stressed their good intentions, while acknowledging that disability topics tend not to make for exciting news, and that structural analysis does not make for good copy. A very experienced NGO professional commented tersely: “Well, sure. Nobody *wants* to know about these things”. That is relevant to individuals’ perception of identity as well. Very few people start out *wanting* to think of themselves as disabled, partly because of the persistence of stigma and disadvantage. Other identity markers – even markers such as “chronic illness” – may often be preferable. If one nevertheless starts to develop an identity as a disabled person – if one starts to tell a story about disability, starring oneself, then there must be some purpose to it.

There is considerable distance between the field of Disability Studies and the field of medical sociology. This has been puzzling to me on a number of levels, as I count myself as a practitioner of Disability Studies who has worked closely with medical sociologists over the last few years while continuing to work on very similar problems. There are of course differences when it comes to interests and perspectives – arguably, Disability Studies is chiefly about the experiences of disabled people, while medical sociology is often more concerned with the experiences of doctors. However, that could just as easily form the basis of collaboration, with each field providing one part of the puzzle. In practice, this has not yet happened. There are still regular calls both from practitioners of Disability Studies and medical sociologists for collaboration, but that in itself is symptomatic – the calls still have to be made on a regular basis because they are not answered.

Illness Stories and Disability Stories

The work of the medical sociologist Arthur Frank, in particular *The Wounded Storyteller* (Frank, 2010), is illuminating as to the key differences between approaches. Frank is one of the medical sociologists who have paid close attention to patient experiences, as the title of his book indicates. The wounded storyteller is not a professional, but a locus of personal experience. In the book in question, he or she is likewise not a disabled person. Frank provides a three-part typology of illness stories: *chaos*, *restitution*, and *quest*. In each case, a temporal dynamic and a paradigmatic shift is at the heart of the story, whether the shift in question is from health to persistent illness (chaos), from illness to health (restitution), or from illness to experience and insight (quest).

These story types are relevant to disability experience and Disability Studies, but because they proceed from the premise of illness-as-biographical-disruption, because they presuppose a healthy, non-impaired body, they cover only part of the ground. Moreover, although Frank is certainly interested in social and interactional aspects of illness, he is chiefly concerned with the internal experience of being ill, and with an account of such experiences that can balance accounts that are clinical and made from the outside. The perspective of medical sociology provides, in this particular case, a different kind of corrective to the classically medical perspective than does Disability Studies – by emphasizing the validity of patient subjectivity, without challenging the primacy of patient identity.

The relatively distinct narrative frames of chaos, restitution, and quest are all familiar from the ME and CFS narratives discussed in Chapter 3. They all share the salient feature of allowing for a return to normality, and of emphasizing a comparison with a prior or idealized former body. The narratives that emphasized the concept of disability, by contrast, were oriented towards a new normality, and a new form of coping – towards establishing a form of identity that was not linked primarily to biographical disruption, but to a tentative stability.

While these could plausibly be framed as variations on the "quest" narrative, this interpretation must necessarily stretch the implied definition and time frame.

A large proportion of disabled people are impaired from birth, which means that the quest concept must then either encompass their full biography, or be restricted in some way to specific impairment-related developments. In the latter case, the illness-frame is re-imposed; in the former case, the "quest" is rather different from (and broader than) the one described by Frank.

There is evidence that many people who "count" as disabled – in terms of benefit payments, capacity to work, and/or illnesses, do not actively identify themselves as disabled. This begs the question of what features of disability discourse contribute to disabled identity both in the public sphere and in private – effectively, how disability comes to be an identity that is in some cases more stigmatizing or problematic than an identity as "having an illness". In the above discussion, the answer appears to be: disability identity is both more stable and more narrow than the identity formations that spring from having an illness. The notion of self that is predicated on being a disabled person is more encompassing than one that is linked to specific biographical episodes. We haven't quite addressed yet, however, what disability identity is *for*. This, in turn, has a lot to do with the kind of discourse in which it is expressed.

The Politics of the Matter: What is Disability Identity For?

Individuals' stories are not just individual stories; narratives are told by people to other people, and so come to shape perceptions and ideas about the world. The subsequent chapter in this book is about the narratives of popular culture and the media, whereas this chapter is focused on everyday narratives. These are nevertheless part of the same dynamic, which sees narrative discourse as closely related to argumentative discourse.

The question at the heart of this dynamic, which is also at the heart of this book, is this: *why aren't there more disabled people?* The World Health Organization estimate of one billion worldwide is not an estimate of people who self-identify as disabled, but of people who count as disabled according to the ICF model. In many societies and social contexts, identifying as a disabled person is more or less pointless. Identification must, in order to be meaningful, have some social, political, economic or other salient consequence. In a society where the category of disability is operationalized in organizations, in welfare provisions, and in legal rights, identification is meaningful. Absent these structures, it is not.

Of course, such structures do not provide sufficient grounds for disability identification in and of themselves. That is borne out by the examples discussed previously, in which "chronic illness" was shown to be an identification frame that can effectively exclude the frames of "impairment, and disability". Myalgic encephalopathy and chronic fatigue syndrome, for instance, can be perceived as potentially *disabling* diagnoses by people who receive them, and yet those people do not see the need to identify themselves as disabled people. Illness remains the primary identity marker; disability serves only to indicate the level of one's debility.

The situation is made possible because people who have been diagnosed with either ME or CFS, who have remained ill for very long periods of time, who experience symptoms and limitations that would definitely qualify them as "impaired", qualify as disabled only through institutional arrangements which are partly invisible to them. Their identity as disabled people is embedded in the discourse of organizations and professionals who do not primarily address individual members, and who, when they do so, often resort to the discourse of illness and health.

Disability narratives can, of course, be personal stories told by individuals. However, they can equally well be told by professionals to other professionals. The way in which disability is embedded in the discourse of the modern state, a phenomenon identified by US, UK and Scandinavian scholars alike, creates a discourse environment ripe for the telling of disability-stories-as-bureaucratic stories. Since disability is a problematic, stigmatizing and closely rationed bureaucratic category, this does not provide an optimal basis for stories with which people willingly identify.

