Disability Studies: Strengths and Dilemmas

Ingrid Baart (†) and Robert Maier

Abstract

Disability studies, and more generally the disability movement, have reached a state of authoritative maturity over the past two decades. Indeed, a comprehensive conceptual framework has been developed which defines and situates disability conceptually, while at the same time forging links with political and policy networks and with a range of interest and pressure groups that advocate the emancipation of disabled people. Moreover, there are clear signs of official recognition as evidenced, for example, by the EU adoption of agenda 2020 for disabled persons, and by the research opportunities opened up by the latest call within the EU research programme, (the 7th framework), or by the adoption of the United Nations Convention on the Rights of Persons with Disabilities. However, these strong points should not conceal the fact that there are also a number of dilemmas that disability studies should confront, such as, for example, a number of problematic elements in the conceptual framework or the contradictory interests to be found in the political and ideological coalitions that have been formed. The aim of this paper is to underline the achievements and to examine the dilemmas without, however, limiting the discussion to a critical note. On the contrary, this discussion will demonstrate how these dilemmas might be overcome.

Contents

Preamble

The Foundation for Disability Studies in the Netherlands (http://disabilitystudies.nl), and Jacqueline Kool and Alice Schippers[1] asked the authors to write a short essay exploring the problems disability studies will encounter, and to focus on the potential dilemmas disability studies will have to confront. As an organization, the Foundation for Disability Studies in the Netherlands stimulates research in the field of disability and promotes theoretical and conceptual knowledge on the subject by developing a consistent programme of research, teaching and knowledge networking.

Ingrid Baart and Robert Maier set out to write this essay together. Regrettably Ingrid Baart passed away after a short illness. She contributed to this essay by helping with the initial draft and by making a number of suggestions for its completion. Her untimely death is a great loss to Disability Studies in the Netherlands. Ingrid will be sorely missed.

Ingrid Baart was a member of the governing board of Disability Studies in the Netherlands. She worked as a lecturer and senior researcher at the Medical Faculty of the Free University of Amsterdam (VUMC). Robert Maier is a scientific advisor to Disability Studies in the Netherlands and emeritus professor with the Faculty of Social Sciences, Utrecht University.

---

[1] Many thanks to Jacqueline Kool and Alice Schippers for reading and commenting on the initial draft.

Introduction

This paper explores the domains of disability studies, and more generally the disability movement[2], and examines the position of the stakeholders involved. The aim is to map out the important issues and debates surrounding disability studies, and in particular to highlight the strong points of the disability movement and the potential dilemmas that emerge when the strong points are examined. The objective is neither to establish fixed boundaries for disability studies, nor to develop a new model. The aim of this paper is much more modest: to demonstrate that a number of dilemmas cannot, at present, be avoided, and that the best solution would be to work with these dilemmas.

The first part presents and explores the strong points of disability studies and the disability movement. The second part examines the dilemmas. To conclude, the discussion points out the difficulty of eliminating these dilemmas while showing, at the same time, that it is possible to strengthen disability studies by accepting these dilemmas.

---

[2] The relationships between disability studies and disability movements are rather complicated and, moreover, also differ widely in different countries. A unified and strong disability movement emerged early on in the US and the UK. Furthermore, the institutional context of decentralized universities there facilitated the establishment of disability studies in teaching and research in partial alliance with the disability movement. However, this evident link between the disability movement and disability studies is not obvious in other countries, as in the Netherlands. This is not only because the movement is not particularly unified, but also because of the more centralized decision structure of institutionalizations in higher education and research. Nonetheless, disability studies currently aspires to an identity of an emancipatory scientific enterprise, and an agent of change, notwithstanding the many internal variations which are either purely research related or which act as a critical voice.

Strong points

'Disability studies' (Goodley, 2011) is a relatively new interdisciplinary academic field that focuses on the conditions of people with disabilities. The terminology used in this paper makes no distinction between British usage that speaks of 'disabled persons' or American usage that speaks of 'persons with disabilities'[3]. Disability studies, as an academic enterprise, with its study programmes, specialist journals and international conferences does, on the one hand, have an independent identity. However, on the other hand, disability studies grew out of the disability movement (see note 1) to which it is still linked more or less organically, depending on the variations throughout countries and on the presence and activity levels of the disability movement. There are extensive study programmes in the UK and in the US, and in a number of other countries. 'Disability Studies' in the Netherlands was only relatively recently established in a limited way in 2009 (Hoppe et al., 2011) as a 'knowledge network' with the remit of stimulating research into and teaching on disability.

The disability movement started in the 1960s and 1970s in the US and Britain. This movement fought and continues to fight to secure equal opportunities and equal rights for people with disabilities. The disability movement was initially inspired by the women's movement and other emancipation movements, and by the civil rights movement in the US. Significant disability rights legislation was passed towards the end of the twentieth century and is still being introduced today.

'Disability Studies' is a complex knowledge arena because - as the disability movement has convincingly pointed out - the forms of exclusion and discrimination a disabled person experiences cannot be explained directly by impairment. When attempting to understand the limitations and exclusions of disabled persons it is necessary to refer to accessibility in transport, architecture and the physical environment and to social and institutional prejudice. Various scientific disciplines are relevant when exploring these knowledge and practice arenas. A wide variety of stakeholders is also involved. Moreover, this knowledge arena is also linked to the

---

[3] In fact the terminology used does not systematically follow these preferred usages.

political, legal and practical arenas. In short, this knowledge arena is at the intersection between science, politics and the practical, social and cultural conditions of living.

A number of strengths of the disability movement, and of disability studies in particular, can currently be identified. First of all, a rich conceptual framework has been developed for understanding – and acting upon – disability, a framework that integrates the former medical and social model, and which makes it possible to capture the multiple forms and the dynamic nature of disability. Secondly, there has been wide recognition of the needs and problems of disabled persons, both by the general public and by national and international organizations, including the necessity to set up suitable interventions, of various types, in order to improve the living conditions of disabled persons. Thirdly, the rights of disabled persons have been solidly anchored in legislation, at national, European and international levels. Fourthly, a considerable amount of data is available that provides a rich picture of the various forms of limitation, discrimination and living conditions of the multiple groups of disabled persons worldwide.

This section briefly examines these strong points. However, it is also necessary at this juncture to state that, despite these strengths, many problems persist. Disabled people are still very much disadvantaged when it comes to poverty and employment, and many other areas. Moreover, the successes have, to a significant extent, transformed the disability movement, which has been partly hedged in by state and international organizations. In Britain, where the disability movement was particularly active, Oliver and Barnes (2006), for example, ask whether the disabled peoples' movement is on the wane, and they suggest the following political strategy: 'We still believe that the only viable long-term political strategy for disabled people is to be part of a far wider struggle to create a better society for all'. We first address the strong points before moving on to discuss the dilemmas in the following section.

One important strong point is the development of a unified conceptual framework which makes it possible to view disability rather consistently, while at the same time establishing linkages with the various practical domains relevant to the disability movement.

