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Felix Sebastian Balzer

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Abbreviations

AAIDD	American Association on Intellectual and Developmental Disabilities
BCODP	British Council of Organizations of Disabled People (*1981)
CMH	Campaign for people with mental handicaps
CRPD	Convention on the Rights of Persons with Disabilities (*2006)
CSDPA	Chronically Sick and Disabled Persons Act (*1970)
DA	Disability Alliance (*1974)
DIAL	Disablement Information and Advice Line
DIG	Disability Income Group (*1965)
DPI	Disabled People's International (*1981)
DRM	Disability Rights Movement
GA	General Assembly of the United Nations
HRMD	Human Rights Model of Disability
ICIDH	International Classification of Impairments, Disabilities and Handicaps (*1980)
ICF	International Classification of Functioning, Disability and Health (*2001)
IL	Independent Living
ILI	Independent Living Institute
OHCHR	Office of the High Commissioner for Human Rights
UK	United Kingdom
UN	United Nations
US	United States of America
UPIAS	Union of the Physically Impaired Against Segregation (*1976)
RI	Rehabilitation International (*1922 as International Society for Crippled Children)
WHO	World Health Organization

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1. Introduction

The existence of the phenomenon of disability poses questions of commonality and difference. The way societies have treated issues associated with disability is often interconnected with the question of who is regarded as a member of society and who is not. The categories of inclusion and exclusion reflect this and are capable of framing social bonds that are either constructed and emphasized or dissolved. Each society (and, in a broader sense, each culture) has its own way of integrating or excluding certain categories or certain subjects, that is, by creating social links or denying them (Ravaud and Stiker 2001).

Processes that constitute inclusionary or exclusionary practices are particularly relevant for persons with disabilities and especially the activities and demands of the Disability Rights Movement (DRM). Especially the beginning of the movement stands exemplary for the effort to create social links for persons with disabilities. The DRM was comprised of persons with disabilities who started to organize on national and transnational levels in the 1960s when similar notions of resistance were translated into political demands. These demands centered on the living conditions of persons with disabilities in their societies and were brought forward in different manners.

In this thesis, I aim at identifying these different manners by collating differing strands of the DRM and by subsuming notions of alignments of the movements, which were part of this “resistance” (Gabel and Peters 2004). The complication of the famous slogan of the DRM “Nothing about us without us” stands paradigmatic for my research interest (Charlton 1998, 3). By asking, who the ‘us’ is in the catchy motto of the movement I want to examine the composition of the emerging DRM (*ibid.* 3).

The early phase of the DRM, which (in my analysis) has taken place in the years 1960–1981 stands paradigmatic for the development of the movement. Highlighting the pioneering processes staged in this time frame will reveal essential aspects of a movement, that was aiming at similar goals but was not as unified, as the central slogan of the movement “Nothing about us without us” insinuates.

Building on a refined analysis of the emerging DRM, I will investigate if and how persons with intellectual disabilities or organizations concerned with representing persons with intellectual disabilities were actively involved in the movement. I will depict possible differences between several definitions of disability and aims of the actors that have shaped the movement. In doing so, I want to examine in how far the emerging DRM has held a coherent definition of who

qualifies as a ‘person with a disability’ or a ‘disabled person’ (the two most commonly used terms for members of the movement).

Has the difference between intellectual and physical disability played a role in the constituting processes of the central organizations of the emerging DRM and if yes, how has this difference been depicted in primary sources and secondary literature?

In retracing such questions of difference, I want to contribute towards an understanding of disability that might be of relevance for the most common form to which political ‘issues of persons with disabilities’ were translated in the 21st century: The Disability-Rights-model. This model was the institutional answer to the pressure created by the DRM (post its emerging phase).

The rise of this movement entailed a politicization of the matter that has changed the conception of disability and disabled persons on many different levels. Most ‘gains’ of the DRM have been translated into rights questions. This can be seen in the clearest reference to disability rights in an international human rights treaty, the adoption of the Convention on the Rights of Persons with Disabilities (CRPD) by the general assembly of the United Nations in 2006. This treaty has proclaimed the rights of persons with disabilities as Human Rights on an equal level with all other humans. The main ‘interlocutor’ to advocate the newly emerging view of disability, that has also been at the base of the CRPD was the social model of disability.

I will take this fact as an incentive to further analyze and exceed the scope of the emerging DRM (1960—1981) by examining whether persons with intellectual disabilities were referenced in this model. In how far has the social model of disability addressed persons with intellectual disabilities? How could a model look, that is including persons with intellectual disabilities? Following these questions, understood as imperatives, I will discuss whether the “Human Rights Model of Disability” that claims to deliver the most refined definition of disability nowadays (Degener 2014) has reflected this issue.

By firstly depicting a prologue of the emerging DRM I will offer insights on the development from the disability movement to the ‘new social movement’ DRM. In doing so, a foundation of the understandings of disability, resting on different tenets will be outlined. This will contribute to a refined understanding of the ‘place’ persons with intellectual disabilities take within the emerging DRM but also in more contemporary settings, such as the CRPD. This examination offers important insights to assess the processes that have led to forms of inclusion or exclusion of persons with an intellectual disability.

2. Research subject and structure

The research objective of this thesis is a depiction of the constituting processes from the beginnings of the disability movement to the DRM from 1960-1981. This time frame will be termed the emerging DRM and references the initial formation processes that shaped the movement.

In depicting the movements' actors and tenets, in the emerging phase of the DRM, defined here as the period of 1960-1981, questions of the condition of the 'momentum' that has led to political commitments for the cause of rights for persons with disabilities shall be examined in this thesis. This 'momentum' is situated in a time frame, which has constituted the emerging DRM. It falls into a period that made it possible for initiatives to exert political demands that opposed the predominant form of encountering questions of disability: the 'individual' or 'medical model of disability'. Such encounters with persons with disabilities were recognized by the emerging DRM and interpreted as producing social contexts, in which persons with disabilities found themselves mostly confronting charity and pity. I will trace these supposedly unorganized 'moments of resistance' against conventional forms of placing persons with disabilities in such contexts. Thus, focusing on the emergence of a movement that is closely associated with its resistance against the politics of disablement (Michael Oliver 1990).

The examination will be undertaken by analyzing records in literature and primary sources of national history records and references of an international organization. This decision has been caused by pragmatic reasoning, as the two national cases of an emerging DRM have been well documented in the United Kingdom and the United States. Therefore, the scope of the research will be limited to the boundaries of two nation states and the example of the international organization.

The status and depiction of emerging formations of organized protest against existing disability policies in other countries is also of great interest and would have to include the "subversive status" of issues concerning disability, as it has been called for the status of Disability Studies in Germany, Austria and Switzerland (Pfahl and Powell 2014). However, the limited scope of this thesis does not leave room to extend the examination in this direction.

A critique of most disability movements and the argument, that most movements neglect the question of race and gender is brought forward by Ayesha Vernon on *The Dialectics of multiple Identities and the disabled peoples movement* (1999). In a similar manner I want to depict

intellectual disability as a submerged field within Disability Studies this thesis: by employing existing literature of the academic discipline, which is generally referred to as Disability Studies, the emerging phase of the DRM shall be contextualized. This examination will be set in this time frame, as rights for persons with disabilities were yet a distant demand of a small number of disability rights activists that only gradually started to engage in the field of “the politics of disability” (Mike Oliver 1984). Rachel Hurst even claims that “no organized DRM, either at the international level or at the national level has existed” (2003, 572). Before the emerging phase of the DRM (1960–1981).

However, the 20th century has been rich in different stances towards disability. These stances, the resistance against these stances and what this has caused will be of interest for this thesis. I have chosen to frame the issues concerning disability by examining one particular aspect within the time frame of 1960–1981. This aspect concerns the depiction and representation of intellectual disability within the emerging DRM on national and international levels.

Has the difference between intellectual and physical disability played a role in the constituting processes of the central organizations of the emerging DRM and if yes, how has this difference been depicted?

To answer this research question, it has been a necessary step to include accessible sources and to consult records of institutions where ‘the’ emerging DRM can be located. These locations are the Disability-Archive established by the University of Leeds and the online library of the Independent Living Institute as a source for documents that have collated records of the DRM in its emerging phase. In addition, this thesis understands itself as a contribution to revelations of different historical and cultural facets of inclusion and exclusion.

This means that it is necessary to determine who is affected by exclusion and inclusion, determine what disabled persons are excluded from or what they are included in, and how and to what degree they are in or out at different times and in different social groupings (Ravaud and Stiker 2001, 490).

The examination will lead to a discussion on how actors of the emerging DRM have treated the matter of intellectual disability in their emerging phase and how this affected the process of ‘establishing’ rights for persons with intellectual disabilities.

In this manner, the depiction of movements of the DRM shall contextualize the main actors and tenets, which describe the focal points of these actors involved. The identification of these tenets is useful to shed a light on certain contingencies and general assumptions concerning the issue. Through the depiction of the tenets, the relevant discourse positions of the relation of physical and intellectual disability will be discussed. The term ‘Discourse’ has evolved as a

stable companion of the vocabulary of the humanities over the past decades. The concept is capable of illustrating a wide range of issues and has been subject to a large number of usages in the social sciences:

[...] discourse means anything from a historical monument, a lieu de mémoire, a policy, a political strategy, narratives in a restricted or broad sense of the term, text, talk, a speech, topic-related conversations, to language per se. [...] thus stretching the meaning of discourse from a genre to a register or style, from a building to a political program (Wodak and Meyer 2009, 18).

By embedding the discourse of this thesis, Critical Discourse Analysis (CDA) will be utilized. This will help to identify manifestations of intellectual disability as expressions and depictions of certain negotiation processes of a social phenomenon, trying to explain its genesis and structure. The arrangement of statements is not only a collection of sentences and texts but a chain of statements, which lets the reader understand the context. What qualifies as a chain of statements? Michel Foucault, who has been one of the first social researchers to deploy work in such terms, proposes to treat discourse analysis as a ‘toolbox’ that helps to research patterns and hidden rules of how language is used, and which narratives are created. In a later publication, he extended his understanding of discourse by stating that:

[...] a discourse is not a slender surface of contact, or confrontation, between a reality and a language (langue), the intrication of a lexicon and an experience; I would like to show with precise examples that in analyzing discourses themselves, one sees the loosening of the embrace, apparently so tight, of worlds and things, and the emergence of a group of rules proper to discursive practice (Foucault 1971, 22).

The tenets of the DRM’s strands are composed by combining statements of the movements, that were part of the emerging DRM. Contemporary publications have picked up the important contribution, that discourse analysis plays for an analysis of the historical trajectory of disability. One example points out the prospects of discourse analysis in the context of theorizing about disability in stressing a certain congruency:

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. [...] discourse analysis can show how the current models grew out of different discourses, and provide an outside perspective on the potential for integrating them (Grue 2011, 534).

It is not possible, however, to cover the discourse in its entirety. As a researcher doing critical discourse analysis, due to the character of discourse itself I, therefore, have to make a distinct choice of which subject exactly, which strand of the discourse and which participants of that strand I want to analyze. The basis of CDA includes a literature review of the most important actors of the DRM, in order to identify the actors and tenets of the various strands of the DRM. By deploying these ‘strands’, the general alignments of these strands will be analyzed according to their alignment in regard to their definition of disability.

In further tracing the ways in which intellectual disability has been defined within the emerging DRM, the last chapter convenes recent trends and research in intellectual disability advocacy. Within this last chapter, a discussion of the social model of disability in relation to intellectual disability, possible prospects of an inclusive social model of disability and the Human Rights Model of Disability (HRMD) will be carried out.