In peer-to-peer forums where people with ME and CFS discuss their diagnoses and their lives, the word "disability" features prominently, but not in a way recognizable from Disability Studies, disability activism, or for that matter this book. Rather, it is used to indicate functional capacity on a numeric scale, e.g. 70 per cent disability. This usage draws on the discourses of insurance, benefits, medical assessment, and legal deliberation, and has not very much to do with social-interactional disability. It demonstrates the persistence of *medicalization*, and coexists with the cure-focused, medically oriented ME and CFS community.

If we accept the premise that stories are about something – that they are told to an audience, and for a purpose, then it is worth examining both the ends and the means of stories more closely. In the case of ME and CFS, the community-building purpose seems clear and evident. The diagnoses in question are contested and problematic; this is one of many reasons for a fraught relationship between patients and doctors.

Problems and Solutions

When patients with ME and CFS tell stories to the world at large, they confirm for themselves and for others their legitimacy as patients. They also define themselves in terms of their relationships to doctors; they perform acts of self-medicalization. Disability narratives, by contrast, at least in the sense understood here, cannot be exclusively or even primarily be about medical topics.

This observation is not exclusive to discourse analysis, but in can productively be framed in discourse terms. The choice of what to talk about – the choice of topoi – is also a choice of explicit and implied arguments. To talk about one's life primarily with reference to medical solutions is to imply that one's problems are chiefly medical in nature. The fraught relationship between the actor Christopher Reeve and many disability activists, a classical example in Disability Studies literature, stemmed at least in part from his consistent thematic emphasis on cure – not necessarily on its own merits, but for its analytical and political implications:

> Reeve was seen as an outsider from the disabled community […] Reeve had made it clear that he considered himself only temporarily disabled. […] The narrative of 'cure' is itself dependent upon the medical model of disability, or the framing of disability as disease. (Scherman, 2009)

The hostility aroused by Reeve's efforts to raise funds for medical research – to find a cure for broken spines – was not tied to the isolated merits of a medical solution. It was linked to the notion that his – and other quadriplegics' – problems were exclusively medical. Medicalization is itself a way of turning complex problems into slightly simpler problems by restricting them to a narrower and more unitary range of discourse; this reductionist mechanism is one of the reasons why medicalization is such a bugbear in Disability Studies.

The "problem" frame is a persistent feature of Disability Studies. It can be paraphrased – Tom Shakespeare prefers "predicament" – and certainly, many attempts have been made to subvert or deconstruct it (Davis, 1997b, 2002; Hughes, 2007). Scholars of critical Disability Studies, and others, have tried to focus on *ableism* rather than disability, so as to locate the problem not in the lives of disabled people, but in attitudes and structures that are effectively relevant for the non-disabled and the disabled alike (Cherney, 2011; Goodley, 2012). Still, ableism is not *primarily* a problem for the non-disabled, just as racism is less of a problem for the powerful majority than for the powerless minority in any given society.

However, for many of the same reasons, the problem/predicament frame is both inevitable in and useful to Disability Studies (I sometimes think of the term "critical Disability Studies" as oxymoronic – it is difficult to preserve a complex concept of "disability" in a non-critical discipline). The discipline has a strong and intrinsic connection not only to ontological problems (what is the phenomenon we refer to as disability?) and epistemological problems (how do we define and operationalize our concept of disability?), but by extension to the social, political, legal, and economic problems that flow from the first two categories.

There are, of courses, discourses and frames of reference in which concepts roughly similar to "disability" are either less problematic or in which they could conceived as corollaries to other problems; theological or mythological discourse, for example, can present physical or mental impairment as logical and necessary solutions to the problem of unnatural or immoral behaviour. But "roughly similar" is not identical, and in approaching such discourses, as historical and anthropological Disability Studies has often done, we must be careful to preserve the salient differences. There is no trans-historical or transcultural concept of disability; there are only the perspectives, concepts, and analyses we impose on whatever data we have available.

For this reason, I think it is important to stress the *function* of contemporary concepts of disability when discussing matters of narrative, self-presentation, and identity. For individuals, “disability” can refer to a number of problems, located in their bodies (the “debility” frame, the discourse of medicalization) or in their relationship with the society in which they live. Is the task of Disability Studies to find out how to shift as many people as possible from the former problem frame to the latter? Not necessarily – it is more of a task for disability activism – but Disability Studies has positioned itself as a discipline devoted to rendering disability more complex. This entails an expansion of the number of topoi relevant to discussing disability, and a diversification of the causes of disablement.

No academic discipline can function without an audience, and that audience cannot be composed entirely of specialists. The success of Disability Studies rests partly on whether it is able to make its concept of disability comprehensible and meaningful – in context. When we ask why there aren’t more disabled people in the world, we are also asking why there hasn’t been a more successful transfer of knowledge from the academic discourse of Disability Studies to other discourses, to wit: politics, medicine, biographical narrative.

I am not making a substantially new argument when I point out that a concept such as “disability” is only useful to the extent that it is linked both to *problems* and to *solutions*. Many if not most of the key personal narratives in Disability Studies include some form of Damascene moment, in which a new understanding of what disability is provides a new perspective not only on the narrator’s personal situation, but on the full complexity of the society in which he or she is embedded. What is notable is the degree to which self-education and analytical awareness is needed in order for the disability frame to be useful – the degree to which “disability” is a complex and demanding concept to master. It seems not unlikely that the success of the British social model in activist circles has something to do with its relative analytical simplicity. Conversely, the conflict between some first- and second-generation disability scholars in the UK is perfectly comprehensible as a choice between two evils: an easily understood but reductive and analytically unsatisfying model, or one that is more complex, nuanced, and ultimately more accurate, but less pedagogically effective.

There is no big, universal solution to these quandaries. There is, possibly, a range of smaller and more specific solutions that lie in the very diversity of disability-related topics. Seen in this light, the discipline of Disability Studies is headed in the right direction. The increasing emphasis on intersectionality and the proliferation of hybrid sub-disciplines is quite possibly the best way to avoid positioning disability as a narrow concept with limited potential for identification. This is not false universalism – not everyone is disabled – but a way of establishing a multitude of points of identification. This, too is disability.

“This, too”, meaning issues that have been more extensively treated in ageing studies, queer theory, and numerous other disciplines that share borders with Disability Studies. Studies of disability identity must necessarily progress in collaboration with other scholarly approaches to identity, since one of the foundational ideas in Disability Studies is that disability need not be approached as a master or hegemonic identity.