This integrated conceptual framework combines and develops in a specific way the formerly opposing versions of the so-called medical and social models of disability. We will first examine a number of recent documents - which also serve to illustrate other strong points - in order to identify the central points of this conceptual framework. We then present this framework more systematically as a model.

We have chosen the following four documents:

(1) The United Nations Convention on the Rights of Persons with Disabilities (United Nations, 2006);
(2) The European Disability Strategy 2010-2020 (European Commission, 2010);
(3) The research call 'Understanding disabilities in evolving societies' in the Work Programme 2012 of the European Commission (European Commission, 2011), and
(4) The World Report on Disability (WHO, 2011).

The choice for these documents is rather arbitrary because there are many other recent documents, at national or international level, that could just as easily have been used: e.g. the Charter of Fundamental Rights of the European Union (Official Journal of the European Union, 2010), or the Community-based Rehabilitation Guideline (WHO, 2010). The four documents selected here are all recent and they mark important milestones at European and international level. These documents constitute either: (1) new formulations of the rights of persons with disabilities at an international level, or (2) a European policy agenda, or (3) a Europe-wide call for scientific research (which is particularly relevant for disability studies), or (4) the first ever world report on disability. They more or less explicitly present a conceptual framework of disability with the following characteristics:

A. All these documents present *disability as complex and dynamic*, with numerous different dimensions. In short, these documents do not refer to any simple model of disability, either medical or social, but integrate these former models, and go beyond the known limitations of these models. Some of these documents refer explicitly to the International Classification of Functioning, Disability and Health (WHO, 2001), a

classification that is continuously updated. This classification is often abbreviated to ICF.

Under this framework, disability is not due exclusively to an impairment, or in other words to problems in body functions or alterations in body structure. Nor can disability be understood by referring to activity limitations, such as difficulty with walking. Nor is it sufficient to point out participation restrictions, such as discrimination in employment or transport. To understand disability, it is also necessary to take account of impairments, activity limitations, and participation restrictions. For example, the Convention on the Rights of Persons with Disabilities (CRPD) states in point e. of the Preamble: '…disability is an evolving concept, and that disability results from an interaction between persons with impairments and attitudinal and environmental barriers that hinders their full and effective participation in society on an equal basis with others'.

In short, individual and environmental factors, and their interaction, must be considered when attempting to understand and act upon disability. Moreover, disability may appear in varying forms in evolving societies with changing conditions.

B. All four documents refer more or less extensively to the connections between *disability and human rights*. For example, the call 'Understanding Disabilities in Evolving Societies' (European Commission, 2011:35) states: 'Recent policy developments have moved away from the medical model of disability and support the view that disability is also a matter of law and policies, which should be approached from a human rights and equal opportunity perspective'. The European Disability Strategy 2010-2020 (European Commission, 2010) refers to the Charter of Fundamental Rights of the EU, and to the United Nations Convention on the Rights of Persons with Disabilities.

Examining the connections between disability and human rights in the four documents proceeds either through the enumeration of the rights of disabled people, for example in terms of education, participation in economic or social domains, or in terms of listing the various forms of discrimination experienced by disabled persons, for example in employment, due to environmental barriers or from strangers.

C. All four documents underline, in varying degrees of detail, the *increasing incidence of disability* (ranging from 10 to 15 % of the population). Moreover, they also recognize the wide range of disabilities that exists.

The World Report (WHO, 2011) and the European Strategy (European Commission, 2010) in particular demonstrate the interdependency between poverty and disability, and formulate the thesis of reciprocal causality between poverty and disability. Particular issues of disability related to gender, race and class must also be considered.

D. All four documents establish the *importance of the role of policy* when approaching the problem of disability. Policy should not only be restricted to endorsing legal conventions and human rights, but should also facilitate, as far as possible, equal opportunities by eliminating the barriers, either environmental or prejudicial, which limit disabled persons' range of activities. The official formulation is that public and also private bodies should effect 'reasonable accommodation' to the situation of people with disabilities.

E. The documents introduce a *large number of relevant stakeholders* who are all involved with disability in important ways: in addition to persons with disabilities, there are also their families and community, policymakers, various professionals, a wide variety of scientists, and finally all the co-citizens, who should be considered, either as potential discriminators or facilitators, or who can indirectly benefit from the specific modification and accommodation of the environment for persons with disabilities.

F. Finally, the different documents underline the necessity of *participation of the various stakeholders*, and in the first place, of disabled persons when preparing, realizing and implementing legal, scientific or policy actions that concern disability. For example, the Convention on the Rights of Persons with Disabilities (United Nations, 2006) stipulates that states 'must consult with people with disabilities and their representative organizations when developing laws, policies, and programmes to

implement the CRPD'. In short, the battle cry of the disability movement: 'Nothing about us without us' (Charlton, 2000) would seem to have been heard.

Linked to this point, the World Report underlines the need to take account of the experience of persons with disabilities, on top of objective measures to manage limitations with participation or discrimination.

We have highlighted these characteristics of the conceptual framework which is more or less explicitly used as the basis for the four documents examined, and we will now summarize the properties of this conceptual framework in a simplified model.

This new and rather complex conceptual framework is presented below.
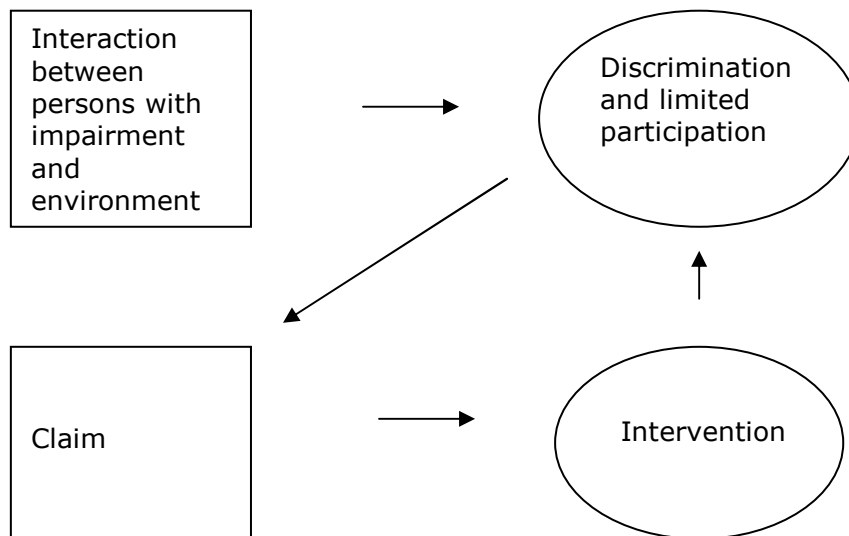
Figure 1: Integrated model of Disability

Figure 1 is an extremely simplified version of this disability model which can be described as an integrated version of the so-called medical and social model of disability. A very simple reading of this model is as follows: when interacting with their environment, people with some form of impairment, whether psycho-social, intellectual, sensory or physical, often experience some form of discrimination. This situation motivates the justifiable claim that discrimination should be eliminated through suitable interventions. In other words, people with functional limitations (impairments) should not be the victims of discrimination, whatever the origin of the discrimination. The problem is not to eliminate the impairment as such but rather the discrimination, related indirectly, through interaction, and in an unjustified way to the impairment.