3. Outlining Disability

There is substantial anthropological and scientific evidence that throughout history people with ‘recognizable’ impairments, who would today be considered ‘disabled’, have existed in relatively large numbers in all societies across the world. It is also quite evident that societal responses to impairment and disability are historically, culturally and geographically variable (Ingstad and Whyte, as cited in Barnes 2003).

The sentence: “Disability is an enigma that we experience but do not necessarily understand” (Albrecht, Seelman, and Bury 2001, 1) describes prevalent receptions of disability in most present societies, which often refer to the phenomenon of disability as a problem. How is a problem solved? Usually by treating this “enigma” as the problem and by accumulating hints to decipher it (ibid. 1). The hints are often diagnosed as deviance, as “humans have always tended to create techniques to measure forms of deviance: from Hippocratic humoral pathology to contemporary endeavors of cataloging genomic sequences” (Fujiura and Rutkowski-Kmitta 2001, 69).

Why do we do so? An easy answer is not to be formulated within this thesis. But naming this section ‘defining disability’ aims at retracing references of the process of conceiving some of the ‘deviance-techniques’. By reflecting the ways in which disability has been defined and by pointing out core questions of definition, it is intended to give an overview of the ordering mechanisms that persons with disabilities have been and still are subject of.

Looking at these defining instruments of disability, it is necessary to bear in mind that “several exist and serves specific purposes in different systems of order and have to be fit to purpose” (Fujiura and Rutkowski-Kmitta 2001, 78). This is specifically observable in 19th century Europe when many medical and statistical techniques were ‘discovered’. An appropriate case, which exemplifies this tendency is the ‘exploration’ of the antagonist of deviance: the norm.

The idea of ‘the norm’ is connected with the development of statistics and was facilitated by the equation of the bell curve, also called the normal curve. In this paradigm, the majority of

bodies fall under the main umbrella of the normal curve. Those that do not are at its limits and are regarded as statistically a-normal. Connected with definite ideas, what society should ‘look like’, an imperative was placed on people to conform, to fit in, under the rubric of normality (Davis 2002). Subsequently, this normalizing logic has been expanded to analyze the human mind and varying ideas of the intellect. In coining terms such as ‘mental illness’, definite stances for the evaluation of such phenomena were given. These phenomena are subsumed in this thesis by the designation ‘intellectual disability’, that is of special interest for this thesis. But before I turn towards this term, the next section will provide an important distinction, often utilized when defining disability.

One of the underlying questions of what constitutes disability is the evaluation of the effects of impairments. The distinction generated out of this contrast is situated at the intersection between the particular needs of a person’s impairment, the social interpretation of this impairment and the larger political and economic context of disability. The process of categorizing impairments is based on the distinction of disability and impairment: “Disability constitutes itself, within a larger social context, while impairment is a biological condition” (Braddock and Parrish 2001, 12). However, the outcome of these reflections often has led to the establishment of categories and questions such as who is to be included in these ‘categories of impairment’. This categorization thus fosters the stereotyping of disabled persons. Since few non-disabled people in the ‘majority-society’ interact directly with persons with disabilities, they rely heavily on stereotypes in their response to persons with disabilities (Munyi 2012).

The categorization of persons with disabilities is thus not capable of taking into account the difference among disabled persons. Jerome Bickenbach, who has been involved in the drafts of several publications relating to concepts of disability stresses, the importance of recognizing the differences of the various conceptions of disability. He points out that the overall debate about a definite, correct scientific definition of disability is ultimately misguided, especially in social sciences: “More than a single definition is needed to understand disability” (Bickenbach 2012, 68). Definitions are usually used to understand phenomena and as Jerome Bickenbach points out a global definition of disability that fits all circumstances is in reality nearly impossible. In the following chapter, I will treat the arising difficulties that come with the aim of defining disability.

3.1. The challenge of defining disability

It has been observed that there is no neutral language with which to discuss disability (Williams 1996; Zola 1993; Linton 1998, as cited in Altman 2001), and yet the “tainted language itself and the categories used to influence the definition of the problem” (Williams 1996, as cited in Altmann 2001, 97). The difficulty to define disability is rooted in the fact that disability is a complicated, multidimensional concept.

Since the early 1960s, there have been various attempts to provide and develop conceptual schemata to describe and explain the complex relationships between illness, impairment, disability, and handicap. This has led to various different attempts of defining disability, as Barnes and Mercer (1996) point out. But the universality of the phenomenon of disability should neither be conflated with what counts as a disability nor with its causes. The statement “disability takes many forms and thus resists universalization” sums up a central ‘problem’ of the ‘disability contradiction’ (Dryden 2013, 1). Describing these ‘many forms’ is a challenge in itself, as the range of different forms of disability varies tremendously, as has been also stated in the *World Report on disability*, by the World Health Organization (WHO):

Persons with disabilities are diverse and heterogeneous, while stereotypical views of disability emphasize wheelchair users and a few other “classic” groups such as blind people and deaf people. Disability encompasses the child born with a congenital condition such as cerebral palsy or the young soldier who loses his leg to a land-mine, or the middle-aged woman with severe arthritis, or the older person with dementia, among many others. (World Health Organization 2011, 7).

Taking into account an international comparison of survey data on disability also reveals how differently the status of disability is categorized. An example of this problem can be found in the divergence of statistics. The official worldwide share of disabled persons in the total population varies widely as exemplified in figures of the World Report on Disability. I have chosen the two countries with the greatest disparity of the total amount of persons with disabilities: “Between 0.8% in the Syrian Arab Republic and 33% (city) and 39% (country) in Norway (1991)” (ibid.).

Despite the non-existence of a universal definition of disabilities as a consequence of the enormous variety of disabilities, the depiction of disability in most Western societies is a quite monolithic and stereotypical one. The perception of disability in these countries has often been associated with “images of wheelchairs, crutches, guide dogs, and so on. Maya Sabatello and Marianne Schulze diagnose this with a particular view onto disability that is concerned with “western obsession with scientific explanation” (Sabatello and Schulz 2014, 18). They also

point to the explanation of “other cultures” for disability by stating that these approaches include a range of sources, particularly religious beliefs about one’s sins, demand for collective restitution, imbalance in one’s own and the communal cosmos (ibid. 18).

There is a general consensus that within Western culture, there is a discernable cultural bias against people with any form of perceived biological ‘abnormality’ or ‘flaw’ that can be traced back to the ancient world of the Greeks and Romans (Garland 1995). The most apparent separation that serves this ‘western obsession’ has caused is a differentiation of physical and intellectual disability. The constitution of physical disability often rests on a distinction of phenomenological, e.g. ‘visible’ otherness, whereas intellectual disabilities cannot be captured and determined as ‘simple’.

The umbrella term “developmental disability” is utilized by the American Association on Intellectual and Developmental Disability (AAIDD) to include many forms of disabilities:

It includes people with severe chronic disabilities that can be cognitive or physical or both. These disabilities appear before the age of 22 and are likely to be lifelong. Some developmental disabilities stem from physical issues, such as cerebral palsy or epilepsy. Some individuals may have a condition that includes a physical and intellectual disability, for example, Down syndrome or fetal alcohol syndrome (Schalock et al. 2010, 22).

The term is rooted in a functional rather than a moral model (Carey 2009, 14). This is generally reflected in the approach western society tends to have towards disability, where the physical observation of bodily limitation has been a focal point in defining disability.

However, when cognitive limitations are referenced, the term Intellectual disability is usually utilized. How intellectual disability fits within the general construct of disability is part of ongoing discussions, that take place in competing worldviews within the conceptualization of the phenomenon disability. Formulations formerly used, are “idiot, imbecile, feeble-minded, mentally subnormal, moron, and retard” (Switzky and Greenspan 2006, 15). Denominations now seen as highly pejorative and stigmatizing. Organizations have responded to community pressure to use more acceptable language – which itself is subject to change over time (Parmenter 2001, 284). The AAIDD, who has also coined the term developmental disabilities, as described above has been central in these renaming efforts. This shows in the AAIDD’s efforts to change the term from the formerly used ‘mental retardation’ to ‘intellectual disability’. In 1992 the association defined “mental retardation” as “involving significant impairment in intellectual functioning with significant impairment of at least two areas of adaptive functioning and age of onset before 18 years” (American Association on Mental Retardation 1992, 5). It is important to note that this definition of mental retardation in 1992 was the first one to view the term as a condition that could be enhanced by the provision of

supports, rather than as a static, lifelong disability. The Association has worked to further develop and refine this term. This has led to a renaming by a ‘minor edit’ that substitutes the term intellectual disability for mental retardation in 2002:

Intellectual disability is characterized by significant limitations both in intellectual functioning and in adaptive behavior as expressed in conceptual, social, and practical adaptive skills. This disability originates before the age of 18. Assumptions are an explicit part of the definition because they clarify the context from which the definition arises and indicate how the definition must be applied. Thus, the definition of intellectual disability cannot stand alone. The following five assumptions are essential to the application of the definition of intellectual disability.

1. Limitations in present functioning must be considered within the context of community environments typical of the individual’s age peers and culture.
2. Valid assessment considers cultural and linguistic diversity as well as differences in communication, sensory, motor, and behavioral factors.
3. Within an individual, limitations often coexist with strengths.
4. An important purpose of describing limitations is to develop a profile of needed supports.
5. With appropriate personalized supports over a sustained period, the life functioning of the person with intellectual disability generally will improve (Schalock et al. 2007, 118).

The approach of shifting the paradigm surrounding the term is more fully fleshed out in the Association’s 11th and most recent manual, *Intellectual Disability: Definition, Classification, and Systems of Supports*. Robert Schalock commented on the shift as having the following benefits:

The term intellectual disability (a) reflects the changed construct of disability proposed by AAIDD and WHO; (b) aligns better with current professional practices that are focused on functional behaviors and contextual factors; (c) provides a logical basis for individualized supports provision due to its basis in a social–ecological framework; (d) is less offensive to persons with disabilities; and (e) is more consistent with international terminology (Schalock 2007, 120).

For this thesis, I will concentrate on the term intellectual disability. The difference between intellectual disability and a mental health condition is a case that needs such a differentiation. The two phenomena are often confused. Mental illness is an illness and may be cured, whereas intellectual disability is a life-long condition. People with intellectual disability are not ill unless they have a common illness. They need easy-to-understand information, education or training to live included in society (Gentile, Manetta, and Jackson 2013, 413). The difficulties of finding a common ground of definitions and the manifold definitions that exist have led to classifications and different conceptions of disability. This classification of disability has itself been viewed as a problem; on the one side needed, but often connected with paternalizing aspects of social policies (Shakespeare 1996).

Nonetheless, I will depict the most important classifications of disability in the following chapter to depict the contexts(s) in which the attempts of defining disability have to be situated.

3.2. Classifications of disability

Modern societies most commonly seek ways to deal with disabled persons by adopting models of disability, proposed by experts. A model is a theoretical construction a priori and not an empirical generalization - it is a structure that usually brings different components into meaningful contexts and thus helps to understand complex phenomena such as disability. Conceptualization in this sense is not in itself true or false - it can only be more or less appropriate, helpful or consistent (Bickenbach 2013, 53). The model versions are used to illustrate the different conceptions of disability and are intended as conceptual starting points for the development of perspectives of complex phenomena with the imperative of using them.

If sociologists had an interest in the sociology of disability, it was somewhat submerged in studies of stigma and stigmatization. The academic field “Symbolic interactionism” that Erving Goffman (1964) was also associated with, developed an array of useful concepts around the idea of “discredited” and “discreditable” identities and studied the management of the interaction between “normal” and the chronically sick and disabled. In a similar fashion, disability in medical sociology has not been a major research interest. Studies of disability typically appeared in research on aging, where it was represented under the heading of “dependency”. In this setting, disability became associated with negative “images of ageing” (Turner 2001, 252).