Identity and Multidisciplinary Approaches

In practice, the multidisciplinary approach puts the onus on disability scholars to carry on doing what they have done for many years – practicing their craft partly by stealth (a notion endorsed by Rosemarie Garland-Thomson, among others), and showing the analytical value of the disability perspective even before introducing disability terminology.

This, of course, is not an approach that is entirely well-suited to establishing Departments of Disability Studies. In a sense, the discipline's dilemma is similar to that of individuals who may, but do not necessarily, identify as disabled: how can the concept of disability be introduced so as to effect a subtle and yet transformative shift in perspective on the world?

Even a theorist of the body as sophisticated as Judith Butler has treated disability and the impairment, in a segment of the film *Examined Life,* as concepts relating novel and surprising insight into embodiment (Taylor, 2008). Such distances between closely related academic disciplines suggest the work that must be done by practically anyone who initially tries to grasp the complexities of the modern concept of disability. They also suggest the need for developing that concept in its relationship to a multitude of discourses, preferably discourses not limited to academic or bureaucratic realms.

This is one of the many reasons why culture and cultural representations form such an important part of Disability Studies. Culture provides what is crucial to any rhetorical endeavour, namely accessible and effective *examples*. Examples are *topoi*, in that they provide shared points of reference (which is by itself one possible definition of culture). That is the topic of the next chapter – representations of disability in popular culture.

It is a little frustrating and possibly even paradoxical to work out the need for diversification and dissemination of the concept of disability in a relatively specialized and academically oriented text such as this one. Granted, discourse analysis has hitherto not been overly concerned with disability, at least not compared with its canonical topics such as gender, ethnicity, and race (and to a lesser extent sexual orientation). Hopefully the discourse perspective communicated here is of some value; the central idea being that the language used to talk about disability, as well as the subject matter to which disability is perceived as relevant, holds real implications for how the phenomenon of disability plays out in the world.

Returning to the starting point of this chapter – Tom Shakespeare's 1996 notes on disability, identity, and difference – I'll stress the following: no, ageing is by no means sufficiently accounted for in Disability Studies, just as gerontology and other approaches to the topic of ageing do not satisfactorily incorporate disability and perspectives from Disability Studies. And no, stereotypical representations do not contribute positively to the identity problematic. This book does not deal particularly with the first matter, although it does address the lack of fit between identities of chronic illness and identities of disability.

This, too, is directly tied to the second matter of representation and stereotypes. If there are to be multiple points of identification for disability narratives, this requires the critical examination of prominent representations of disabled people – not for the purpose of dismissing them as unsatisfactory or unfit, but for the traditional purpose of critique: examining the grounds on which they come into being, and their alternatives.

The following chapter is structured around examples that are on the one hand very explicitly flagged as representations of disability, and on the other – hardly at all. The point is partly to introduce disability into a moderately novel narrative context, partly to show the lines of identification connecting the first example to the second. Disability narratives can bring us to unexpected places.

Chapter 6

Media Discourse and Popular Representation

While identities of disability are in flux both for individuals and groups, depending on contexts and purposes of identification, it is possible to delineate *figures of identification* in discourse. There is ample research on cultural representations and strategies of representation in Disability Studies, perhaps particularly in the United States (Garland-Thomson, 1996, 2009; Siebers, 2010; Snyder & Mitchell, 2000, 2006). This is partly because representations of disability and disabled people are "potentially allegorical in the sense that the act of characterization encourages readers or viewers to search for a larger concept, experience, or population" (Snyder & Mitchell, 2000: 40). They serve as reference points both for individuals who definitely consider themselves disabled, individuals who definitely consider themselves non-disabled, and for the large number of people who may or may not see themselves as disabled.

The topic for this chapter is *media discourse*, which provides easily available ideal types and stereotypes of disabled people, thus generating both descriptive and normative conceptions of disability. It is not a comprehensive review of media representations – any more than previous chapters have been comprehensive investigations of medical or political discourse, but it provides some examples that form the basis of narratives and arguments along medical and political lines, among others.

There are multiple familiar narratives that provide ostensibly descriptive but effectively normative trajectories for how disabled people lead and should lead their lives. Such narratives may centre on the idea of a "tragic victim" or a "resilient hero". These ideal types are discourse objects, i.e. symbolic constructs with social effects, insofar as they are embedded in social practice. For example, disabled people who attempt to secure media attention must negotiate with such narratives and types in order to gain access – they must "fit the narrative" of reporters, editors, and publishers. Disability advocates and activists must address, combat, and subvert their counterproductive aspects. As before, the discourse approach is aimed not at criticizing narratives primarily for their lack of representational accuracy, but at producing a critique of narratives which shows their status as bottlenecks for disabled peoples' access to the media as well as media stories' relevance for the everyday lives of disabled people.

This chapter works from these premises in order to examine three recent variations of a familiar allegorical figure of disability, as represented in mass media and popular culture. The figure is predicated on *compensation* and *overcoming*. It has many names in different parts of the literature, but I will refer to it chiefly as the *supercrip* (Hardin & Hardin, 2004; Harnett, 2000; Kama, 2004; Norden, 1994). The name is usually given to people who are clearly – visibly – disabled, but who nevertheless achieve something remarkable and impressive (particularly something that requires physical exertion).

The supercrip is interesting because it frequently structures positive or upbeat narratives, and so provides the basis for stories about disability as a *solvable problem*. The supercrip shares this characteristic with other disability-related constructs, particularly the *cyborg* (Haraway, 1991; Reeve, 2012) and the *techno-marvel* (Norden, 1994); they are all figures of modernity and late modernity, in that they embrace technological optimism.

The link between supercrips and cyborgs depends, too, upon their mutual association with social fields, including sports and rehabilitation and ultimately medicine (Howe, 2011), while cyborgs and techno-marvels share an affiliation with genres of fiction, particularly science fiction. Supercrips may simply be people with impairments who display superhuman willpower and fortitude, whereas techno-marvels and cyborgs are augmented in some way – blurring the line between the natural and the technological. All three analytical figures, however, share a defining feature in that they rationalize and legitimize impairments as positive attributes by representing them as causes of achievement and transformative experience.