This model is simplified for the following two reasons. (1) The arrows between the four blocks are presented with the same symbol. However, the arrows point to quite different types of connections. For example, the first arrow, between the interactions of a disabled person with his/her environment and discrimination, can be interpreted as existing objectively, as, for example, established by percentages of participation in

the labour market, or as experienced by the disabled person. Whatever the case, the arrow should not be read as pointing to any particular causal relation. The second arrow, between discrimination and claim, points to quite a different connection, i.e. to the normative conviction that according to some norm (human rights, citizenship rights, civil rights, etc.) discrimination violates this norm. The third arrow, between claim and intervention, again points to as different connection. It means that the unacceptable situation of discrimination should be eliminated by the appropriate action. (2) This model is oversimplified because, for the sake of clarity, a number of connections have not been given. For example, the condition that disabled people should be actively involved in the preparation and execution of the intervention does not appear here. Moreover, generally speaking, interventions do not immediately succeed in the attempt to eliminate discrimination. A complex process of evaluation, adjusted interventions etc. is usually called for. A different type of simplification concerns culture. Indeed, the model conceals the fact that the interactions between persons with impairments and their environment and also the forms of discrimination can vary widely in different cultures, a point clearly made by Devlieger (2005). However, these variations can easily be captured with the help of this model. This simplified model does not consider these connections or variations. Nonetheless, this simplified model does give a good overview.
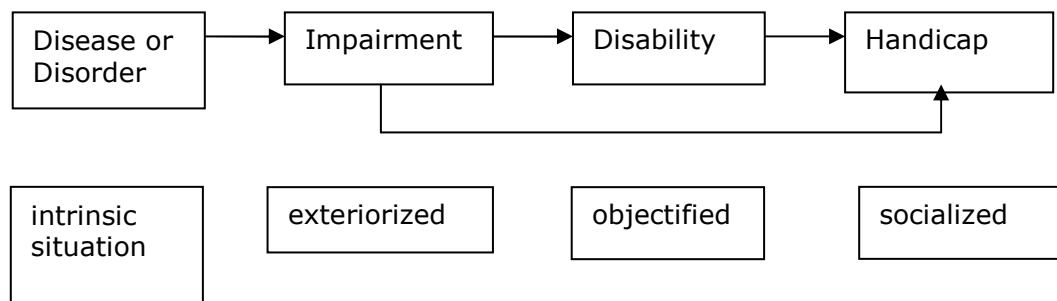
Any model, as a simplified diagram, is developed from a theory. A model has a heuristic value, and enables us to visualize complex realities and point out possible actions. Models are static and have a heuristic function. A model should not be confused with the theories that were used to develop the model. Theories change continuously, and changes are driven by empirical studies, by critical and methodological discussions and by interventions of involved stakeholders. The theories help explain the phenomena under study and guide suitable interventions, whereas the model is static and serves above all as a handle.

The model above was developed from a combination of theories: biological and medical theories, psychological and social theories of emotion, of discrimination and exclusion, of meaning, such as ethical theories, and also from theories of intervention. This paper does not intend to present an exhaustive overview of the theories that are involved in the study of the complex area of disability. We restrict ourselves here to

referring to the literature, such as the book by Barnes and Mercer (2011), the Disability Reader edited by Davis (2010), and in particular the article by Gustafsson (2004) and the paper by Devlieger (2005), all of whom make truly worthwhile suggestions.

This model integrates to some extent the well-known medical and social models of disability, while modifying them in important ways. The medical model was predominant up to the 1980s, and was attacked by the disability movement which put forward the social model as an alternative. The medical model (see Barnes and Mercer, 2010, Chapter 2) is of a purely individual nature. A disease or a disorder is the origin of an impairment (defined as a defective limb, organ or mechanism of the body) that leads to disability, which in turn forms a disadvantage or restriction to activity. Such a model can be presented by the figure below (Barnes and Mercer, 2010:21):

Figure 2: Medical model of disability

| Disease or Disorder	→	Impairment	→	Disability	→	Handicap
intrinsic situation		exteriorized		objectified		socialized

This model was inspired by medical models of illness, and refers to biological and medical theories, and eventually at a secondary level to theories of rehabilitation. This model in no way considered the limitations imposed by the physical or social environment. This is why the disability movement rejected this model as inappropriate for understanding the discrimination disabled persons are subjected to.

The disability movement put forward the social model of disability, which breaks the connection between impairment and disability. Disability is defined as the disadvantage or restriction of activity caused by the contemporary social organization

and is therefore not related to any impairment. The social organization does not take into account people with impairments, and therefore excludes them from participating in social activities. (See for example: Shakespeare and Watson, 1997; Barnes and Mercer, 2010: Chapter 2.) In short, the contemporary social organization (of space, of contacts, etc.) causes disability, and must be changed if persons with impairments are to be offered equal forms of participation. This simple and rather forceful social model is a clear alternative to the medical model, and facilitated the formulation of clear aims of action for the disability movement. The social model refers above all to sociological and philosophical theories.

Figure 3: Social Model of Disability
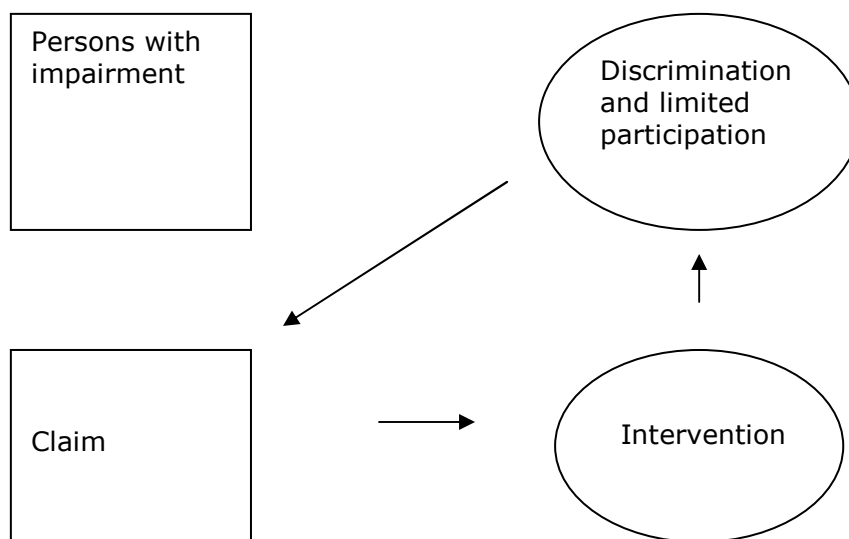
As this model eliminates any connection between impairment and disability, a number of critical voices were raised (Harris, 2001; Gabel and Peters, 2004; Meekosha, 2004; Shakespeare, 2005; Hughes, 2007; Shakespeare, 2010), focusing on the one hand on the question that people with impairments have to cope with all kinds of problems, such as pain, tiredness, shame, etc., and on the other hand with the question that such

a model has the tendency to isolate disability from other excluded groups. This last point in particular seems to have motivated Shakespeare, for example, to adopt the International Classification of Functioning, Disability and Health, also referred to as the 'biopsychosocial' model of disability. This issue will be addressed in the section on dilemmas.