This chapter is comprised of the main ways to classify disability, that is the individual/medical model of disability, most fit for classification of disability. Historically, people with all kinds of impairments were viewed as socially inadequate and systematically excluded from all manner of economic and social activity. Since the nineteenth century, their interests were increasingly represented by cadres of disability professionals and professionally led impairment-specific organizations that perpetuated an individual medical view of disablement. This medical model of disability is mainly reflected in the discipline of medical sociology. Herein, medical diagnoses play a central role and are the main form of analysis for the categorization of disability. The ‘problem of disability’ is expected to be solved by adapting the individual to his or her environment. It asks, to what extent physical or intellectual ‘defects’ are present, and the subsequent focus of on malfunctions in ‘performance’ as a result of these defects. This rather simple but efficient derivation of disability is shown in Figure 1.

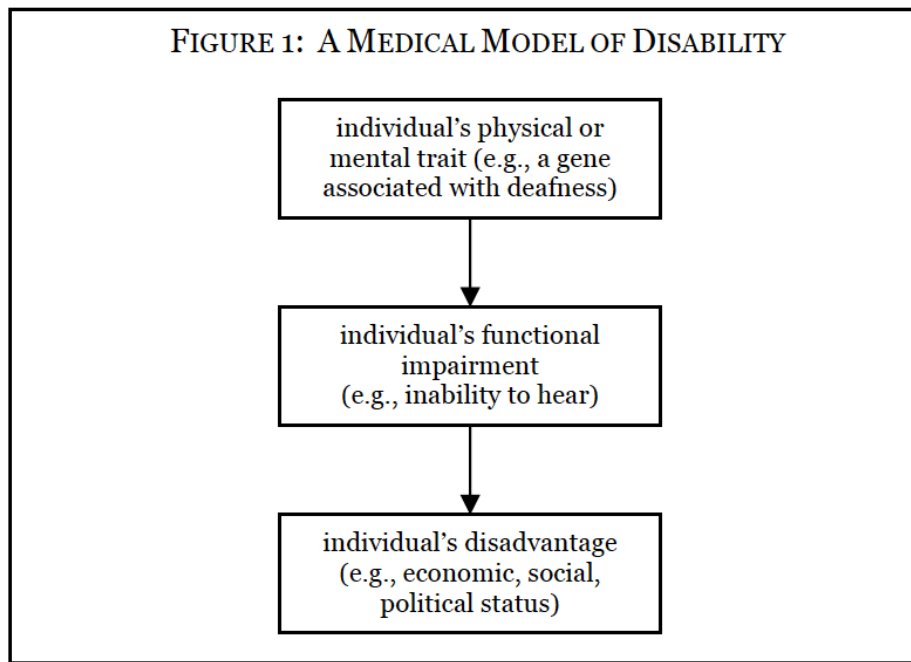


Figure 1. A Medical Model of Disability. Reprinted from M. Samaha, Adam M. 2007. "What Good Is the Social Model of Disability?" SSRN Scholarly Paper (Rochester, NY: Social Science Research Network.): 74.

This form of assessment of disability has been very influential in creating tools. One tool that needs to be mentioned is the classifications of the World Health Organization (WHO). The organization has established disability classifications as measurement methods, which function as derivatives of the medical model of disability with a logic of standard and deviation. The first version of the 'tool' is the International Classification of Impairments, Disabilities and Handicaps (ICIDH), which was first published in 1980. This WHO directive was intended to stress a theretofore insufficient understanding of disease. The ICIDH criticized, among other issues, that a purely pathological diagnosis of a disease offers an insufficient general medical perspective on the health status of individuals. As a result of this reorientation of theoretical-medical practice, a new definition of the concept of disability was established (Rosenbaum and Stewart 2004, 4). For the first time, the distinctions between damage (impairment), disability and handicap were included:

- (a) Impairments, concerned with abnormalities of body structure and appearance and with organ or system function) resulting from any cause; in principle, impairments represent disturbances at the organ level.
- (b) Disabilities, reflecting the consequences of impairment in terms of functional performance and activity by the individual; disabilities thus represent disturbances at the level of the person.
- (c) Handicaps, concerned with the disadvantages experienced by the individual as a result of impairments and disabilities; handicaps thus reflect interaction with and adaptation to the individual's surroundings (World Health Organization 1980, 14).

As a result of this of this classification, the WHO was criticized at length for the utilized terms, which held negative connotations. The orientation of the classification was too focused on the medical context, and that the living circumstances of the persons, which were ‘affected’ could not be described with sufficient accuracy. This is also referenced in the applicational aspects of the model:

Most problems concerned the nature of the relationship between disability and handicap and the distinction between these concepts. Perhaps the crux of this difficulty is that handicap may be seen as being a direct consequence of impairment and disability. That the relationship between these two aspects cannot be easily defined is a thread of concern which runs through many of the papers. These concerns have in common the need to build more social and environmental elements into the model (Badley 1987, 122).

The criticism was ‘handled’ by the WHO through adjustments that resulted in the International Classification of Functioning, Disability and Health (ICF) in 2001. This new classification formally replaced the ICIDH and an expanded its definition of disability, as the organization put forward, the components of the model offer a “biopsychosocial perspective” on health (World Health Organization 2001, 4). Furthermore, the authors of the model claim that the ICF is a “classification of the consequences of disease towards a classification of the disease components of health and takes with respect to the etiology of a neutral point of view and emphasizes functional health” (ibid, 4). The term handicap, which was a key term in the ICIDH was abandoned because the term is linked with derogatory connotations. In addition, the terms injury and impairment or malfunction are summarized as an impairment. Disability is now considered an umbrella term for limitations in social participation opportunities as well as expressing social discrimination due to an impairment. And it further constitutes, a “complex dimension and potential social disadvantage manifests itself in various forms and is influenced by a variety of intervening factors” (World Health Organization 2001, 28):

Body functions are the physiological functions of body systems (including psychological functions). Body structures are anatomical parts of the body such as organs, limbs and their components. Impairments are problems in body function or structure such as a significant deviation or loss. Activity is the execution of a task or action by an individual. Participation is involvement in a life situation. Activity limitations are difficulties an individual may have in executing activities. Participation restrictions are problems an individual may experience in involvement in life situations. Environmental factors make up the physical, social and attitudinal environment in which people live and conduct their lives (World Health Organization 2001, 10).

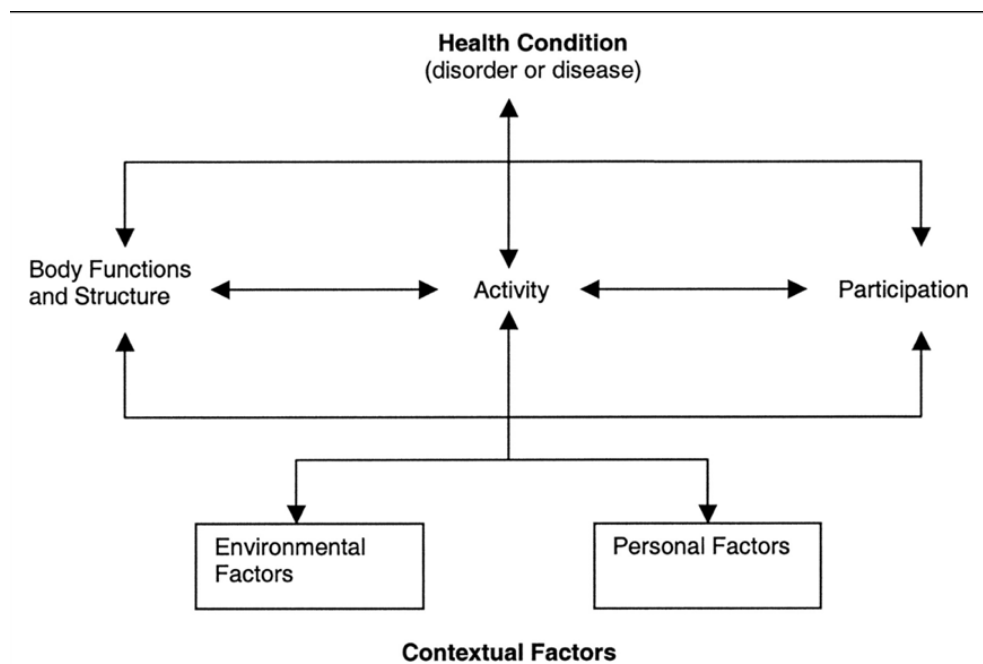


Figure 2. The International Classification of Function, Disability and Health (ICF). Figure reprinted from World Health Organization. 2001. "The International Classification of Function, Disability and Health (ICF)." Geneva, Switzerland: 18.

Scholars and activists have rejected the assumptions which underpin the models and questioned the adequacy of them as a sufficient basis for empirical work (Mike Oliver 2017). This resistance can be traced back to the 1970s when research of the application of the medical model of disability and the consequences of the model for persons with disabilities began.

One of the criticisms, that exemplifies the critique is one that frames disabled persons as "socially dysfunctional" in such a model. The *A life apart: A pilot study of residential institutions for the physically handicapped and the young chronic sick*, set out to examine the effects of the medical model for persons with disabilities and concluded with the rather extreme diagnosis that "in a medical model of disability, persons with disabilities are socially dead" (Miller and Gwynne 1972, 80). In the following chapter we will take a closer look at how this resistance has emerged and which difference facets played a role in formulating central ideas of this resistance against the medical model of disability.

3.3. A social model of disability

The social model of disability has exerted pressure on the individual model of disability. This model derived out of the dynamic created by the emerging DRM, which we will look at closer in the course of this examination. However, what we will pay attention to in this chapter is a basic understanding of the social model of disability and how it has been crafted and conceptualized.

The sociologist Mike Oliver was one of the first to take up the ideas of the Union of the Physically Impaired Against Segregation (UPIAS) which we will encounter more often in the course of this research. For now, it is important to note, that Mike Oliver took up their ideas and contextualized them in the notion of “the social model of disability” (Shakespeare 2006). Herein, the social construction of restrictions for persons with impairments, which was crucial for the debate at the time, was highlighted. Advocates following the social model of disability criticized the life-world prevailing paradigm of a personal tragedy model and claimed that disabled people (the term preferred by the proponents of the social model of disability) are made outsiders of societies not by physical limitations, but by structures, norms, rules and ideals of the respective society. Though impairment was seen as a prerequisite of disability lies a “conceptual severing of any causal connection between impairment and disability” interpretation (Oliver 1996, 108) at the heart of this social interpretation. This is also exemplified in the following Figure 3.

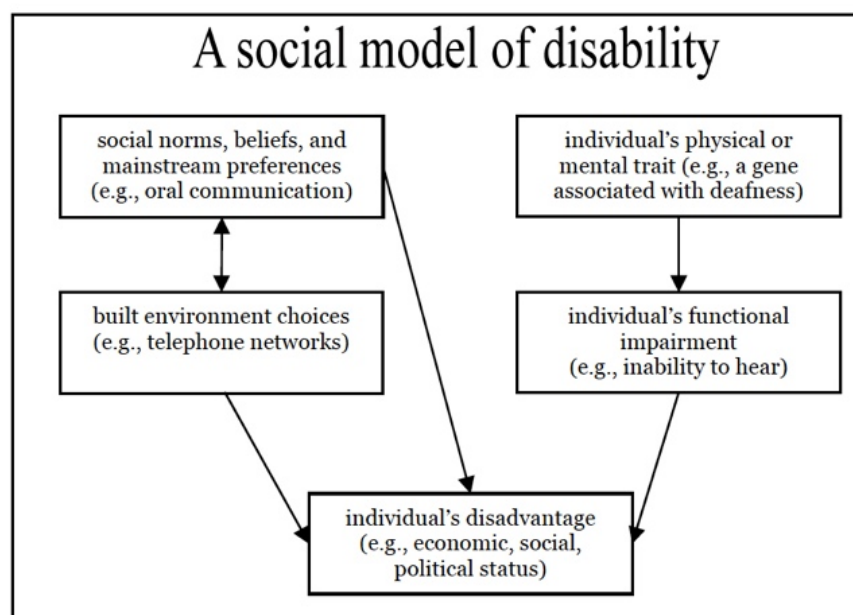


Figure 3. A social model of disability. Figure reprinted from M. Samaha, Adam M. 2007. “What Good Is the Social Model of Disability?” SSRN Scholarly Paper (Rochester, NY: Social Science Research Network.): 9.