From the discourse point of view of, this process of legitimization is crucial to delineating the potential impact of any ideal type. Supercrips tend to form points of contention and conflict between the mainstream media and scholars of Disability Studies and activists. Since they so clearly manifest positive representations of disabled people, direct criticism either of the person filling the role as supercrip or of the institutions that produce supercrip discourse can easily be framed as "sour grapes". It is therefore important to identify the topoi and warrants that supercrips draw on and strengthen, and thus reconstruct their connection to coercive ideologies of compensation and achievement.

The argumentative topos grounds claims and propositions in common or accepted knowledge, and may be phrased as a conditional. It performs the allegorical work suggested by Snyder and Mitchell by providing a link between the specific and the general. The cultural construction of supercrips depends, for example, on the topos of *cause to effect*, which is usually instanced as the simultaneous mention of impairment and achievement. A key example is this context is the figure of Franklin Delano Roosevelt, whose world-historical achievements positions him, perhaps even beyond supercriphood (we may eventually need another term, perhaps "übercrip"). As Eleanor Roosevelt claimed in her autobiography, "Franklin's illness proved a blessing in disguise, for it gave him strength and courage he had not had before" (Roosevelt, 1992 [1961]: 142).

The causal link may be understated, implicit, or even paradoxical, as in this example: "Oscar Pistorius has already inspired a generation with his 400m performance, despite being a double amputee" (Hendricks, 2012). The causal direction of flow is essentially the same as in the Roosevelt example: Pistorius' inspirational status (preceding, of course, his indictment for the murder of his girlfriend) was positioned as a consequence, even if an indirect one, of the existence of his impairment.

We can extrapolate a formula:

(S)upercriphood = (A)chievement / (I)mpairment

This is not strictly or literally mathematical, of course. Although impairments can be ranked numerically, e.g. on a scale from 1.0 to 4.5 for Paralympic ranking purposes (Peers, 2012; a lower number denotes a greater degree of impairment), even in the age of New Public Management there is no intersubjectively valid, universal numeric indicator of human achievement. An underlying principle of proportionality nevertheless holds: the magnitude of the impairment correlates negatively with the required magnitude of achievement.

A rather trickier question is that of *value polarity*. Achievement and inspiration are positives. Supercriphood appears to be positive to most people who are not actually disability scholars, disability activists, or … disabled. Presumably, then, impairments are positive, because you can't produce a positive quality from a positive and a negative. And in fact this appears to be the reasoning behind at least one attempt to represent disability in a positive light, i.e. the "affirmation model" of John Swain and Sally French, which they've summarized as follows:

> An affirmative model is being generated by disabled people through a rejection of the tragedy model, within which their experiences are denied, distorted or re-interpreted, and through building on the social model, within which disability has been redefined. The affirmative model directly challenges presumptions of personal tragedy and the determination of identity through the value-laden presumptions of non-disabled people. […] Embracing an affirmative model, disabled individuals assert a positive identity, not only in being disabled, but also in being impaired. In affirming a positive identity of being impaired, disabled people are actively repudiating the dominant value of normality. (Swain & French, 2000: 578)

The affirmation model of disability supposedly "encompasses" impairment, but it is unclear to me what this means. Swain and French are quite clear in presenting their reasons why being a part of a disability movement may be a basis for positive identity – these reasons include solidarity and shared experience as a way to reject identity threats. When it comes to impairments, however, valorization appears to depend on achieved outcomes that are not intrinsic to or do not follow directly from the concept of impairment, certainly not in the way that solidarity and shared experience follow from progressive concepts of disability.

For example: one Malaysian woman receives better health care and education because of her visual impairment (p. 574). Shakespeare et al. (1996) are invoked in order to claim that a rich, non-traditional sex life is made possible because of the need to circumvent the limitations of impairments (p. 575). Certainly, impairments represent many facets of human experience, and it would be unwise to categorically deny that the experience of impairment may entail positive qualities. My quarrel, rather, is with the supposition that the experience of impairment is valorized because good things sometimes happen to or are achieved by people with impairments. A better sex life, better education, or better health care can all be achieved by non-impaired people, and I've yet to see an argument that impairment necessarily has such consequences.

Still, the affirmation model seems to need a positive conception of impairment, which at times threatens the basic integrity of the concept. One critique of Swain and French, which aims to develop their model, proposes a definition of impairment as "physical, sensory and intellectual difference to be expected and respected on its own terms in a diverse society" (Cameron, 2008: 23). Such a definition dovetails with mystifying euphemisms like "differently abled" (whose usage frequency, according to the Google Ngram Viewer, appears to have peaked in 1996).

Taken to its logical extreme, this attitude may be referred to as Impairment Vitalism. I borrow this particular phrasing from a recent work (Overboe, 2012), for its connotations. Vitalist connotations (strength, physicality, transcendence) suffuse all three examples of impairment representations discussed in this chapter, and vitalist principles seem to characterize the spirit of many affirmational slogans (e.g. "Lame is Sexy!") rather more aptly than more neutral phraseology might. And while Impairment Vitalism superficially differs from, say, the cyborg as conceived by Donna Haraway, because of its focus on natural biological properties, there is, as Donna Reeve (2012) points out, following Tobin Siebers (2008), plenty of vitalism underlying the notion of cyborgs as fusions of perfectly functioning machines and flawless bodies. Cyborgs aren't disabled, they are super-abled. No supercrip has an impairment that he or she cannot transcend.

Effectively, there is a recurring dilemma when it comes to disability and representation: positive framings of the concept of impairment entail either a) logical inconsistency, or b) a compensatory moral calculus. If impairments cannot be negative at all, if they merely entail "difference", then the concept is superfluous. If impairments *do* have negative aspects, however, then in order to maintain an overall positive impression, there must be compensations – as in Swain and French's examples.

The figure of the supercrip, as well of the cyborg, therefore, thus embodies a compensatory argument that is deeply embedded in Disability Studies' attempts to dismantle negative representations of disability and disabled people. The (reconstructed) topos in question might be phrased as follows: "If a person with an impairment Z displays positive quality X or achieves positive accomplishment Y, then impairment Z is itself validated". This, of course, preserves the general premise that impairment Z must be validated, and is therefore intrinsically problematic.

Impairment as a Problem: The Rhetorical Perspective

Disability has been analysed as appearing always-already as a problem. It "typically generates the requirement for explanation and amelioration, but little else", according to the analysis of Titchkosky & Michalko (2012: 127). Unlike "natural" or "normal" bodies, which may be described neutrally, in terms of their capacities or features, bodies with impairments require explanation and action: an explanation of what went wrong, of how deviance from the norm came about, and action aimed at restoring normalcy in one way or another.