In any case, the integrated model of disability presented above clearly overcomes a number of the presented limitations of the medical and the social model of disability. Indeed, the integrated model attributes a place to the individual and to the environment, and also considers the interaction between the individual and the environment. Moreover, this model can be interpreted either objectively, or it can make room for the experiences of individuals with impairments. The importance of including the individual experience has been underlined by Leonardi et al. (2006).

Moreover, this integrated model makes it possible to consider the multiplicity of forms of disability, and also their dynamic character, when introducing temporal cycles of the model. Therefore, this model offers rich opportunities to understand disability, to design objectives for research and the goals of actions and interventions. However, as we will see in the next section, some questions cannot be satisfactorily answered by this model.

As the presentation has demonstrated, recent documents such as the four documents presented above, use this integrated model of disability more or less explicitly. This fact demonstrates that this model has been widely acknowledged. However, there is one reservation: The World Report (WHO, 2011) does not use this model, but refers explicitly to the International Classification of Functioning, Disability and Health (ICF) (WHO, 2001). This exception is understandable because that same organization (WHO) promoted the ICF and was behind the compiling of the World Report. Moreover, Tom Shakespeare, a well-known spokesperson for the disability movement, who had already formulated critical comments on the social model, was involved in writing the World Report.

The other three strong points mentioned in the introduction to this section: (2) the wide recognition of the problems of disabled people; (3) the formulation of rights for

disabled persons, and (4) the extensive provision of data on the living conditions of disabled persons, do not need to be justified with the same attention as the first point, the formulation of an integrated model of disability.

The documents analysed in this section, and other documents cited (such as the community-based rehabilitation guidelines (WHO, 2010) or the Charter of Fundamental Rights of the European Union (Official Journal, 2010), are clear signs that the problems of disabled people are widely recognized, and that disabled persons are explicitly attributed rights. We believe that these two points require no further justification here. As far as the last point is concerned -the provision of an extensive and ever growing database- one can refer to the World Report (WHO, 2011), which in 350 pages gives the first worldwide overview of the incidence of disability (estimated to be some 15% of the world population), and sets out the specific problems encountered by diverse categories of disabled people in different countries. Moreover, it is worth mentioning that the institutionalization of disability studies, with study programmes in many universities and with research facilities, and with the inception of a number of international specialized scientific journals, such as 'Disability & Society', 'Disability Studies Quarterly', 'Journal of Disability Policy Studies', contribute towards providing the results of many studies conducted throughout the world into the conditions of disabled people. Moreover, these journals also provide conceptual elaborations and debates pertinent to the understanding of disability.

We can conclude this section now that the four strong points of disability studies in particular and of the disability movement in general have been established. After decades of struggle and militancy, the disability movement, and disability studies in particular, have become major and serious actors in the disability field. The old medical model has been rejected and integrated, to some extent, in a new disability model; the problems of disabled persons are now widely recognized; and their rights have been formulated in clear and binding ways. Moreover, a wealth of data helps to furnish a serious basis for the ongoing implementation and development of further initiatives.

Dilemmas

Disability studies, and the disability movement, have matured. The main characteristics were briefly outlined in the previous section. The question is whether this image is acceptable or whether it is, to some extent, misleading. This may be the case when the successes and the strong points, as mentioned above, mask problematic points and dilemmas, which we believe is the case.

We have identified three important families of dilemmas, which will be discussed in this section. The first one is related to the new, integrated model of disability. The second one is a direct consequence of the success story. Indeed, the wide recognition of disability has meant that a large number of connections and alliances with various actors, all of them involved stakeholders, have been established. Yet at the same time it was necessary to take account of the divergent interests of these actors, which necessitates the making of difficult choices. The third family of dilemmas is connected with the universal recognition of the rights of disabled people and the translation of these rights into their daily life. This is something that is difficult to achieve in full and at once - priorities have to be set.

The presentation and discussion of these three families of dilemmas cannot be done in the same way as the presentation of the strong points. Indeed, when presenting the strong points it was assumed that the reader is, to some extent, familiar with the recent history of the disability movement, and that concise references to documents or events suffice to establish these points. Where dilemmas are concerned, we cannot proceed with the same presuppositions. The dilemmas must be concisely defined, and solid arguments must be put forward to justify the steps in the presentation.

The *first family of dilemmas* is related to the integrated model of disability. This model would appear to be very widely used, either implicitly or explicitly, as for example in three of the documents examined in the previous section. Two different types of dilemmas can be identified within this family: the first is related to the model as such, and the second to the question as to whether or not this model has to be maintained or developed, or whether it should be abandoned altogether in favour of

the International Classification of Functioning, Disability and Health (ICF) (WHO, 2001), as some authors recommend.

The integrated model combines observations from the medical and the social model, albeit modifying them significantly. This model makes is possible to take account of the individual person and his or her personal problems, such as the environment, and includes interaction. It also gives a clear indication of the relations between discrimination, claim and intervention. However, this model focuses on impairments simply because the idea behind it is to present a simplified model of a complex conceptual framework of disability. Consequently, disability is and continues to be strictly linked to impairment, however in an indirect way, mediated through interactions. This relationship inevitably leads to questions of demarcation of disability, which cannot be resolved in a general manner.

Indeed, impairments are defined as problems in body function or alterations in body structure as, for example, paralysis, deafness or blindness. This definition can easily accommodate mental illness or intellectual disability, when referring to brain structures. However, strictly adhering to this line of reasoning means that any limitation of activity can be related to a specific impairment because the brain and the body change over the lifecycle. But this is clearly not the intention of this model of disability. For example, illiteracy imposes limitations of activity, generally hidden in subtle ways by the illiterate from others. However, illiteracy should only be included in the model when it results from an intellectual disability. Many elderly or sick people would qualify, which is not the intention behind this model. As a result, this model must continuously solve the question of how disability can be demarcated from other types of limitations of activity, with all the possible forms of overlap between the different forms of limitations. Drunks: no - but drunk, intellectually disabled persons: yes. This caricature throws up a real problem that cannot be avoided with the integrated model. The problem can only be tackled on a case by case basis, following, to some extent, new scientific insights and social recognition of impairments.

Another problem emerges when considering groups of disabled people, such as for example many deaf people whose inclusion is not in doubt. However, many refuse to be considered as having an impairment. On the contrary, they defend their conviction

that they form a particular culture, and they have adopted a term to designate this culture as suggested by Ladd (2003): 'Deafhood'. This group, which under the definition should certainly be included, would therefore, without a doubt, vehemently reject the integrated model because of its reference to impairment. To put it briefly, the integrated model itself leads to a number of dilemmas that have to be dealt with on a case by case basis, or to dilemmas that cannot be avoided, as the reference to 'deafhood' demonstrates.