It is important to stress the impact the social model had on the responses towards disability, especially since the 1970s. It has inspired the self-organization of people with disabilities and a growing tendency to see disability as a Human Rights issue (Üstün et al. 2003). Its creation has been akin to a new social movement whereby disabled people can gather and challenge their experiences of oppression through political activism (Oliver 1990). In the words of Vic Finkelstein, the social model of disability represents a “tool for gaining insight [...] so that the future may be changed” (Vic Finkelstein 1996).

This future, that Vic Finkelstein refers to has had a very vivid past. This past will be depicted in this thesis by examining different strands of the emerging DRM. To frame this examination, we will look at the concepts of new social movement theory and a typology of Disabled Persons Organizations in the following chapter.

3.4. New social movement theory and Disabled Persons Organizations

According to Campbell and Oliver, the main difference between new social movements and “traditional movements” lies in the scope of their actions and ways of campaigning (Campbell and Oliver 1996, 21). Whilst older movements tended to focus on single issues and were led by experts, new movements are dealing with a broad range of issues and use a variety of campaign strategies (Magdolna 2014, 34).

‘Older’ disability movements accepted the terms of charity and rehabilitation (See the case of the dispute between Rehabilitation International and Disabled Peoples International in chapter 4.4.). This new movement then is comprised of actors that rally around the issue of rights to demand manifold different improvements for their life situation. As Magdolna BIRTHA states in her examination of new social movements: “Political aims, voice and empowerment are other key elements in the emergence of new social groups, in particular, representing those people who have been silent before” (Magdolna 2014, 24). Mike Oliver and Gerry Zarb (19819) establish four characteristics that constitute the Disability movement as a ‘New social movement’. In the course of the following examination, I want to use them as a ‘point of departure’ to frame and collate the features, that mark the emerging DRM.

The first characteristic the authors mention that ‘new social movements’ tend to “be located at the periphery of the traditional political system and, in fact, sometimes they are deliberately marginalized.” As they stress, the concept of self-help arises in this environment and has linked

the personal and the political, which is an “integral feature of these new social movements” (Oliver and Zarb 1989, 230). The second characteristic of new social movements is that they offer a critical evaluation of society as part of “a conflict between a declining but still vigorous system of domination and newly emergent forms of opposition” (ibid, 230). The third characteristic of new social movements stems from fundamental changes in the constitution of the political agenda and is reflected in an “increasing predominance of . . . ‘post-materialist’ values over those that have to do with income, satisfaction of material needs and social security” (ibid, 230). This feature concerns the ‘quality of life’-aspect that the new social movement was concerned with and stems from the material deprivation that many persons with disabilities have faced in the time frame of the emergence of the new social movement. A final characteristic of new social movements is that they sometimes tend to focus on issues that cross national boundaries and hence they become internationalist (Oliver and Zarb 1989, 231).

Researching the ‘disability movement’ as a new social movement, I will depict the interlocutors between the four above-listed characteristics and society: organizations that were involved with promoting and raising awareness of political issues concerning persons with disabilities. Mike Oliver first crafted a typology in 1984 to depict these ‘disability organizations’. He classified them (solely in the UK) according to the type of approach they employ and introduced a differentiation, which has become a general reference when analyzing disability organizations. The distinction rests on the differentiation “between organizations that are controlled by disabled people themselves, thus being organizations /of/ disabled people, and those led by non-disabled people; that is, organizations /for/ disabled people” (Oliver 1984).

Six years later, Mike Oliver (1990) revised the typology and introduced five categories of disability organizations. Furthermore, he strengthened the differentiation of organizations ‘for’ and ‘of’ persons with disabilities by emphasizing, that only 3 types of these disability organizations were part of the disability movement. He called these organizations: Disabled Peoples Organizations (DPOs). The following figure shows this revised typology of disability organizations (1996).

Oliver's typology of disability organisations	
Type 1	Partnership/Patronage
Type 2	Economic/Parliamentarian
Type 3	Consumerist/Self-help
Type 4	Populist/Activist
Type 5	Umbrella/Co-ordinating

Figure 4. Oliver's typology of disability Organizations. Figure reprinted from BIRTHA, Magdolna. 2014. "Making the New Space Created in the UN CRPD Real: Ensuring the Voice and Meaningful Participation of the Disability Movement in Policy-Making and National Monitoring." PhD Thesis, School of Law, NUI Galway (Ireland): 54.

Oliver clearly remarks that he considers only DPOs as part of the disability movement. As Mike Oliver (1990, 118) states "Consumer/Self-help, Populist/Activist and Umbrella/Coordinating Organizations are organizations of persons with disabilities, but not the other two categories" (ibid.). DPOs are characterized as representative organizations or groups of persons with disabilities. The specific shape of such organizations is an important contribution to the identification of organizations, which are a part of the disability movement up until today:

It is a prerequisite of these Organizations that persons with disabilities constitute a majority of the overall staff, board, and volunteers in all levels of the organization. However, they can also include organizations of relatives of PWDs (only those representing children with disabilities, people with intellectual disabilities, and/or the Deafblind) where a primary aim of these organizations is empowerment and the growth of self-advocacy of persons with disabilities (Hayes and Bulat 2017, 18).

By coining this typology and, Mike Oliver crafted a distinction that has highlighted an "increased awareness by persons with disabilities that, in order for their rights to be recognized, they needed to set up their own organizations and become responsive and responsible their own agenda" (Oliver 1990).

In the next chapter, I will highlight some of the 'outcomes' of this awareness. These are collated in depicting the disability movement, which centered around the question of rights for persons with disabilities, formulated and put forward by DPOs.

4. The emerging Disability Rights Movement (1960–1981)

The emergence of the DRM cannot be presented as a singular development of one distinct movement, which is classified as such in the ‘record books of history’. No coherent form of organization or initiative existed, which can be subsumed as having assembled monolithic forms of expression with congruent aims. Towards the end of the 1960s, there was a rapid growth in organizations that were concerned with issues of persons with disabilities. Before the 1980s, there was no organized DRM either at the international level or at the national level. Internationally, there were organizations of medical and rehabilitation professionals, organizations concerned with service provision in relation to specific impairments and two or three organizations of disabled people and parents whose major objectives at that stage were services for their membership and raising awareness of their specific needs (Hurst 2003, 572). Furthermore, as Large (1981) notes, “Organizations for the disabled outnumber organizations of disabled people by 100 to one and disabled people are missing from the governing bodies of the former and from their workforces” (Oliver 1984, 29).

What has sparked the emergence of DPOs is a contested question of historical interpretation. However, I identify two denominations, which not only refer to the numerical enlargement of the movement but also to the new way in which disabled persons began to see themselves and their place in society. Firstly, the insight that has motivated many activists in this time was the knowledge of historical atrocities committed against persons with disabilities. These atrocities countered long pre-existing attitudes towards disabled persons and have culminated in the eugenics movement, with the starkest example of Nazi Germany, which offers the most extreme example of the eugenics movement, where about 200,000 people, in particular, those with a “mental illness or congenital malformation” were exterminated in the hospitals and death camps because of their disability (Ravaud and Stiker 2001, 502). Secondly, the DRM’s aim to influence the public sphere and to create awareness for the conditions and issues of persons with disabilities in the respective societies. The intention of creating this awareness was meant to contribute to a renewed definition of disability and is connected with the objective to transform the lives of persons with disabilities among the societies they are living in for the better. This renewed definition was meant to lead to a refined understanding of ‘disability’ that did not define persons with disabilities *per se* as suffering individuals. This gesture also stood against the conceptualization of disability as an extraordinary medical problem and highlighted political components of the ‘disability-debate’ which was prevalent at the time:

Beyond the medical realm, disability rights activists have increasingly demanded citizenship rights and participation, contested their incarceration in institutions, and drawn attention to the exclusion and discrimination they encounter in daily life. Moreover, the disability rights movement is best characterized as a movement ‘from below’, with most of the leadership in the hands of persons with disabilities (Bill, as cited in Barnes, Barton, and Oliver 2002, 60).

The demand of rights for persons with disabilities, formulated by persons with disabilities, was a central motif of the DRM and represents the ‘strategic vehicle of the movement’ that allowed it to become a warrant for social transformation:

The clearest recognition of persons with disabilities as subjects under the law that are empowered to demand, on an equal basis with others what they are entitled to as an integral part of the human race. This understanding marks a stark shift – and a crucial development – from the historical conceptualization of persons with disabilities as objects who lack reason and ability to make decisions, and hence who cannot be bearer of rights (Sabatello, as cited in Adams, Reiss, and Serlin 2015, 445).

The demand to recognize (in this phase often unspecified) rights for persons with disabilities constitutes the common denominator for the examination of the emergence of the DRM. The possibility of collective mobilization sparked first initiatives of collective mobilization, which resulted in resistance that opposed “conventional forms of societal forms of dealing with disability” (Grue 2011, 533). This move constitutes the basis for a critical turn in disability discourse. This coincides with the observation that “from the end of the 1970s onwards, the ways in which society creates disability by allowing barriers to be built, whether social, economic or architectural, have become impossible to overlook” (ibid, 530).

What this thesis sets out to comprehend are respective tenets that motivate this diverse movement and how ‘they’ take intellectual disability into account. Therefore, I will trace the objectives and aims that constituted early forms of a “philosophy and politics of disability”, and thereby put a special emphasis on disability understood as a political category (Oliver 1984, 22). I will examine the varying forms in which these attempts took place by looking at the different movements that were part of the emerging DRM (1960–1981).

A number of initiatives were founded in this time frame that have exercised an influence of protesting and/or advocating for the rights of persons with disabilities. In taking a step back and depicting the composition of the emerging DRM, I will draw a picture of the formation of the movement and depict the oppositional force, that was criticizing the status quo of social policies for persons with disabilities and called for barrier removal and social inclusion for persons with disabilities by various means (Shakespeare 2013, 3).

Even though manifold initiatives (movements and organizations) existed and still exist, I will concentrate on paradigmatic examples of the newly emerging politics of disability in depicting the movements, comprised of the actors and tenets of the emerging DRM.

If there is one statement that has over the years manifested the claim to represent the DRM, it is the oft-cited slogan: “Nothing about us without us” (Charlton 1998, 3). When and in which context the expression was first used remains unclear. James Charlton, who extensively researched the foundation and political influences of the DRM, mentions that he first heard the expression in South Africa in 1993. Michael Masutha and William Rowland two leaders of Disabled People South Africa separately invoked the slogan, which they had heard used by someone from Eastern Europe at an international disability rights conference. The slogan’s power derives from the condensation of the sources of many types of disability oppression and its simultaneous opposition to such oppression in the context of control and voice (Charlton 1998, 3). The dictum lies at the heart of political claims of the movement and has served as a unifying juncture of the DRM. However, I examine the emerging phase of the DRM, which took place at an earlier stage than this expression has been circulated (1993).