This is a matter of ontology, the exploration of which is becoming more central to Disability Studies (Hughes, 2007), and which is intimately tied in with the matter of representation. It is one thing to say that *disability* is ontologically problematic, and to represent it as such. It is another, and potentially quite a scary thing, to represent *disabled people* as intrinsically problematic, and scarier still to represent *people with impairments* as problematic. Even when the problem of impairment is represented as having a potential solution, it remains a problem – notwithstanding Swain and French's argument that the "non-tragic view of disability […] is not about 'the problem'" (2000: 571).

In rhetorical terms, impairment remains an *exigence* – something that must be addressed and solved. In the work of Lloyd Bitzer (1968), a "rhetorical situation" was originally defined as a scene or situation originating with an exigence, something that cannot be passed over in silence. Rhetorical action, therefore, is the response to a problem that requires a solution. Notably, the most influential critique of Bitzer's position was made from a constructionist point of view (Vatz, 1973). Causation does not run from exigence to rhetorical action; rather, it is rhetorical discourse that manufactures and sustains the social reality of the exigence. To pose a question is to act in a way that demands an answer (Austin, 1962), but equally, answers presuppose the existence of questions (Grice, 1975).

This is a potentially valuable contribution of rhetoric and discourse analysis to the study of disability and representation. In order to elicit the way that problems are framed – in order to reconstruct the presumed or presupposed exigencies, and see how the rhetorical situation is framed – we can look for topoi. Which conditionals and causal links are asserted or implied? How are specific representational examples linked to general knowledge?

One advantage of this discourse-centred approach is that it doesn't automatically begin with a familiar problem set. It forces a re-examination of assumptions about models and theories of disability, and their normative as well as epistemological status. The medical model of disability, for instance, can be linked to the set of topoi that treat disability as a *medically solvable problem.* Such topoi aren't just found in the discourse of the medical professions. An organization of disabled people may in some contexts appear to be a forum for political activism, but it may also be a patients' rights organization – and use medical topoi – in other contexts (J. Grue, 2011c). There are times when impairments may productively be construed as problems, and other times when the problem frame is utterly inappropriate.

The study of disability and representation should, among other things, address the difference between such times.

This in fact is one of the things Disability Studies does best: look at the answers/representations in order to tease out the questions/problems that are already present in the culture. Disability has been described as a hidden history (Longmore, 1987), though of course it has been hiding in plain sight. Just like normate bodies, extraordinary bodies are already prominent in the culture (Garland-Thomson, 1996, 2009). Whether they are recognized as *disabled* bodies is another matter. Disability Studies claims extraordinary bodies for disability; it also tries to show that these bodies are represented in ways that influence perceptions of disability and disabled people. The problem frame is only one option among many.

Disability Studies can, a little facetiously, be conceived as an imperialist project: it tries to claim vast amounts of territory. If this (somewhat questionable) metaphor holds, the closest model is the British Empire: with humble origins and limited resources, it can only succeed in its ambition by exploiting the contradictions and conflicting interests of local populations. Explorers originating in Disability Studies may also range quite far from home: this suggests the trajectory of the remainder of this chapter. I wish to look at some prominent and widely disseminated representations of people with impairments in popular culture today, in order to provide a *reduction ad absurdum* of the problem frame and the compensatory achievement stance.

My examples are representations of a) ordinary people with impairments, whose compensatory achievement lies within the realm of everyday experience, b) exceptional people with impairments, the representation of whom focuses on remarkable achievements, and ultimately c) fictional people, whose impairments serve only to provide motivation and legitimacy for their fantastical compensatory achievements. They are, in order:

a. Participants on *Beyond Boundaries*, a TV series originally developed for the BBC, since exported to multiple countries.
b. Paralympic athletes, notably the sprinter Aimee Mullins.
c. Hollywood superheroes, in some of their recent iterations.

All three examples draw on the topos of cause and effect – there is a strong link between impairment and achievement. They also share the problem frame, and represent “having an impairment” as a highly *solvable* problem. Through the twin forces of willpower and technological intervention, impairments are framed as obstacles that can be, and should be, overcome. Thus, they also reproduce the supercrip/cyborg figure.

My examples are of course not chosen at random. Rather, they constitute *exemplars*, in Thomas Kuhn’s sense of the word – “concrete problem-solutions” (Kuhn, 2012 [1962]: 186). Their relevance to Disability Studies must be inferred. Disabled people have impairments, and inferences made about people with impairments may be transferred to disabled people. Sometimes the people in the examples are explicitly identified as disabled, sometimes they are not, but they all belong to the set of people who have extraordinary bodies – bodies with impairments.

If representations of bodies with impairments are to be interesting to disability researchers, interest should be generated on multiple levels – on the level of critical appraisal of social and cultural phenomena, but also on the level of pragmatic usefulness. My last goal, stated before I proceed to actual analysis, is to develop a critique that provides insight into the kind of disability construal that might conceivably have socio-political purpose. This applies, of course, to everyday representations of impairments, impairment effects, and disability as well. Examples from media discourse are included here because they provide particularly stark reminders of the more general mechanisms on which they draw.

First Example: Beyond Boundaries/Ingen grenser

Beyond Boundaries is a reality TV series in which a group of people with physical impairments go on an expedition through challenging terrain, supervised and led by an experienced outdoorsman (a man, at least, both in the British original and the Norwegian edition that is the example at hand). The BBC, which developed the original concept in 2005, has so far broadcast three series, taking place in Nicaragua, Africa, and the Andes Mountains.

Beyond Boundaries was a popular format in Sweden and in Mexico, as well as on Flemish television, but it became a national phenomenon in Norway with the title *Ingen grenser* (literally: *No Boundaries* – for clarity I will keep the Norwegian title from here on). The second series, the most successful so far, reached a market share of 67 per cent at its highest, with 1.4 million viewers – in a country of approximately 5 million people. There was, it seems, an enormous audience for the story of disabled people struggling and succeeding in a fight against nature as well as against their bodily limitations.