The second type of dilemma arises when asking whether this model should be maintained and developed, or whether it should be abandoned altogether in favour of the International Classification of Functioning, Disability and Health (WHO, 2001), which replaced the previous International Classification of Impairments, Disabilities, and Handicaps (ICIDH). It might be interesting here to refer to the critical remarks Tom Shakespeare (2010:272) made when presenting the social model of disability in the book edited by Davis (2010). Shakespeare recognizes that the social model was beneficial for launching the disability movement, and that it helped promote a positive disability identity, and also that it encouraged the fight for civil rights legislation and the eradication of barriers. However, he concludes that the social model, at present, constrains any further progress of the disability movement. He identifies the following limitations of the social model: (1) it does not facilitate understanding of the complex interplay of individual and environmental factors in the lives of disabled people. (2) As far as policy is concerned, it only provides a blunt instrument for explaining and combating social exclusion. (3) In the political sphere, this model has generated a form of identity politics that have become separatist and inward looking. Shakespeare believes that a social approach to disability is indispensable. However, a more sophisticated and complex approach is needed, which might be found when building on the 'biopsychosocial' model of the WHO (2001), the International Classification of Functioning (ICF).

Indeed, Shakespeare certainly has a point when he addresses the limitations of the social model of disability. In his critical evaluation of the social model, he does not consider the fact that in recent years an integrated model has been developed and used, which actually disposes of his first and second critical points. As to the third point, i.e. that the social model has generated a form of identity politics favouring a

separatist outlook, the question remains as to whether the integrated model makes it possible to overcome this limitation. Indeed, the integrated model is explicitly a model of disability, which can therefore be criticized as leading to a separatist outlook.

Shakespeare's choice to build on the International Classification of Functioning (WHO, 2001) does not refer to the conceptual framework that currently predominates in Disability Studies. However, Shakespeare is not the only one. Leonardi et al. (2006) make a similar choice, as do many other authors such as Bickenbach (2009, 2011). It is therefore worthwhile briefly examining the model as developed by the WHO: the International Classification of Functioning, Disability and Health (ICF).

Figure 4: The International Classification of Functioning, Disability and Health
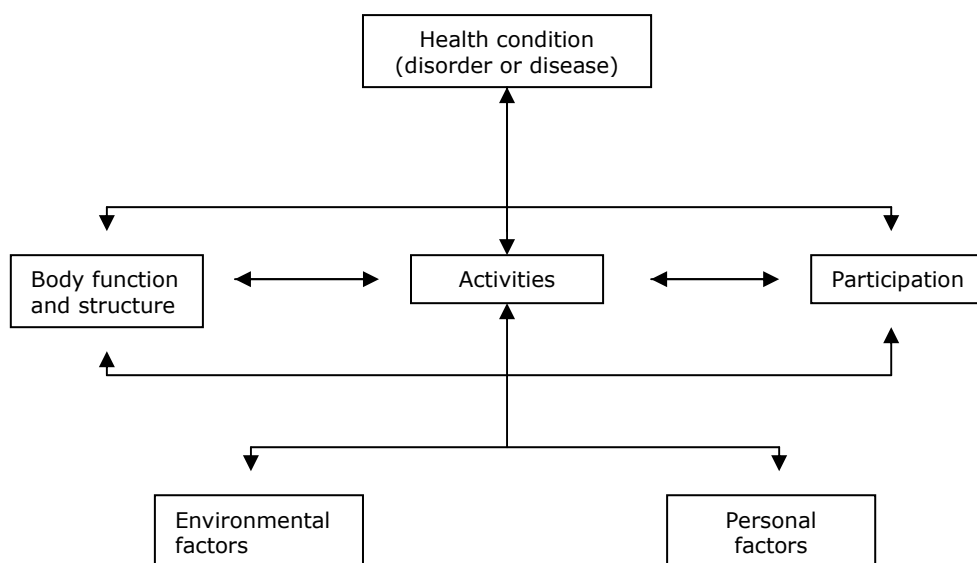
Not only scientists and clinicians contributed towards developing this model, they were also assisted by people with disabilities. This model shows a general classification of limitations of activities. In other words, it is no longer a model of disability. It highlights the range of interconnected factors that influence activities, and those that are influenced by activities, such as health condition (disorder or disease), body functions and structures, participation, and in particular personal and

environmental factors. In short, the model places activities at the centre, connected by arrows in both directions to all the other factors, which are partly interconnected. Impairments of any kind have a place in this model, as problems in body functions or alterations in body structure. Therefore this model does not apply exclusively to disabilities but to all limitations of activities. What is interesting is the fact that this model recognizes personal factors, such as motivation and self-esteem, which can influence the quality of someone's participation in society. Moreover, a distinction is made between a person's capacities to perform actions and the actual performance of those actions in real life, a difference that might result from modifications to the environment, which may either constrain or facilitate activities. As a consequence, the personal experience, and also the meaning given to interactions with the environment, can be captured with this model.

According to this model, disabled persons no longer form a separate group. Disability in this model is a matter of limitations of activities, to whatever degree, and no longer a question of being included or excluded in the model. However, there is once again a problem of demarcation because if disability is a question of limitations of activities, the problem of demarcation re-emerges, albeit in a different way from before.

This model is derived from the insights of biological, medical, psychological and social theories and it gives a rich overview of the various factors which, in isolation or in interaction, influence activities. However, in contrast to the integrated model, the ICF refers to ethical theories related to human rights and not to other ethical theories, which could provide the justifications for the claims, nor does it explicitly refer to intervention theories. Nonetheless, an ethical reference is made, namely to the United Nations Convention on the Rights of Persons with Disabilities (United Nations, 2006). Moreover, the ICF offers a certain specifications on the ethical issues related to the values of respect, confidentiality, beneficence and the duty to do no harm. The ICF, referring to UN Convention on the Rights of Persons with Disabilities, has also expanded a number of relevant points, such as the nature of the universality of the rights, their interactional structure (because of the interactions between persons with the environment inherent in the ICF) and the specification of necessary 'etiological neutrality', or in other words, the need to take into account the fact that disability is a matter of the experience of living with impairments and limitations of activities

(Bickenbach, 2012). The ICF does therefore put forward a number of important steps towards developing ethical theories linked to human rights. However, the lack of reference to different ethical theories not related to human rights seems to be a serious limitation of the International Classification of Functioning, Disabilities and Health (WHO, 2001).

Three points can be formulated to conclude this discussion of the first family of dilemmas: firstly, some problems are unavoidable, such as the refusal of some deaf people to be considered disabled. Secondly, it is impossible to escape from the problem of demarcation when considering disability. Thirdly, disability studies, and the disability movement, refer to a wide range of ethical theories (universal, contextual, utilitarian, and also to the ethics of care (Mckenzie and Macleod, 2012)) in order to gauge discrimination and justify claims and interventions. This third point means that the real choice is not between the integrated model of disability or the ICF, because the ICF does not refer to this range of ethical theories. The real choice can therefore only be to combine these two models in some way. This can be done either by incorporating the rich insights of the ICF in the integrated model, or by adding references to supplementary ethical theories in the development of the model of limitations of activities (ICF).