Regarding the slogan that functions as the basis of this chapter, I ask the question: who is the ‘us’ in “Nothing About us without us?” (Charlton 1998, 3). I will re-examine the influential dictum and thereby identify the significant actors of the movement. This brings the challenge of arranging the conglomerate of different actors that appeared in a certain time frame (from 1960 onwards) and in certain contexts of industrialized, Western countries (UK and US), as well as in an ‘international sphere of collaboration’ claiming to express the rights of persons with disabilities. The movements depicted in this examination are united by the motifs of either political origin or group related identity questions. Their aim was to foster understandings of how disability as a societal phenomenon is treated and therefore based their actions and aspirations on certain tenets that stressed their respective political aims. These diverse, national, or regional disability movements have “developed their own ‘flavor’ and characteristics of a distinct form of politics of disability” (Magdolna 2014, 46).

A paradigmatic feature of the first actors of the DRM is the resistance against ‘traditional forms of organizing around the issue of disability’ motivated by the notions of charity and pity. I will trace these ‘notions of resistance’ by depicting the movement’s actors that organized around rights for persons with disabilities and formulated their principles. These principles will be

searched for in documents, writings of singular authors or legislation of the respective actors. I will identify these movements, by depicting central actors and the contexts of their foundations and include the central tenets of the respective actors. These will form the analytical categories that are examined in this thesis and relate which ideological grounds their conceptualization of disability rested upon.

The first two general emerging DRM movements of inquiry will be the British disability movement and Independent Living. Subsequently, I will also include two other actors, that were part of the emerging DRM: The self-advocacy movement and Disabled People's International (DPI).

4.1. The British Disability Movement

The British Disability Movement stands paradigmatically for the establishment of disability as a political category. The origins of the movement are situated in the UK in the late 1960s–1970s, when disabled people began to organize around issues of income, employment, rights and community living rather than institutional care:

Disabled people began to self-organize in a significant way and offer an alternative discourse of the body and mind. In the 1960s and 1970s there was a very strong tradition of charitable fundraising in the disability sector, which was controlled by non-disabled people, and relied solely on projecting the disabled body and mind as deserving and needy (Blackmore and Hodgkins 2012, 71).

This trend continued in the 1970s in representative politics, when the passage of the Chronically Sick and Disabled Persons Act (CSDPA) was signed in Parliament in 1970. Alf Morris, a *Labour Member of Parliament*, submitted a “private member’s bill”, which is today widely regarded as the first piece of legislation to introduce policies in order to improve equal opportunities for disabled people in community-based services, education, housing, and public buildings and it can be seen as one of the first expressions of a trend of decreasing support for traditional organizations for disabled people (Campbell and Oliver 1996, 21). The emergence of organizations controlled and run by disabled people was an expression of this trend and aimed at improving the quality of life and promoting inclusion in society. This has been a process of detaching from conventional forms of organization of disability policy.

The beginnings of this process can be described by referencing two organizations that gained momentum from the 1960s onwards but were superseded by the foundation of one of the most important organizations of the emerging DRM. These processes, which stand paradigmatically for the aim to change existing disability policies within the UK also show the difficulties that

arose in challenging the ‘societal behavior’ concerning disability. This will be taken up in the next chapter.

4.1.1. The Disability Income Group and Disability Alliance

The Disability Income Group (DIG) and the Disability Alliance (DA) highlighted in particular one pressing issue of persons with disabilities in the period of the emerging DRM: the poverty, that many persons with disabilities faced. Both initiatives are precursors of the British disability movement. The DIG was founded in 1965 by two disabled housewives and focused on campaigning for a national income to compensate for a loss of income due to their disabilities. From its beginning it had massive support from disabled people, rallying with the issue of poverty among persons with disabilities. The group provided a major focus for pressure group activity and published plans for a national disability income comprising two elements; a disablement costs allowance and an income maintenance scheme (Oliver and Zarb 1989, 226). A decade later, a similar initiative was formed: the DA. The foundation of this organization had similar reasons to the one of DIG, but with a central difference: The DA, who was formed in 1974 planned to “incorporate a separate, independent benefit for those who care for a disabled person, whereas DIG argued that if disabled people were given a proper, adequate income, it would be unnecessary to pay ‘carers’ separately” (Jameel 2016, 187).

However, it soon became apparent that both organizations were not capable to mobilize for disabled persons’ rights in the ways many disabled activists had envisaged, as they rather “carried out research to prove that the financial position of disabled people is considerably worse than that of their able-bodied counterparts” (Oliver and Zarb 1996, 227). This approach led to criticism, which was most prominently formulated by one of the best-known organizations of the DRM: The UPIAS. The Union criticized that the ‘single issue’ (centered around incomes) campaign would be of no success and that the issue should be brought to a “political stage” (Swain et al. 2004, 14). The character of the early formation of UPIAS is characterized by Tom Shakespeare as a “small, hardcore group of disabled people, inspired by Marxism, who rejected the liberal and reformist campaigns of more mainstream disability organizations such as the DIG and the DA” (Shakespeare and Watson 2001, 29).

The next chapter will trace the context of the foundation of this important organization of the emerging DRM.

4.1.2. Union of the Physically Impaired Against Segregation

The impulse to form an organization was given by Paul Hunt in 1972/73, when he invited disabled people to form a group to confront disability issues. He wrote two open letters: One to *The Guardian*, a well-known National newspaper in 1972, and the second one to the bimonthly magazine *Voice of the Disabled* in 1973. In the letter to the magazine, he wrote the following lines:

During 17 years of living in various institutions for the disabled, and in the 2 years since I left, certain questions have nagged insistently at me. What can be done to improve residential centers, homes and hospital units for the physically handicapped? What alternative forms of care might be devised which would prove more satisfactory? What changes in society are required if severe disability is either to be eradicated or to become no bar to full social participation? (Hunt, 1973)

In both letters, Hunt invited other disabled people to join him in his protest and proposed the creation of a consumer group of disabled residents of institutions. He was inspired to form such a group after his experiences at and wanted to further the demands of the rights of disabled people to control their own lives and living conditions. His views had been shaped during the residents' struggle in Lee Court Cheshire Home for the right to exercise some democratic control over the running of the 'home' and for alternatives which would enable disabled people to live in the community (Swain et al. 2004, 14). His call was taken up by Ken Davis, a former miner who had become quadriplegic after a diving accident. He had been involved in 'disability activism' before, as he had established Britain's first telephone Disablement Information and Advice Line (DIAL) in 1972. DIAL operated from a "tiny cloakroom in Cressy Fields residential Home in Derbyshire" (Barnes, 2008) and provided a model that triggered the development of a nationwide network of similar local services. Ken Davis and his wife Maggie Davis, who was also physically disabled, were intrigued by Hunt's article. Both had been deeply involved in the creation of the UK's first "integrated housing complex", a housing scheme they had commissioned for their "special needs" at Grove Road in Sutton in Ashfield in the UK (ibid.). During their involvement they were confronted with manifold problems. These were caused by a view that was still very prevalent in the 1960s, that 'severely disabled people' were regarded as incapable of functioning independently in the community. It was clear that moving into the community required both accessible public facilities and appropriate support systems. This campaign could not be comprehended without radically rethinking the prevailing interpretation of 'disability'.

Hunt was also joined by Vic Finkelstein, a South African, physically disabled psychologist who had been involved in anti-apartheid activities in his country. Forms of "active protest activity" (in which Nelson Mandela was also involved) got him arrested in 1966. Following this, he had

to serve a 10-month prison sentence after being charged as an “enemy of the state” after a protest. After his release, he completed his master’s degree in South Africa but decided to emigrate to the UK in 1968. After “striking up a friendship” with Paul Hunt, who pointed out the similarities between apartheid and England’s unofficial segregation of people with disabilities, Vic Finkelstein focused much of his energy in the emerging DRM (Bickenbach 2012, 186).

Together these individuals established the UPIAS and published a ‘manifesto’ which they named the *Fundamental Principles of Disability* (1975). This publication is often referred to as the intellectual heart of the emerging DRM (Hunt, as cited in Campbell and Oliver 1996, 68). It manifested the critique of the UPIAS regarding the way society treats persons with disabilities and highlighted the stance that these persons were disabled by environmental barriers created by the society they live in. Its general course was to demand “to replace segregated facilities with opportunities for people with impairments to participate fully in society, to live independently, to undertake productive work and to have full control over their own lives” (Shakespeare 2006). The paragraph *Aims* of the document also diagnoses the situation in which many disabled persons find themselves:

We find ourselves isolated and excluded by such things as flights of steps, inadequate public and personal transport, unsuitable housing, rigid work routines in factories and offices, and a lack of up-to-date aids and equipment (UPIAS 1975).

The document also took up the issues which were tackled by the DIG and the DA and critiqued a ‘systematic impoverishment of persons with disabilities’:

It follows from this view that poverty does not arise because of the physical inability to work and earn a living – but because we are prevented from working by the way work is organized in this society. It is not because of our bodies that we are immobile – but because of the way that the mobility is organized that we cannot move...It is not because we are physically impaired that we are rejected by society – but because of the way social relationships are organized that we are placed beyond friendships, marriages and public life. Disability is not something we possess, but something society possesses (UPIAS 1975).

Contrasting the DIG and the DA, UPIAS decided to reject the registration with the ‘Charity Commissioners’ that the DIG and DA were part of. The first policy statement of the UPIAS also refers to this issue:

All registered charities receive valuable tax concessions, but they are not allowed to campaign directly for political change. We regard political involvement as essential if disabled people are ever to make real advances. So in order to protect our independence of action we are not registered with the Charity Commissioners (UPIAS 1975).

Another argument expressed by the UPIAS has been the critique of the professionalization of the care for persons with disabilities. This stance is expressed in a paragraph in the principles of disability.

In our view, it is only the actual impairment which we must accept; the additional and totally unnecessary problems caused by the way we are treated are essentially to be overcome and not accepted. We look forward to the day when the army of "experts" on our social and psychological problems can find more productive work (UPIAS 1975).

What UPIAS is best known for is its conceptual distinction between the impairment (biological) and the disability (social). This argumentation helped the organization in actualizing the national agenda social policy of the UK by pointing out ways for the social, political and theoretical emancipation of persons with impairments (Oliver 1990). This "big idea" (Hasler 1993) of the DRM has been formulated in the *Fundamental Principles of Disability*, defining impairment as "lacking part of or all of a limb, or having a defective limb organism or mechanism of the body" and disability as "the disadvantage or restriction of activity caused by a contemporary social organization which takes no account of people who have physical impairments and thus excludes them from mainstream social activities" (UPIAS 1975).

The UPIAS declaration was a pivotal moment in the disability movement in the UK. By rejecting medical and rehabilitative conceptions of disability and, instead, insisting on the understanding of disability as a social and political construct, it began to open up new ways of understanding disablement in society. It highlighted, that the problems faced by disabled people were not caused by personal impairments, but by the way society was exclusively arranged for able-bodied living.

4.1.3. Social oppression theory

The British disability movement rests foremost on the basic tenet of social oppression. The resolute answers of activists following this societal analysis were expressed by the demand to change this situation by a modification of the "built environment" that has been constructed with a stereotyped "normal body in mind" and thus "dooms" members of society with a "mental or physical difference to a disabling position (UPIAS 1975). This has been affirmed by Mike Oliver and Colin Barnes, who are proponents of the British social model. They have argued, that "social oppression, inequality, discrimination, and prejudice are the predominant barriers persons with disabilities are facing". These social and cultural conditions are what disables persons with disabilities from fully participating in various aspects of life (Swain et al. 2004).