It should be noted that the success of the Norwegian programme probably had something to do with its appeal to national character. While its UK precedent was tinged with colonialist imagery, playing out in locales associated with Victorian explorers, the Norwegian programme appealed to popular sentiment through images of familiar, national landscapes. The expeditions in the first and second series were conducted across Northern and Central Norway respectively, and the expedition leader in both cases was Lars Monsen, a “wilderness expert” with national standing (somewhat comparable to the UK’s Bear Grylls). The use and enjoyment of unsullied nature is a Norwegian national pastime and source of pride, and the goal of the second expedition, Snøhetta Mountain, is a national icon.

The second series in particular spawned much media coverage, with many participants becoming minor celebrities. The breakout star was Birgit Skarstein, then in her early twenties and a recent paraplegic after botched surgery. Her star turn lead to further media coverage and celebrity status: she spoke with the prime minister by phone, participated on the country’s largest chat show, and is at the time of writing a rising Paralympic athlete. All participants, however, have also been the subjects of multiple media stories that track their progress after being on the programme.

Ingen grenser emphasized group solidarity, cooperation, and above all *willpower*. This motif, which is familiar from the fields of rehabilitation and athletic achievement, was introduced and emphasized from the start of the programme. The following voiceover was played at the start of every episode, as the participants and their quest were laid out:

> Lars Monsen on a trip through the wilderness with 11 participants with very different resources for carrying out an expedition. The participants have different physical impairments. They have to want more, give more, and cooperate more than everyone thinks possible. […] Together they will show that nothing can prevent them from carrying out a gruelling expedition. Together they will show that abilities and optimism have … *no limits*.

The qualities of wanting more and giving more play themselves out in various physical challenges. The distance is traversed partly on horseback, partly by canoe, but mostly by foot and over fairly rough terrain. The participants have been supplied with two cross-country wheelchairs, which are solidly constructed but have to be operated manually. Three of the participants need to use them at various stages, and the duties of pushing and pulling have to be taken up by the stronger and more mobile participants. There is therefore a need both for cooperative efforts, and for each participant not to tax himself or herself beyond the point of exhaustion. The quality and capacities of the equipment is not a matter of discussion or arbitration, but are part of the given framework of the expedition. Some leeway is given on occasion – how far to go, when to pitch camp – but the participants are constrained in terms of the overall trajectory and goals.

Ingen grenser was, at the time of broadcast, accused by disability rights advocates and others of playing to voyeurism and reproducing freak show dynamics with its audience, the central argument being that the display of people with extraordinary bodies performing physical feats is inherently tied to the history of freak shows and freakery. These accusations should be addressed because of their implications for identification and for their ideological implications.

Historically, freak shows were displays that contested and played with boundaries between humanity and alterity (Bogdan, 1990; Orning, 2012). They were unsettling and disturbing, and intentionally so. When they disappeared, in a historical development that coincided with the expansion of modern medicine, they did not take the display of extraordinary bodies with them. What disappeared was a particular way of looking at such bodies, as well as a social and commercial framework for doing so. There is ample freakery in modern reality television, but *Ingen grenser* does not fit the format. It is a profoundly normalizing programme, which emphasizes the latent ability of people with extraordinary bodies to do ordinary things – if they have sufficient willpower.

By way of contrast, emphasis on willpower, physical mastery, and normalization, connects *Ingen grenser* to the historical and contemporary discourse of rehabilitation, in which the central problem to be solved is the problem of disciplining one's body to the point where one can be admitted (or re-admitted) to everyday life. That discourse arose as freakery waned – particularly in the wake of the First and Second World Wars. In rehabilitation discourse, abnormality is neither entertainment nor commercial opportunity. Rather, the *process* of normalizing abnormality – the problem of disciplining the body – constitutes grounds for moral instruction and moral approval.

Ingen grenser, with its month-long trek across rough terrain, is both a television programme and a strenuous exercise programme. Its goals and constraints, which were developed ahead of time by professionals, not participants, are enforced by the same agents. Participants that do not display a sufficient degree of enthusiasm or effort are, at various times, encouraged and admonished. Their lack of willpower is a problem that is both equal to and entwined with their impairments.

This framework of benevolent paternalism allows for two subject positions for the participants: enthusiastic or recalcitrant. To exceed one's previously assumed limitations (the "boundaries" of the title) is to be morally laudable; to fail to do so is a moral failure. Early press on the programme's third Norwegian series introduced a new host/expedition leader, who "cried when participants refused help".

There is no more call for a reality series featuring disabled people to represent that group in a statistically accurate way than there is for *Big Brother* to accurately represent the British population in general. Nevertheless, some observations can be made about the participants on *Ingen grenser*. There were 11 participants on the second series, all of whom had physical impairments. Some had sensory impairments, most had mobility impairments. Some of these had mobility impairments resulting from cancer, but were in remission at the time of filming. Although the distinction between impairments and chronic illnesses is not easily made, all participants had impairments that were fairly stable or very stable in terms of predictability and secondary effects.

Such a selection of people with impairments is a clear precondition for a programme such as *Ingen grenser*. Too many wheelchair users or people with unpredictable chronic illnesses, and there is no month-long trek through the wilderness. Too many such people, in fact, and there would be no way to move beyond bodily boundaries. Instead, a balance is struck in which impairments are manageable, and disability is a solvable problem. As in the discourse of rehabilitation, disability can be overcome, though it cannot be transcended. For that, we go to the second example.

Second Example: The Paralympic Athlete as Inspirational Figure

Significant global media coverage of the Paralympics began with the Sydney Games in 2000 (Cashman & Darcy, 2008); the 2012 Games in London were probably the most widely disseminated Games in history. As host nation, the UK broadcast 150 hours of live coverage.

The iconography used to portray the event is that of physical achievement despite (clearly visible) physical limitation. The Paralympics, as a "complex of elite disability sport" (Purdue & Howe, 2012: 904) represents something of a paradox. The performance must be at a level that will interest a generic, presumably able-bodied audience, while there is an expectation that the Paralympic athletes will serve as credible role models for other people with impairments (Joukowsky, Rothstein, & Paralympics, 2002).

The paradox has been explicated by the double amputee, former Paralympic sprinter Aimee Mullins, who has questioned, through argument and performance, the assumptions that support the Paralympics as a separate arena for competition. Her argument focuses on the dividing line between "natural" and "cyborg" bodies, i.e. the point at which a compensatory prosthesis becomes interpreted as a performance aid, and at which the rationale for requiring an athlete to compete in the Paralympics rather than the Olympics is not the presumption of disadvantage, but of advantage.