The *second family of dilemmas* involves the success of disability studies, and the disability movement, over the last two decades. General recognition of the problems of disabled persons has gone hand in hand with establishing a multiplicity of forms of collaboration with various stakeholders from the scientific field, from policy and politics, from professional organizations, and also from other organizations, such as unions or employer organizations, local citizenship initiatives, etc. The social and political landscape has undergone significant change in recent decades. Here we only wish to mention the emergence of the concept of governance, which points to the fact that issues of general interest (and disability is clearly one of these issues) are increasingly handled and managed by a combination of state and local agencies together with private enterprise and various citizenship organizations. This transformation means that the militant organizations fighting for the rights of disabled

people have been integrated, to a large extent, into the networks of governance. Oliver and Barnes (2006), for example, are rather critical about this transformation.

While this process is evidence of disability movement success, it also leads to new problems because collaboration among these stakeholders means that it is inevitable that divergent and even contradictory interests become manifest and this may influence the collaboration process.

We restrict ourselves here to examining collaboration with scientists, which is particularly relevant for disability studies. This collaboration is necessary and beneficial because research leads to new insights into the problems disabled people experience. However, scientists also have their own agenda: they must obtain funds for research, they have to publish, and they have to consider their own career. Notwithstanding their indisputable sympathy and involvement, scientific researchers must take account of the existing conditions for getting funds and for publishing. These interests do not necessarily clash with the interests of disabled persons. However, the conditions stipulated by disabled people (e.g. to be involved as participants in the whole research process, and not only as research 'subjects') are often rather difficult to achieve within the constraints of the research field. Indeed, while participation is deemed necessary on the one hand, both by disability studies and in a general declaration such as the Convention on the Rights of Persons with Disabilities (United Nations, 2006), the status of the 'lay' knowledge of disabled people is still very much contested in the academic world. Moreover, when trying to bring about the participation of disabled persons in research, clear limitations come to the surface, which Carlson (2010) examines in her thought-provoking book on the faces of intellectual disability. She observes that it is impossible in many cases of intellectual disability to establish communication or full reciprocity with intellectually disabled people. In these cases, she believes that the will to understand the other can lead to questionable and counterproductive effects. She states (Carlson, 2010:204) that for this very reason that there are dimensions of severe intellectual disability that will always lie beyond the grasp of the researcher, or the grasp of a family member. Therefore 'to acknowledge this is to engage in a form of "loving ignorance", whereby we "accept that we cannot know"'.

These two examples should suffice to illustrate this rich family of dilemmas which raise numerous challenges for Disability Studies.

Once more, the authors of this essay believe that these dilemmas cannot be avoided. On the contrary, disability studies must, in each case, and in a process of negotiation, solve what might be considered an acceptable compromise for the time being, bearing in mind the local political, institutional and economic context. For example, Bickenbach (2012:1122) states: 'At the end of the day, rights must be negotiated because rights are held equally by all and circumstances often make it impossible for everyone's rights to be equally implemented (or in especially hard cases, implemented at all).' A combination of references to universal ethical theories with contextual, temporal and utilitarian ethics will be necessary to work with this family of dilemmas.

The *third family of dilemmas* involves the gulf between established rights on the one hand and the effective implementation of these rights on the other. As already mentioned, much legislation has been introduced in recent decades that sets out equal rights for disabled persons, both on national and international levels. The recent adoption of the United Nations Convention on the Rights of Persons with Disabilities (United Nations, 2006) and the Charter of Fundamental Rights of the EU (Official Journal, 2010) are significant milestones. The European Disability Strategy 2010-2020 (European Commission, 2010) states that the full economic and social participation of people with disabilities is essential if the EU's Europe 2020 strategy is to succeed in creating smart, sustainable and inclusive growth. This strategy focuses on eliminating barriers in order to create a barrier-free Europe, and identifies eight main areas for action: accessibility, participation, equality, employment, education and training, social protection, health and external action.

The adoption of these anti-discrimination regulations and rights charters and conventions, and the attendant action plans, serves to demonstrate that the serious problems of disabled persons in terms of poverty, educational disadvantage, low participation levels, and the many forms of discrimination disabled persons encounter have all been recognized. The significance of this must be underlined. However, the effective implementation of the rights and the abolition of the various forms of discrimination pose a daunting challenge. A number of reasons can be given to

explain the difficulties implementation will encounter. Firstly, insufficient funding - a point strongly emphasized by the World Report on Disability (WHO, 2011). Moreover, it is generally recognized that the discrimination of disabled people has deep historical and cultural roots (see for example Carlson (2010) on intellectual disability) that are difficult to get to grips with. It is undeniable that information campaigns can effectively influence prejudice, though the results are rather limited and the effect is not immediate. This difficulty with implementing measures effectively is well known. We would like to focus here on a different, though relevant point: i.e. the nature and quality of the rights that are addressed.

The rights of people with disabilities are formulated as basic rights, the nature of which is absolute and unconditional. For example, the UN Convention states the following principles: a. Respect for inherent dignity, individual autonomy including the freedom to make one's own choices, and independence of persons; b. Non-discrimination; c. Full and effective participation and inclusion in society; d. Respect for differences and acceptance of persons with disabilities as part of human diversity and humanity; e. Equal opportunity; f. Accessibility; g. Equality between men and women; h. Respect for the evolving capacities of children with disabilities and respect for the right of children with disabilities to preserve their identity. Bringing these principles into practice presupposes that the other two difficulties mentioned have been overcome, namely sufficient funding, e.g. for accessibility, or the elimination of discrimination. Other points included in the UN Convention, such as the points on full and effective participation and inclusion in society, or equal opportunity, can only be fully accomplished through welfare arrangements, which are traditionally situated in the so-called welfare state. For example, full and effective participation and inclusion does not just assume that the civil and political rights of disabled people are guaranteed, but also that social rights are fully provided for them. Social rights can be understood as entitlements, or as claims on resources (in terms of monetary transfers or in terms of services to be provided) which makes it possible to escape exclusion due to poverty or due to total dependency on kinship networks (generally families).

Marshall (1964) has theorized the different citizenship rights, and he was also the first person to state that the nature and the quality of social rights is substantially different from the other citizenship rights, i.e. civil and political rights (Marshall, 1950).

Whereas according to Marshall, civil and political rights are rather absolute in nature and are defined unconditionally, social rights are in principle more relative and conditional. Social rights are conditional because there are no universal social rights that would guarantee a kind of universal citizenship. As social rights are connected to entitlements (concerning monetary transfers or services to be provided), these entitlements depend on various conditions. For example, for acquiring pension rights one has to participate in the labour market; entitlement to social benefits is often means tested; or entitlements involving disability depend on strictly-defined assessment criteria. In short, the multiple social rights depend on conditions that can be changed and renegotiated continuously. Reforms in the welfare system generally involve amendments to the conditions that allow one to acquire social rights. This feature of social rights means that social rights are not only conditional but also relative because they can change all the time.