This is also paradigmatically expressed by UPIAS. The Union's understanding of disability was not reducible to impairment or the medical condition but was part of complexity of social and political attitudes and relations that did not value disabled people. In this view, disabled

people were conceived of as oppressed by society, in which their status was conditioned by structural, not personal, factors:

[...] In our view, it is society which disables physically impaired people. Disability is something imposed on top of our impairments by the way we are unnecessarily isolated and excluded from full participation in society. Disabled people are therefore an oppressed group in society. [...] Physical disability is therefore a particular form of social oppression (UPIAS 1975).

Social oppression theory also entailed the ‘identity question’ of persons with disabilities. As there is a great deal of variety within the disabled population many disabled people do not necessarily regard themselves as disabled, or even if they do, would not contemplate joining an organization for disabled people. As a consequence of disability, some people may disengage from political activity, either because their physical impairment poses limitations of a physical or psychological kind, or because they are aware that in many contexts they lack any basis for exercising power, for example through the withdrawal of their labor (Oliver 1984, 23). Proponents of the social oppression theory of disability clearly accounted forms of disability as social oppression and were grounded in a materialist reading of capitalist modes of production which exclude disabled people from economic and social activity (Finkelstein 1993, 198). It is important to recognize that, for Vic Finkelstein as one proponent of the social oppression theory, the diagnosed separation did not mean that living with the effects of impairment posed no difficulties for disabled people. What it did mean was that these difficulties did not make up the substance of disability and should remain private and personal matters (Finkelstein 1993).

Anne Borsay added the notion of a ‘resisting-credibility’ gesture that has been deployed in the charity criticism of the UPIAS and stems out of the services “for the handicapped” that “all too often disable those they are supposed to help” (Maitland 1987). All the more she stresses that many of the disability organizations, which are based on the charity-principle, have succeeded in building relationships with the state but remain with too little power (Borsay, as cited in Maitland 1987, 16). She embeds this in a general notion of asserting credibility to certain organizations, which is based upon “history and tradition rather than the claim to representativeness of these organizations.” Furthermore, she adds that the “key decision-makers” of such organizations usually are “salaried professional staff who articulate their own assumptions about the needs of disabled people rather than the needs of disabled people as they themselves express them” (Oliver and Zarb 1989, 224). The UPIAS also took a stance in regard to these ‘professional staff’ in an early document:

The Union's unambiguous position forms the basis of all our policies and activities, and similarly the basis of our challenge to those involved in disability struggle. The clear explanation of our situation not only enables us to identify the true source of our sufferings, but also helps us to draw together our diverse struggles for a better life by facing directly and consciously the challenge of an oppressive society which

singles out particular groups of people for particular forms of discrimination. Because the discrimination levelled at our particular group (disability) is one of many forms of social oppression, it follows that the first lesson that we (physically impaired people and our supporters) must learn - if we seriously intend to oppose oppression - is that ours is essentially a social and not an individual struggle. This struggle of necessity requires the active and leading participation of the oppressed group. Others speaking on our behalf, typically the so-called “expert” or charity spokesperson, can only perpetuate the oppressive social relationship that is disability (UPIAS 1981).

This claim of ‘active and leading participation’ demanded by persons with disabilities stands paradigmatically for Social oppression theory, that is the central tenet of the British Disability movement.

4.2. Independent Living

Another substantial component of the emerging DRM is the concept and dissemination of Independent Living (IL). The phrase ‘independent living’ first entered the English language in the 1970s following its adoption by disability activists in the USA. It emerged partly from within the campus culture of American universities and partly from repeated efforts by American disability activists to influence US disability legislation.

One of these activists was Ed Roberts, a young person from California, who became disabled at the age of fourteen as a consequence of the disease polio. He had to stay in a hospital for 18 months and the effects of the virus remained throughout his lifetime. “He retained some movement of two fingers on his left hand and two toes on his left foot. The rest of his body, including his lungs, remained paralyzed” (Brown 2000, 32). Ed Roberts is one of the central figures in the emergence of IL. After having finished his high school diploma, which was connected with extreme difficulties, because of his health condition, he applied to college. The application was initially rejected by *the California Department of Rehabilitation* because he was “too disabled to work” (Driedger 1989, 28). However, he went public with this rejection and after one week of doing so, he was approved for financial aid by the state (ibid. 28). After he earned his associate degree at the College of San Mateo, he applied for admission to the *University of California* at Berkeley. After initial resistance on the part of the university, Ed Roberts was accepted. The university let him use the campus hospital as his dormitory because there was no accessible student housing (none of the residential buildings could support the weight of Ed Robert’s 800-lb. iron lung). Furthermore, he received attendant services through a state program called *Aid to the totally Disabled*. This is an important note because this was consumer-controlled personal assistance service, which means that the attendants were hired, trained, and fired by Ed Roberts. One of his most famous sentences as a leading figure of the

IL movement was: “If we have learned one thing from the civil rights movement in the US, it’s that when others speak for you, you lose” (Ed Roberts, as cited in *ibid.* 28). Ed Roberts’s experiences and actions nurtured a narrative, which stands paradigmatically for the beginnings of IL being a counter-reaction to programs, that some American universities had introduced in the 1960s to enable students with ‘severe physical impairments’ to attend mainstream courses. These schemes were rarely available outside university campuses and the resistance against this exclusive situation marks the beginning of the IL movement.

The movement was sparked, certainly by the actions of Ed Roberts, but several other students of the *University of Berkeley* (California, USA) joined forces and established the *Disabled Student Program*, a program designed to meet the needs of wheelchair users on campus. Furthermore, they founded the political group *Rolling Quads* that worked to create a barrier-free environment on campus (Carey 2009, 137). The experiences of these early organizational efforts were taken on a broader level in the IL movement and these “new organizations of the disability rights movement stressed the American values of independence and participation in ways that made such groups acceptable to public officials and the general public” (Carey 2009, 387).

The IL movement concentrated on the question of services for persons with disabilities. Postulating that people with disabilities are the best experts on their needs, they must take the initiative, individually and collectively, in designing and promoting better solutions and must organize themselves for political power. Besides de-professionalization and self-representation, the IL ideology comprises de-medicalization of disability, de-institutionalization and cross-disability solidarity (i.e. inclusion in the IL Movement regardless of diagnoses). The underlying motivation, which has guided the IL movement can be found on the Independent Living Institute’s (ILI) website:

Independent Living does not mean that we want to do everything by ourselves, do not need anybody or like to live in isolation. Independent Living means that we demand the same choices and control in our every-day lives that our non-disabled brothers and sisters, neighbors and friends take for granted. We want to grow up in our families, go to the neighborhood school, use the same bus as our neighbors, work in jobs that are in line with our education and interests, and raise families of our own. We are profoundly ordinary people sharing the same need to feel included, recognized and loved (Ratzka 1997).

The traditional paradigm, which was the medical model of disability at that time, defined a problem of disability as actual physical or mental impairment. IL reformulated this problem by highlighting the dependence of persons with disabilities upon professionals and others and

emphasized the notions of choice and control for persons with disabilities, that makes the person with a disability, i.e., the consumer ‘the person in control’:

In the traditional paradigm, the desired outcome of service delivery is maximum physical or mental functioning (or, as in vocational rehabilitation, gainful employment). Desired outcomes in independent living are tied to having control over one's daily life. Control does not necessarily mean having the physical or mental capacity to do everyday tasks for one's self. For some disability groups, complete control may not be possible, but the independent living movement continues to work toward complete consumer control wherever and whenever possible. What may be even more critical is that a person with a disability identifies him or herself as a “normal” person and has pride in self, including the disability (Shreve et al. 1988, 141).

The stark momentum of deinstitutionalization has also supported the moment of liberation from the institutionalized form of dealing with disability and the feature of self-help. Self-help groups became a powerful source of mutual support, education and action among people affected by particular health concerns or disabilities (Crewe and Zola 2001). As Gerben DeJong has observed, there appeared to be self-help groups for almost every conceivable human condition or problem: “drugs, gambling, death, homosexuality, child abuse, women's health, old age, sex, neighborhood crime, cigarette smoking, childbirth, and of prime interest here, physical disability” (DeJong 1979, 439). Such organizations view themselves as mutual aid groups that serve as adjuncts or as valid alternatives to established human service agencies. They usually address problems and needs not dealt with by other institutions in society. Claire Schlaff reaffirms the central reformulations, that the Independent Living movement established:

Being consumers (not patients), adults (not perpetual children), capable of independent living with supports (not in need of institutionalization), contributors to society (not burdens), self-directed (not controlled by others), in need of personal assistance services (not caregiving), and in need of rights (not cures). It is also assumed that learned helplessness is a result of the attitudes of society toward people with disabilities and that a change in attitudes is needed (Schlaff 1993, 943).

IL stands paradigmatically for a change of public perception of disability issues. This has been achieved by the systematic organization of major protests over contested issues of disability rights. Persons with disabilities began to identify themselves with the struggles of other disenfranchised groups. This is reflected in the mobilization potential of the movement. As an example, counts the ‘504’ Sit-In in 1977 Disability Rights Protest, who exemplifies the power of this newly emerging movement.

For 25 days in April 1977, a group of roughly 150 disability rights activists took over the fourth floor of a federal building in San Francisco. They would not leave, they said, until President Jimmy Carter's administration agreed to implement a four-year-old law protecting the rights of people with disabilities. The sit-ins were, according to Disability-rights activist Kitty Cone the public birth of the DRM, as for the first time, disability really was looked at as an issue of civil rights rather than an issue of charity and rehabilitation at best, pity at worst (Grim, 2015).

4.2.1. Centers for Independent Living

The newly acclaimed demands, that persons with disabilities formulated in various ways also found form in the foundation of Centers for Independent Living (CILs), that confronted the traditional forms of dealing with persons with disabilities with different practices. Unlike other services for disabled people controlled by mainly non-disabled professionals, CILs are self-help organizations exclusively run and controlled by disabled people themselves. Further, in contrast to other professionally dominated provision that focused almost exclusively on medical treatments and therapies within institutional settings that effectively removed disabled people from everyday life, CILs provided a new and innovative range of services and support systems designed to enable people with impairments to adopt a lifestyle of their own choosing within rather than apart from the local community (Barnes 2003).

One of the first CILs that was established was the Berkeley CIL, which was incorporated in 1972 as a self-help group, to be managed primarily by persons who were themselves disabled. The Center provided a wide range of related services, such as “peer counseling, advocacy services, van transportation, training in independent living skills, attendant care referral, health maintenance, housing referral, wheelchair repair, and others” (DeJong 1979, 437) .

Among disabled persons, CILs in the US became the primary self-help unit:

they seek to serve both as an adjunct to the present human service system and as an alternative service provider. As an adjunct to the system, the centers at times serve as conduits for funding human services such as attendant care. As an alternative to the system, the centers may provide peer counseling and advocacy services not provided by mainly human service organizations. The self-help movement is fueled by the same distrust of professionally dominated services as exists in consumerism. Self-help organizations are intended to give people the opportunity to exercise control over their own lives and services they use. They are the knowledge-giving, awareness-providing organizations that help to confer sovereignty on the consumer (DeJong 1979, 438).

CILs represent both an attempt to achieve self-actualization, and a form of direct action aimed at creating new solutions to problems defined by disabled people themselves (Oliver 1987).

4.2.2. Minority Group Rights

Group rights are central to the political theory of liberal democracies – multiculturalism and identity politics have been promoted within such political systems. The IL movement clearly stands in this tradition by claiming ‘minority group rights’. It has opened up ways of forming groups of “political identity, pride and sense of self-determination” (Sabatello and Schulze 2013).