Mullins, who has explored the topics of prosthetics and technological development via the TED conference format, has also pointed out the limitations placed on technological optimism by economic realities. Her "12 pairs of legs" are her possessions not only because they have been built, but because they have been bought. To her, the problem is systemic.

Such points do not survive the transition to meme-hood. Originally coined by Richard Dawkins as the cognitive equivalent of a gene, i.e. a maximally effective mechanism for transmitting of information, in current usage "memes" refer to images with captions, usually encapsulating a claim or an attitude, and heavy in pop-cultural references. One such meme is "What's your excuse?", variations on which feature that phrase superimposed on images of double amputees running – including images of Mullins. Much like the promotional imagery for the 2012 Paralympic Games in London, which feature wheelchair users and amputees hovering in mid-air, "What's your excuse?" shows Mullins in mid-stride, on a beach in a black bikini, blocking out the sun so that her body is surrounded with a halo effect. Her status as a star athlete, including any mention of support systems, is transmuted into iconic transcendence.

"What is your excuse?" is also, of course, a potentially hostile question. Variations of the text include the phrase "What the fuck is stopping you?" Variations in the imagery, which extensively feature well-muscled people with impairments, are also directed at obesity, here interpreted as the direct result of a deficit in willpower.

The Paralympic athlete is a questionable figure in more than one sense: he or she may literally be questioned by examining boards that certify degrees of disability in order that competition be fair, but may also be positioned as being of questionable morality if his or her achievement is too great, if the achievement appears insufficiently effortful. There must be a problem of the right order. The world of iconic imagery demands transcendence, while real-world institutions demand the very bodily features that make transcendence impossible. The only place where these contradictions can be resolved is in fiction, which provides the third example.

Third Example: Hollywood Superheroes

Superhero fiction constitutes one of the most important, if not the most important genre in popular cinema during the last few decades. Drawing on the sources of audience familiarity (through comic books), spectacle (through sophisticated special effects) and ample potential for long-term brand and franchise building (through sequels based on the comic books' open-ended narratives), Hollywood studios and their conglomerate owners have increasingly turned to superheroes, along with fantasy-themed movies, to maintain profits in a beleaguered entertainment market.

A mainstay in superhero fiction is notion of heroism paired with extraordinary ability as a compensation for trauma, injury or even impairment. To give some examples, Bruce Wayne embarks on a training programme to become the masked crime-fighting Batman because of his parents' murder, and Matt Murdock develops superhuman echo-location abilities after being blinded by radioactive material.

The superhero Iron Man emerges from injury done to his alter ego, Tony Stark. In the 2008 film, the energy source that powers Iron Man's cybernetic exoskeleton also powers a magnet that prevents shards of metal from reaching Stark's heart and killing him. Stark's egoism and vanity are tempered by his heroic calling; his impairment makes him vulnerable and dependent on a technological device, but also turns him into a force for moral good.

Superhero cinema takes impairment vitalism to its logical conclusion: there is no injury without benefit, and no impairment without corresponding ability. The mutants of the X-Men universe, the 2000 film of which arguably inaugurated the current onslaught of films, are probably the clearest expression of this logic. Professor X, the mentor and guide of the "good" mutants, is a paraplegic with telepathic powers. His second-in-command, Cyclops, shoots energy bolts from his eyes, thus requiring special goggles in order to interact normally with the people around him. (Without his goggles, he must always keep his eyes closed, and so is blind.) The fan favourite Wolverine has a metal skeleton, grafted onto his bones through painful surgery. The list, not surprisingly, goes on.

The mutant superheroes are not disabled by economic arrangements and lack of labour power. They are stigmatized, ostracized, and legally discriminated against; particularly in the 2000, 2003, and 2006 films, "mutation" is developed as a metaphor for difference in sexuality and sexual orientation. The alternative metaphorical reading of mutation as ethnic difference has also been proposed; readings of mutation as impairment have been fewer and less developed.

In a superhero universe, impairments are, perhaps unsurprisingly, entirely subservient to narrative requirements. The 2012 film *The Dark Knight Rises* has Batman placed in an underground prison with a broken back and worn-out knees. He recovers through intensive training and defeats his enemies: the damaged body is the visual expression of a mind plagued with doubt – lacking the self-confidence and absolute willpower that defines his archetypal character.

This narrative schema, in which injury is inevitably followed by overcoming, has little to do with medicine and much to do with martial discipline. The superhero's injured or impaired body exemplifies the narrative prosthesis of Snyder and Mitchell. It provides a reason for the audience to care. Even Superman, the most god-like of all superheroes, must have at least the potential for bodily weakness, provided *ex machina* by the substance kryptonite. Once the reason to care has been established, however, it can be dispensed with. What really matters are the subsequent feats of heroism.

Retracing our Steps: Who Gets Left Behind by the Cyborgs, Techno-Marvels and Supercrips?

Through the three examples, I've traced an exponential and quite speculative curve. Superheroes are not, in fact, disabled. But representations of superheroes provide a funhouse mirror for the assumptions about bodies with impairments that are made in coverage of the Paralympics and in reality television, where disability is an explicit and central feature. Such representations are worth examining because disability, though often perceived as a special category, one that doesn't touch on other forms of bodily experience, could be and should be a prism for such experience in the most general, most fundamentally human sense. We should be worried when representations of what is effectively bodily impairment lose touch with reality.

To reiterate, the assumptions I am most critical of are: a) that impairment and injury is the source of extraordinary willpower and achievement; and b) that impairment and injury *ought to be* the source of extraordinary willpower and achievement. They both constitute variations on the topic of cause and effect, which spuriously assumes that impairments cannot be and should not be considered or represented on their own, as instances of human variation.

It is perhaps not surprising that those assumptions are made in the context of super-heroism or the Paralympic Games. It is not terribly surprising that they are made in the context of a reality TV programme. All three examples represent narrative genres, which depend on implicit and explicit relations of cause and effect. What is slightly more surprising is the extent to which those assumptions underlie affirmation models of disability, and influence notions of positive disability identity.