Welfare systems throughout Europe have, in recent decades, undergone profound transformation, where the general trends have been cost containment and the establishment of an active welfare state. The latter is also referred to as a welfare-to-work perspective, or in a word: 'activation' (for an overview see: Albers and Gilbert, 2010). We will give a few examples here of the changes that are particularly relevant for disabled persons. The best known example is from the Netherlands where almost one million people received disability provisions right up to the 1980s. This was deemed to be excessive, and reforms introduced in the 1980s revised the conditions under which people participated in the Dutch disability scheme. Other examples are: (1) The cash-for-care schemes that have been introduced in many European countries in the last twenty years. Under these schemes people in need of care (following assessment) have at their disposal a certain amount of money which they can spend at their discretion on care assistance. These cash-for-care schemes have enabled many disabled persons to attain a more satisfactory quality of life. However, many countries have reduced this social provision in recent years, or are planning to do so. (2) Activation means that the allocation of social benefits depends on actively engaging in training or work, often supported by activation programmes set up either by the state or by private enterprises. The effects of these activation programmes for disabled people have turned out to be rather disappointing, and they are sometimes really appalling. In a systematic review of effectiveness of the UK's welfare-to-work

programmes for people with a disability or chronic illness, Bambra et al. (2005) conclude that these programmes seem to have a very limited impact on employment, and that no single UK welfare-to-work approach stands out as the best way of solving the problems. Holmqvist (2009) examined in detail the Swedish activation programme for disabled people (Samhall). His conclusion is truly alarming because he finds a clear mismatch between the programme goals and the practical results. Indeed, contrary to intentions, the Samhall activation programme actually leads to passivity. Finally, we cite the work of Pope and Bambra (2005) who examined the effects of the programmes since the implementation of the Disability Discrimination Act in the UK in 1995. The results are shocking: this legislation has not increased the employment rates of people with a limiting long-term illness or disability. In an ironic last phrase, the authors state: 'It seems likely that additions to the legislation are required if the Act is to be a more effective policy tool in increasing the employment rates of people with limiting long term illness or disability'.

We can conclude that there is a big gap between established fundamental rights on the one hand, and the effects of social rights intended to achieve these rights on the other. The title of an article by Marta Russell (2002) captures this problem well: 'What disability civil rights cannot do: employment and political economy'. Indeed, not only insufficient funding or forms of discrimination hamper the effective implementation of the adopted rights of disabled people, but also the fact that these rights have, to a large extent, to be realized within welfare arrangements, which are related to social rights, and therefore, with the relative and conditional nature of these rights.

A dilemma can therefore be diagnosed. While adopting the rights of people with disabilities must be applauded, an unbridgeable gap remains. This is due in part to the different nature and quality of the general rights on the one hand, and the relative and conditional social rights on the other. This conclusion also supports the claim that disability studies calls for subtle ethical theories, including references to theories of negotiations, which are not limited to considerations of human rights, but which study how and why contemporary societies have characteristics of decency and solidarity and what kind of possibly limited realization of social rights can be ethically justified - for the time being. This formulation refers to the terminology used in the UN Convention which is 'reasonable accommodation', and which we have translated as

limited realization of social rights. (An interesting discussion of the possibilities the UN convention offers can be found in Harpur, 2012.) In this context we would like to suggest using an adapted version of the concept of 'evenhandedness', a kind of contextual exploration of ethical justification of justice, introduced by the Canadian political philosopher Joseph Carens (2000). Carens does not develop this concept of evenhandedness for disabilities, and in particular for provisions of the social state for persons with functional limitations. He discusses the situation of ethnic minorities, and enters into a very stimulating discussion on how, with the help of the concept of 'evenhandedness', it is possible to justify, at least temporarily, some evident inequalities. Applying and developing this concept for people with functional limitations could certainly be a worthwhile task for disability studies.

Conclusion and discussion

Do the dilemmas discussed threaten the further development and viability of disability studies, or the disability movement? Or are these dilemmas simply signs of the maturity and power of disability studies? We tend to favour the second statement. Indeed, the disability movement has changed by being partly assimilated in advocacy networks characteristic of the new types of governance, but at the same time there are clear signs of success such as the wide recognition of the needs of disabled people and the adoption of new and binding legislation on the rights of disabled people. 'Disability studies', conceived of as an important knowledge arena of the disability movement, provides opportunities to develop the knowledge base concerning disability through the stimulation of teaching and research, while it is, as a movement, partly assimilated in structures of research funding and of teaching. This state of affairs goes hand in hand with the emergence of new dilemmas, which we believe can be interpreted as signs of the growth of the knowledge base on the one hand, and of the enlarged forms of collaborations with stakeholders and the growing influence of the intervention initiatives in favour of disabled people, on the other.

However, the ever growing knowledge base and broad initiatives are situated in the present world with all its complexities, which not only involves trends to develop more decency and solidarity, but also sees a multiplicity of struggles and conflicts, mostly of a mixed nature, with various social, political, economic and cultural aspects.

These struggles and conflicts are necessarily reflected to some extent in the knowledge base and the initiatives undertaken by disability studies, and the disability movement.

As far as the first family of dilemmas is concerned, it is clear that a number of decisive steps have been taken, which have made it possible to go beyond the limitations of the medical and the social models of disability. Efforts on the part of scientists in collaboration with various disciplines and representatives of disabled people, have led to the development of a new and subtle classification of functioning, disabilities and health (WHO, 2001). However, inspiration from different ethical theories which allow for the formulation of justified claims is missing in this model. We therefore suggest that it is necessary to maintain and develop the so-called integrated model of disability, which stimulated the inspiration to refer to a variety of ethical theories. The other two families of dilemmas related to the partial contradictory interests of all the stakeholders involved and to nature and quality of social rights seem to support such a choice. Indeed, collaboration with other stakeholders while they have partly divergent interests, assumes that disability studies has the capacity to formulate clear ethical guidelines on which kind of compromises are acceptable and on those that must be rejected. A similar argument holds when taking into account the relative and conditional nature of social rights. In short, when acting in the present world, one can strive for optimal solutions and value-free knowledge. However, the practical realization of intervention initiatives and the development of a knowledge base will necessarily be limited and influenced by the present conflicts and struggles, and can only be achieved with the help of a diversity of ethical references, including contextual and utilitarian ones.

Conflicts surrounding demarcations, concerning disability, cannot be avoided in any classification. This conclusion can also be justified when considering the fact that achieving the rights of disabled persons can only be accomplished – at least in part – through welfare arrangements. As social entitlements are in principle conditional, the acquisition of rights presupposes assessments by the designated institutions of the welfare state, which necessarily work with classifications and therefore with demarcations. Here once again, a substantial ethical study seems an essential instrument when studying these procedures.