The rise of IL at the turn of the 1970s was particularly influential in drawing attention to the importance of self-help, user-led services situated within the CILs, and political campaigning. Following the arguments of the American women's and civil rights movements, the IL maintained that disabled people were a minority group denied basic civil rights and equal opportunities that could only be resolved by legislative change. I identify this as an underlying tenet of the IL movement. With the argumentation lines of the minority group rights, the cause of the movement was identified. This was also taken up by the Federal legislation and regulations thus established a minority group definition of the position of disabled people. Consequently, disability rights groups were able to take a role in the Washington scene which had been established by other civil rights advocates. As this role became institutionalized, disability rights leaders were accepted into formal and informal associations of civil rights lobbying. In general, Disability activists developed the minority group model in response to the exclusion of people with disabilities from classical liberal versions of rights (Scotch 1989).

Despite terminological differences, there is general agreement amongst disabled activists and their allies that the philosophy of 'independent living' is founded on four basic assumptions. These include:

- 1) that all human life, regardless of the nature, complexity and/or severity of impairment is of equal worth;
- 2) that anyone whatever the nature, complexity and/or severity of their impairment has the capacity to make choices and should be enabled to make those choices;
- 3) that people who are disabled by societal responses to any form of accredited impairment – physical, sensory or cognitive – have the right to exercise control over their lives; and
- 4) that people with perceived impairments and labelled 'disabled' have the right to participate fully in all areas, economic, political and cultural, of mainstream community living on a par with non-disabled peers (Barnes 2003).

4.2.3. Self-advocacy movement

The self-advocacy movement started as a civil rights movement by people with developmental disabilities who were rebelling against being underestimated, deprived of choices, treated like "eternal children, and believed to lead lesser lives" (Ward and Meyer 1999, 135). As early as in the 1960s, the first Self-help initiatives of people with intellectual and learning disabilities were set up, which turned against institutionalization, segregation, and discrimination and demanded a community-based life. The self-advocacy movement is a living testament to the group activity of people with learning difficulties in challenging institutionalized prejudice and oppressive hegemony within society (Williams and Shoultz 1984).

The most fundamental concern of the movement considers the need to address and value the “basic humanity of people with an intellectual disability that had been historically denied them” (Parmenter 2001, 276). One of the first proponents of such formulations was Bengt Nirje, an early advocate for persons with intellectual disabilities “came to the realization” (Ward and Meyer 1999, 135) that persons with intellectual disabilities could and should have a role in their own choices. Self-advocacy and Self-determination grew out of this principle that has been later referred to as the “normalization principle” (ibid. 135). This principle required making available to the ‘mentally retarded’ patterns and conditions of everyday life which are as close as possible to the norms and patterns of the mainstream of society; Bengt Nirje extended the normalization principle by teaching self-advocacy skills through adult education coursework for persons with intellectual disabilities. He offered courses in contemporary society, political science, and parliamentary techniques provided an orientation to the process of decision making, the roles, and functions of group members, and financial control. In teaching these courses for persons with intellectual disabilities he laid the essential foundations for courses provided by self-advocacy groups up until today (ibid. 136).

Self-advocacy means that individually or in groups (preferably both), people with “mental retardation” speak or act on behalf of themselves or others or on behalf of issues that affect people with disabilities. In its most literal sense, it means speaking up on one's own behalf and deciding what is best for oneself: “It means that individually or in groups (preferably both), people with mental retardation speak or act on behalf of themselves or others or on behalf of issues that affect people with disabilities” (Williams and Shoultz 1984). As such, self-advocacy is concerned with ensuring that people with intellectual disability can have a say about issues important to them, but it is also concerned with building individual (and collective) capacity among people with intellectual disabilities. For instance, Dan Goodley has described self-advocacy primarily as an opportunity for people with intellectual disabilities to have a say and to develop their skills to do so (Goodley 2001).

Furthermore, self-advocacy is about independent groups of disabled people working together for justice, helping each other to lead their lives and fighting discrimination. It aims at:

Showing each other how to make decisions that affect our lives, so that we can be more independent, we are informed about our rights, but as we learn about our rights, we also learn about our duties. The way in which we learn to speak for ourselves is mutual support and mutual help in gaining self-confidence in expressing what we believe in (Dybwad and Bersani 1996, 2).

Consequently, for people with intellectual disabilities, self-advocacy means gaining more control over their own lives and determining decisions on their own (Dumbleton 1998, 151).

There is no particular date that has parked the movement, but in 1968 a Swedish parents' organization for people with developmental disabilities held a meeting with the motto 'We speak for them'. This motto refers to the role of the parents, who are speaking for their children. The persons with intellectual disabilities, which attended the meeting decided they wanted to speak for themselves (in contrast to the overarching institutions) and made a list of changes they wanted in their services and gave this list to the parent's organization (ibid. 151). In the course of the next five years meetings like this took place in England and Canada and although the idea for self-advocacy originally came from Sweden, the origins of the self-advocacy movement today are most commonly dated with the development in the US (Theunissen 2001, 14). The reason for this lies in the processes surrounding the first convention for the 'mentally handicapped' in November 1973. The convention was called *May We Have A Choice* and was organized by The Arc of British Columbia (Canada). The Arc was founded earlier in 1950 when a small group of parents and other concerned individuals came together to act as voices for change for persons with intellectual disabilities. In their own words, they describe their objective as follows:

At the time, little was known about the condition of intellectual disability (at the time referred to as 'mental retardation') or its causes. There were virtually no programs and activities in communities to assist in the development and care of children and adults with intellectual disability or to support families (The Arc 2019).

May We Have A Choice was also attended by two staff workers and three residents from the Fairview Hospital and Training Center in Salem, Oregon (USA). These individuals were dissatisfied with the conference because they believed that the professionals did all the talking. They came back to Oregon excited about the possibility of people with developmental disabilities speaking for themselves and decided to organize 'their own' convention. Thus, this convention was planned to have an emphasis on the issues concerning persons with intellectual disabilities. This emphasis was already noticeable in the planning phase of the convention. In contrast to the Canadian convention, which had been organized by 'professionals', the 'attendees from Oregon' dreamed of a convention that was planned by persons with disabilities, with assistance from advisors only when needed (People First of West Virginia, 2016). The following self-planned, organized meeting was conducted in October 1974 in Otter Crest, Oregon, and has been decisive for the further dissemination of the self-advocacy movement. During this meeting, the well-known slogan of *People First* was coined when utilized for the first time by "someone" (Shoultz, as cited in Schalock, Baker, and Croser 2002, 222) who said: "I'm tired of being called retarded. We are people first" (ibid. 222). The name *People First* also represents the potential to demonstrate one central claim of the meeting which was "that we are

first and foremost humans and our disabilities come second” (ibid. 223). The *People First of Oregon* group, which derived out of this congress is considered the first to seek support and assistance from a non-disabled ‘advisor’ who should help them (members of the group) to speak for themselves, but not lead the group. In October 1975, they held their first convention and calling it *People First*. In the aftermath, numerous other groups in the US emerged “People in Action, The Advocates Voices, Speaking for Ourselves, Self-Advocacy in Action, or Members Council” (ibid. 223). They all had and still have the same concern: Self-determination and equal rights for people who are considered “mentally or learning-disabled” (ibid. 224). In the UK, two conferences for “mentally disabled” took place even before the *People First* convention in 1975. These “participation events” were organized by the Campaign for people with mental handicaps (CMH). The first event was called *Our Life* (in June 1972) and brought together a number of residents from long-stay hospitals to talk about where they would like to live in the future. When written up by Shearer (1972), it was the first publication in the UK to consist of the comments by “mentally handicapped” people about the services they received. The following year another conference took place called *Listen* (Shearer 1973). However, the “one-off” nature of the events was criticized and it was demanded to have more regular meetings. (Goodley and Ramcharan 2005).

4.3. Disabled People’s International

The foundation of Disabled People’s International is closely associated with the history of Rehabilitation International (RI), that was an international organization made up mainly of rehabilitation professionals doctors, physiotherapists, nurses, and social workers. It represented the only international organization that addressed the needs of people with disabilities until the emerging DRM. “RI was founded in 1922 as the International Society for Crippled Children” (Driedger 1987, 31). Ultimately it changed its mandate to include adults and changed its name. But this organization tended to view disabled people as sick and childlike. RI held World Congresses every four years to discuss rehabilitation and social issues as they related to disabled people. Professionals from around the world attended. Even though the discussion concerned the lives of persons with disabilities, very few disabled people ever participated as speakers, delegates or observers. There were several reasons for their lack of participation. One was a lack of resources. Disabled people, even in the developed Western world, were some of the poorest people in their societies. Often, they depended solely on a small disability pension or begging to support themselves (ibid. 31).

According to Rachel Hurst, who was one of the founders of DPI, the organization started in 1980 in Winnipeg, Canada, at the Rehabilitation International Congress attended by 2000–3000 non-disabled rehabilitation and charity experts. When about 250 disabled people were attending the Winnipeg conference from all over the world to express their shared experience of social exclusion and oppression (Hurst 2000). The cause of their attendance was incited by the preceding *World Congress* of RI, where persons with disabilities were not able to attend sessions, because lack of accessibility of the venues (Driedger 1989, 30). After sharing the commonalities of their oppression and realizing the need to organize themselves together for a real change, disabled people ‘decided to go to the council of RI and demand substantial voice in the decisions that were being made’. The Leaders of RI refused this, with the result that disabled people left the room, held their own meetings and eventually decided to form their own international organization. By that point they wanted to put participation and the voice of persons with disabilities as the “focus of the agenda instead of social services” (Hurst 2005, 66). As RI refused their requests, resistance among the disabled persons attending the conference was fueled. The refusal generated the determination of disabled attendants fight against oppression in a more organized form. This led to the establishment of DPI. The constitution of DPI was subsequently signed in Singapore in 1980. It is the only DPO, that acted on an international level from the very beginning after its foundation. DPI’s constitution centered around the formulation of rights that were demanded: equal citizenship rights, freedom of choices, and dignity. They aimed to contest their incarceration and draw attention to the discrimination they encounter in their daily lives (Sabatello and Schulz 2014, 14).

The newly founded *Steering Committee* of DPI had representatives from all five regions of the world and in their constitution, they declared it to be a cross-impairment organization. They stressed that disability had too long been viewed as a problem of the individual and not the relationship between an individual and his/her environment. For DPI the prerequisite for change lay in the “promotion of grassroots organizations and the development of public awareness of disability issues” (Hurst 2005, 67). DPI moved the definition of disability away from the individual to limitations in society. (Hurst 2005, 67). Furthermore, DPI stands for the motif to pursue legally binding international disability rights. The agenda complies central motifs of the tenets introduced before and introduces these at a ‘higher policy level’. Diane Driedger devoted a book to the foundation of DPI and named it the “last civil rights movement” (Driedger 1989). DPI was the first effort of disabled people to create a united voice at the international level. The establishment of DPI has had a very important impact on the empowerment of persons with

disabilities all over the world and in organizing the international disability movement in the spirit of the social model (Magdolna 2014, 52). The organization became interwoven with supranational organizations at an early stage, as it had been granted consultative status with the United Nations (UN), United Nations Educational, Scientific and Cultural Organization (UNESCO) and the International Labor Organization (ILO). Also the founding year of the Organizations 1981 coincides with the International Year of Disabled Persons by the UN (Driedger 1989, 55).

5. Alignments of the emerging Disability Rights Movement (1960–1981)

The preceding chapters have captured the emerging DRM as a conglomerate of different movements, comprised of different actors that were founded in varying contexts and have highlighted different aspects of disability in their underlying tenets. For the “first time in history” a wide and diverse number of fragmented organizations and groups for and of people with many kinds of disabilities joined together to press for a fundamental, in their view, long overdue change of attitudes to and legislation for disabled people (Hurst 2010). The growth of new organizations of disabled people during the two decades from 1960–1980 has been compared to the “development of the black and feminist movements for civil rights” (Oliver 1984, Abberley 1986, Driedger 1989).