Although far from being dominant modes of thought about disability, affirmation and identity paradigms are important. They are particularly important because they have to do with the self-perception of disabled people – most of whom, in a statistical and demographic sense, probably do not identify themselves as disabled. It is a recurring topic in academic and activist circles that "coming out" as disabled is a difficult process. Most people would probably prefer just to be a little ill, or having a bit of trouble, and not actively identifying as *a disabled person*. Disability connotes stigma. That is probably inevitable. Ableism can be fought, but the *defeat* of ableism is as much of a utopian project as the elimination of racism or sexism.

In the meantime, the representation of disability and disabled people as a basis for identification is a topic that is potentially even more troublesome than in the context of race and gender, even as it engages with both those topics. The emphasis placed on inherent, essentialist *strength* by activists in any identity category usually risks embracing ableism. Moreover, that risk applies equally to disability advocates.

We have, perhaps, arrived at an *aporia* – one that has implications for disability identification. Talking about impairments and injuries in positive ways tends to result in a displacement of qualities: it is never the injury or impairment itself that is positive, but its potential for achievement that is presumably unlocked by the traumatic experience. Sociologists of health and illness have long employed this perspective (Frank, 2007, 2010). Once this attitude is vulgarized, it becomes a moral imperative to treat illness as an instructive and transformative experience (Ehrenreich, 2010).

Is there an antidote? Possibly, expectations could be reversed. Franklin Delano Roosevelt (in)famously underplayed, concealed and reframed his impairment in public life (Gallagher, 1985). Although there is disagreement as to the extent and impact of public knowledge about Roosevelt's impairment (Tobin, 2013), it is clear that he did not represent himself as *disabled* and was generally not represented as such until fairly recently. Although an extreme example, the reframing of the FDR story shows the potential of Disability Studies as a critical discipline. Paul Longmore's hidden history of disability holds relevance for our understanding of contemporary phenomena: to point out, repeatedly, that "this is disability" isn't always effective, but the claim nevertheless has to be made. This, too, is *to do* with disability, because it is connected to bodies, bodily experience and bodily reality.

Superhero stories exist in a fantastical space – they take place in a narrative space where not only bodies, but everything down to and including the laws of physics may be altered. The fact that the laws of narrative still apply, however, makes them subject to analysis of representation and its strategies. This, in turn, connects them to bodily and embodied reality. The study of representations of disability may not be – shouldn't be – an act of lobbyism in itself, though it may produce an occasional white paper. And the study of disability is tied to the study of discourse wherever discourse deals with various forms of embodiment.

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A Final Note

Discourse analysis in general and CDA in particular provides tools and methods for analysing representations and constructions of disability sourced from a variety of contexts. Their methods can treat analytical examples from social, cultural, economic, and political spheres, thus underscoring disability's status as a phenomenon influenced by and influencing all of them. The unifying feature in the CDA approach is the view of language as an influential factor not only in shaping perceptions of the world, but framing the world so that it appears naturally amenable to certain courses of action and forms of organization.

Given that disability is a phenomenon already saturated in representation – there is no shortage of disability discourse – CDA can provide tools for discussing how different representational strategies work, and what implications they might hold. This analytical approach is also a way to de-naturalize the phenomenon of disability, and to highlight both the factors that contribute to its social construction and the factors that remain relevant across contrasting representational strategies. This approach is also relevant to central debates in Disability Studies, by representing their models and theories as elements of discourse – making it clear that the theories and models do not exist independently of their representational objects.

This book has emphasized certain dichotomies in the disability field. One of these is that of chronic illness versus impairment, which is arguably the most pervasive and the least productive way to divide indisputably disabled people from people who are disabled but not explicitly identified at such. The dichotomy is not baseless – it derives from organizational structures and political considerations – but it is also shaky and inconsistent, and should be undermined further with critical analysis as well as through empirical description.

There is much to be gained in describing how and in what ways disability relates to chronic illness in relation to a second dichotomy, too: that which runs between social models and medical models of disability. Here, I have argued that the dichotomy is fundamentally illusory, in that it can be maintained only with a highly particular view of two constructs called "the social model" and "the medical model" of disability – constructs that are often deployed in order to (mis-) characterize the positions of others instead of defending analyses of one's own.

The above dichotomies play out against a background of complex, socially embedded discourse, and it is against this background that they lose their sharp edges. There isn't *a* social model of disability, and certainly not one that can be effectively employed across discourse realms and areas of society. Similarly, "the medical model" can only be effective by confining discussions of disability to a single topic and field – through medicalization – since any effort to discuss disability in relation to its full range of relevant topics will inevitably explode a narrow medical conceptualization of the phenomenon.

This book is an attempt, among other things, to show the futility of trying to maintain the purity of narrow models of disability, which are of very limited use in approaching disability-in-the-world. *Concepts* and *theories* are widely useful, certainly, but many *models* have very specific ranges of functional application, and lose their utility beyond this range. In practice, models become embedded in discourse and discourse practices, which means that their meaning often changes according to who is using them, and for what purposes. Specifically, it is necessary to pay attention to how models are developed, put to use, understood, and interpreted within those fields that draw on insight from academic Disability Studies but are not themselves academic.

Another aim of this book is to point out the relationship between discourse, narrative and identification. In an ecumenical view of Disability Studies, in which the time is ripe for theoretical pluralism and pluralist investigation, there is greater room than before for developing points of identification for people who haven't yet identified as disabled. This point is an argument for introducing disability into new discussions, for using the concept of disability in unexpected ways, and of conceiving of new kinds of narratives as disability narratives.

Another way of framing this is to repeat the book's big unanswered question: What is the concept of disability *for*? It is a concept for critical analysis, certainly, but simultaneously a concept for identifying need, developing solidarity, and implementing inclusion. It is, however, also a concept that is constantly in danger of being appropriated for reactionary purposes, and which must therefore be continuously re-appropriated by its own discipline.

These three goals are, or should be, closely intertwined. Reductionist or exclusive concepts of disability serve only to alienate people who are at the fringes of disability identity, people who might have seen disability as relevant to their own life situation. The critical analysis of concepts is not inherently a destructive endeavour, and it is not a project that results in an absence of meaning or definitions. Rather, it is a strategy for showing the relationship between concepts and their contexts, and, in the case of this book, the way in which concepts depend utterly for their meaning on the discourses and societies in which they are embedded, while simultaneously shaping them in return.

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