To conclude, we would like to formulate the following perspective: The dilemmas presented here cannot be avoided because they emerge naturally from the growth of the knowledge base and from the multiple intervention initiatives of disability studies. They constitute challenges for disability studies. Accepting these challenges will mean working with these dilemmas, and coming up, on a case by case basis, with varying partial and temporary solutions for the dilemmas. Our thesis is that this course of action can only serve to support disability studies.

References

Alber, J. and Gilbert, N. (eds.) (2010) *United in Diversity? Comparing Social Models in Europe and America*. Oxford: Oxford University Press.

Bambra, C., Whitehead, M. and Hamilton, V. (2005) Does 'welfare-to-work' work? A systematic review of the effectiveness of the UK's welfare-to-work programmes for people with a disability or chronic illness. *Social Science & Medicine*, 60:1905-1918.

Barnes, C. and Mercer, G. (2010) *Exploring Disability*. Cambridge: Polity Press.

Bickenbach, J. (2009) Disability, culture and the UN convention. *Disability and Rehabilitation*, 31(14):1111-1124.

Bickenbach, J. (2012) Ethics, Disability and the International Classification of Functioning, Disability and Health. *American Journal of Physical Medicine & Rehabilitation*, 91(13):163-167.

Carens, J.H. (2000) *Culture, Citizenship and Community. A Contextual Exploration of Justice as Evenhandedness*. Oxford: Oxford University Press.

Carlson, L. (2010) *The Faces of Intellectual Disability. Philosophical Reflections*. Bloomington: Indiana University Press.

Charlton, J.I. (2000) *Nothing about Us without Us: Disability, Oppression, and Empowerment*. Berkeley: University of California Press.

Davis, L. (ed.) (2010 Third edition, 1997 First edition) *The Disability Studies Reader*. New York: Routledge.

Devlieger, P.J. (2005) *Generating a cultural model of disability*. Paper presented at the 19th Congress of the European Federation of Associations of Teachers of the Deaf (FEAPDA), October 14-16, 2005.

European Commission (2010) *European Disability Strategy 2010-2020: A Renewed Commitment to a Barrier-Free Europe*. Brussels, 15.11.2010.

European Commission (2011) *FP7 Cooperation Work Programme: Socio-Economic Sciences and Humanities. Work Programme 2012*. Brussels, 19.07.2011.

Gabel, S. and Peters, S. (2004) Presage of a paradigm shift? Beyond the social model of disability toward resistance theories of disability. *Disability & Society*, 19, (6): 585-600.

Goodley, D. (2011) *Disability Studies. An Interdisciplinary Introduction*. Los Angeles: Sage.

Gustavsson, A. (2004) The role of theory in disability research – springboard or strait-jacket? *Scandinavian Journal of Disability Research*, 6 (1):55-70.

Harpur, P. (2012) Embracing the new disability rights paradigm: the importance of the Convention on the Rights of Persons with Disabilities. *Disability & Society*, 27(1):1-14.

Harris, J. (2001) One principle and three fallacies of disability studies. *Journal of Medical Ethics*, 27:383-387.

Holmqvist, M. (2009) *The disabling state of an active society*. Farnham: Ashgate Publishing Ltd.

Hoppe, S., Kool, J. and Schippers, A. (2011) *Disability Studies in Nederland. Verbinding in de context*. Utrecht: DisN.

Hughes, B. (2007) Being disabled: towards a critical social ontology for disability studies. *Disability & Society*, 22, (7):673-684.

Ladd, P. (2003) *Understanding Deaf Culture: In Search of Deafhood*. Clevedon: Multilingual Matters Ltd.

Leonardi, M., Bickenbach, J., Ustun, T.B., Kostanjsek, N. and Chatterij, S. (2006) The definition of disability: what is in a name? *The Lancet*, 368:1219-1221.

Linton, S. (1998) Disability Studies/Not Disability Studies. *Disability & Society*, 13, (4):525-540.

Marshall, T.H. (1964) *Class, Citizenship and Social Development*. Westport: Greenwood Press.

Marshall, T.H. (1950) *Citizenship and Social Class and other Essays*. Cambridge: Cambridge University Press.

Mckenzie, J.A. and Macleod, C.I. (2012) Rights discourses in relation to education of people with intellectual disability: towards an ethics of care that enables participation. *Disability & Society*, 27(1):15-29.

Meekosha, H. (2004) Drifting down the gulf stream: navigating the cultures of disability studies. *Disability & Society*, 19, (7):721-733.

Official Journal of the European Union (2010) *Charter of Fundamental Rights of the European Union*. 30.03.2010.

Oliver, M. and Barnes, C. (2006) *Disability politics and the disability movement in Britain: Where did it all go wrong?* http://www.leeds.ac.uk/disability-studies/archiveuk/Barnes/Coalition%20disability%20politics%20paper.pdf

Omansky Gordon, B. and Rosenblum, K.E. (2001) Bringing Disability into the Sociological Frame: A comparison of disability with race, sex, and sexual orientation statuses. *Disability & Society*, 16, (1):5-19.

Petersen, A.J. (2011) Research with individuals labeled 'other': reflections on the research process. *Disability & Society*, 26, (3):293-305.

Pfeiffer, D. (2002) The Philosophical Foundations of Disability Studies. *Disability Studies Quarterly,* 22, (2):3-23.

Pope, D. and Bambra, C. (2005) Has the Disability Discrimination Act closed the employment gap? *Disability and rehabilitation*, 27 (20):1261-1266.

Russell, M. (2002) What Disability Civil Rights Cannot Do: Employment and Political Economy. *Disability & Society*, 17 (2):117-135.

Shakespeare, T. and Watson, N. (1997) Defending the Social Model. *Disability & Society*, 12, (2):293-300.

Shakespeare, T. (2005) Review article: Disability studies today and tomorrow. *Sociology of Heath & Illness*, 27, (1):138-148.

Shakespeare, T. (2010) The Social Model of Disability. In: Davis, L. (ed.) (2010 Third edition, 1997 First edition) *The Disability Studies Reader*. New York: Routledge, pp 266-273..

Smith, S.R. (2005) Equality, identity and the Disability Rights Movement: from policy to practice and from Kant to Nietzsche in more than one uneasy move. Critical Social Policy, 25: 554-576.

Thomas, C. (2004) How is disability understood? An examination of sociological approaches. *Disability & Society*, 19, (6):569-583.

Townsend, C.E. (2011) Developing a Comprehensive Research Agenda for People With Intellectual Disability to Inform Policy Development and Reform. *Journal of Policy and Practice in Intellectual Disabilities*, 8, (2):113-124.

United Nations (2006) *Convention on the Rights of Persons with Disabilities*. United Nations, UN Web Services Section.

Wengelin, A. (2011) The disabling state of an active society. *Disability & Society*, 26,(3):381-383.

WHO (2001) *International Classification of Functioning, Disability and Health*. WHO.

WHO (2010) *Community-based Rehabilitation: CBR Guidelines*. WHO.

WHO (World Health Organization) (2011) *World Report on Disability 2011*. WHO.