However, the movement experienced many difficulties. One of which lies in the fact that persons with disabilities are often reluctant to form a unitary movement, which focuses on the aspect of their identity that is often most negatively stigmatized by the rest of society and mobilize politically around it (Scotch 1988, 162). Tom Shakespeare also points to the important point of a “central difference” of the Disability movement in distinction to other movement, that want to liberate from suppression:

Yet while disabled people do face discrimination and prejudice, like women, gay and lesbian people, and minority ethnic communities, and while the disability rights movement does resemble in its forms and activities many of these other movements, there is a central and important difference. There is nothing intrinsically problematic about being female or having a different sexual orientation, or a different skin pigmentation or body shape. These other experiences are about wrongful limitation of negative freedom. Remove the social discrimination, and women and people of colour and gay and lesbian people will be able to flourish and participate. But disabled people face both discrimination, but also intrinsic limitations. (Shakespeare 2006, 220)

Such difficulties have led to unfortunate phenomena, which are for example examined in the research *A Hierarchy of disability* (2003), a literature analysis. The work shows that, from the perspective of the disabled, an internal ‘impairment-hierarchy’ exists. This results from the fact

that people with disabilities do not want to be associated with other impairment groups and subsequently try to become self-reliant to separate independently (Deal 2003, 897). Such an impairment hierarchy often hinders a ‘unitary alignment’ of a disability movement: A contribution by Mark Sherry mentions a ‘damage hierarchy’, which points at a dissociation within the disability movement:

People with physical impairments have long been at the top of the disability hierarchy. It is through their advocacy and political power that the universal sign for accessibility includes the image of a wheelchair. This pedagogical move – to center disability theorizing around a problematic notion most closely associated physical impairment – is equally disempowering for the vast majority of disabled people, who do not have physical impairments (Sherry 2013).

This chapter aims at taking a closer look at the causes of such developments within the disability movement. Therefore, I will subsume the commonalities and variety of the movements, laid out in the preceding chapter and extract these notions by analytically capturing their alignments along two lines.

The first line accounts for the different contexts in which the movements emerged as they cannot be separated from the distinct political atmospheres within the countries that they emerged. In the second line of examination, I will trace the question of the alignment of the tenets, which were important for the transformation from a disability movement to the emerging DRM. I will do so by laying open a distinct difference within the conceptualization of disability: a line of division that distinguishes between movements of persons with physical and of persons with intellectual disabilities. This is necessary, because the term disability is often conflated to one single understanding of disability, especially when applied in international treaties concerning the issue. However, multiple understandings of disability existed. These understandings shall be depicted in this paragraph.

5.1. Commonalities

A commonality between the key components of the emerging DRM rests on the feature which has nurtured resisting notions against the medical and administrative dominance that persons with disabilities have historically faced. James Charlton identifies this commonality as the notion of control, which has acted as a common denominator of the emerging DRM.

The DRM’s demand for control is the essential theme that runs through all the activism that is characteristic of the emerging DRM. Regardless of political-economic or cultural differences. Control has universal appeal for DRM activists because the need of people with disabilities and the potential for meeting these needs are everywhere conditioned by a dependency born of powerlessness, poverty, degradation, and institutionalization (Charlton 1998, 3).

Further, the realization, that persons with disabilities frequently find their opportunities limited because of social rejection, discriminatory employment practices, architectural barriers, and inaccessibility to transport has fueled resistance that united the emerging DRM. In highlighting the societal attitudes which “largely determine the extent to which the personal, social, educational and psychological needs of persons with disabilities will be realized” the patronizing mindsets and prejudices, that persons with disabilities were often confronted with, were identified as obstacles for leading an ‘independent life’ (ibid. 3). The ‘individual tragedy model’ of disability was challenged and rights for persons with disabilities were promoted in various ways. Social oppression theory, the basic tenet of the British social model, contrasted the existing charity models and the minority group rights agenda highlighted the distinction that consumers are not patients. The People First movement proposed the tenet of self-advocacy for persons with intellectual disabilities and DPI countered the existing charity model of RI and introduced the rights of persons with disabilities in the ‘international sphere of rights’.

All these attempts are basic forms of resisting a patronizing prejudice that disability is the product of environmental barriers and attitudes that specifically discriminate against people with impairments. This discrimination, an ideological construction of disability through individualism and medicalization, has been called the “politics of disablement” (Oliver and Barnes 2012). However, there are also some fundamental differences between the respective movements of the emerging DRM. The next chapter is tracing these differences in describing its variety.

5.2. Variety

A major debate in disability theory relates to the importance of acknowledging a variety of differences between people with disabilities. Some argue that the social approach towards disability should focus on the common social oppression which people with disabilities face, and on their need to unite politically to fight this oppression (UPIAS 1976). Others contend that the conceptualization of disability as a monolithic experience ignores existing differences between people with disabilities based on class, gender, race and ethnicity, sexual orientation and age (Mulvany 2000, 586). Associated with this failure to acknowledge difference, it is claimed, that this is due to a disinterest in people’s perceptions of living with impairment and disability.

If one regards the depicted tenets of the emerging DRM, it becomes clear that two major strands of disability politics emerged, resting on two different tenets: The social oppression and the minority group rights tenets.

To varying degrees, each of these approaches shares a basic political commitment to improving the lives of persons with disabilities – they can, therefore, be considered parts of the DRM. However, the minority group rights approach, with political action being “based on the individualization of disability”, tends to omit the UK social model materialist focus on oppression (Meekosha and Soldatic 2011, 1385). The vast body of work in North America explores important social, cultural and political dimensions of disability, but does not distinguish between impairment and disability akin to the UK social model. North America’s disability movement has also developed its own flavor, largely based on a minority group or identity approach to disability. Under this model, the means to overcome prejudice and discrimination against persons with disabilities are set by civil rights legislation, bearing in mind the social, cultural, and political dimensions of disability. In addition, the struggle of persons with disabilities is framed in terms not merely of achieving equality and non-discrimination but also of recognition as a separate minority group consisting of multiple subgroups. Each subgroup has its own political identity, pride in its physical/mental characteristics, and sense of self-determination and self-identification.

The case of ‘coining terms’ illustrates the differences between the two approaches rather well: The US term ‘people with disabilities’ has not gone as far in redefining ‘disability’ as social oppression, as the British social model does it in coining the term ‘disabled people’. Instead, the North American approach (Canada included) has mainly developed the notion of people with disabilities as a minority group and is tied closely to the tradition of U.S. political history. This difference is also taken further, as the standpoint within the UK is more focused on issues of ‘equality in political and material participation’, such as politics, social services, and rights, whilst North America is more focused on issues of ‘psychology, identity, personal affirmation and moral development’ (Meekosha and Soldatic 2011). This fragmentation is partly due to the different alignments the organizations followed and is expressed in the varying tenets of the emerging DRM.

In highlighting the varying aspects of the emerging DRM, I have aimed at shifting the attention towards a notion of difference within the movements regarding their differentiation of the

definition of disability. These differentiations have been based on different understandings of disability, for example within the differences of the social oppression model (disabled people) and the minority group rights approach (people/persons with disabilities). This notion of difference that translates into a variety of the emerging DRM is also reflected in differentiation between the movement of persons with physical disabilities and the movement of persons with intellectual disabilities.

5.2.1. The movement of persons with physical disabilities

As has been specified in chapter 4.1.2., one of the first publicly acclaimed documents that testified a 'voice of disability' were the letters of Paul Hunt. While I already cited the letter by Hunt, that he wrote to the magazine 'Voice of the Disabled' to recruit allies for his cause of founding a Union for persons with disabilities, I want to depict another letter, that he wrote simultaneous, in this section. He also wrote a letter to the newspaper 'The Guardian' in 1972, proposing the creation of a consumer group of disabled residents of institutions, following media coverage of the CMH. In this letter he writes:

Sir, – Ann Shearer's account of the CMH conference of and not on the so called mentally handicapped, challenges our patronizing assumptions about such people. It also has important implications for anyone who genuinely wants to help other disadvantaged groups (Hunt 1972).

The letter has to be seen as a reaction to national media coverage in the context of the CMH conference *Planning for a Change* in 1969 in London. Following a "wave of mental hospital scandals", the conference tried to seek answers for the existing difficulties and the maltreatment of persons with intellectual disabilities in national hospitals (Cochrane 1991, 3).

Hunt took the relevance of this conference up and tried to mobilize people for his cause: People that were physically disabled. He took the experience of physical disability as a basis for his activism:

ALL MY adult life has been spent in institutions amongst people who, like myself, have severe and often progressive physical disabilities. We are paralyzed and deformed, most of us in wheel-chairs, either as the result of accident or of diseases like rheumatoid arthritis, multiple sclerosis, muscular dystrophy, cerebral palsy and polio. So naturally this personal experience forms a background to the views on disability that follow (Hunt 1966, 1).

Vic Finkelstein also added to the stance to unionize among persons with physical disabilities in early writing:

My argument as to why I feel the organization must be kept firmly in the hands of its physically disabled members follows from the thesis above and my concept of disability as a social condition (which I argue more fully later). I have said society oppresses its physically impaired members and that when "conditions are ripe this oppressed group begins to organize itself in defense." I am emphasizing the fact that physically impaired people do not choose to be disabled, but society causes this. Consequently, a whole class of strangers are grouped together despite themselves. We are, in reality, united (and have to come to recognize this in the course of struggle), because of the common social oppression of the physically

impaired members of society. Physical disability is a social, not an individual, condition. The formation of a union of this oppressed group is the logical outcome of a group consciousness, developed historically, which recognizes its real social condition (Finkelstein 1972).

This is also reflected in the latter policy of the UPIAS that only persons with physical disabilities are allowed to be part of the organization. This becomes clear in chapter 22 of ‘Foundational Principles of Disability’ where the UPIAS takes a stance regarding ‘other oppressed groups’:

The particular forms which oppression takes in this society differ somewhat for each distinct oppressed group. Some, such as people who are called mentally handicapped, or those mentally ill, clearly have a great deal in common with us. Full membership of our Union is however based simply on the fact of physical impairment. This is because we believe the important thing at the moment is to clarify the facts of our situation and the problems associated with physical impairment. But it is fundamental to our approach that we will seek to work with other oppressed groups and support their struggles to achieve a decent life. What all oppressed people share is a vital interest in changing society to overcome oppression, and the Union is therefore anxious to join in common action to achieve such change (UPIAS 1974/75).

Apparently, a tendency existed within the emerging DRM to unite under the common cause of changing an able-bodied society but has stayed exclusive within. UPIAS explicitly referenced that persons with intellectual disabilities could not become a part of the Union and somehow underlined its exclusive character. This differentiation has not been as sharply articulated by IL, but the tendency to appeal more to persons with physical disabilities is commented by Gerben DeJong:

The movement has concentrated its energies on a relatively few major disability groups: those with spinal cord injury, muscular dystrophy, cerebral palsy, multiple sclerosis, and postpolio disablement. And the ILM had an overwhelming proportion of physically disabled persons (DeJong 1979, 435).

Another feature of the movement for persons with physical disabilities is, that it relied on strong individuals to start of the movement: Paul Hunt and Ed Roberts have both dedicated their life’s work to the establishment bodies of work, centered around a social oppression theory and the IL paradigm. Persons with intellectual disabilities often face different challenges, that were not distinctly concerned with contributing to theoretical discussions by writing theoretical bodies of work. However also a movement of persons with intellectual disabilities emerged within the phase of the emerging DRM. This movement is depicted in the next chapter.

5.2.2. The movement of persons with intellectual disabilities

Prior to eugenics, people with intellectual disabilities were already seen as failing to meet “criteria of competence and autonomy” (Carey 2009, 39). The law defined incompetence as an inability to adequately understand the implications and consequences of one’s actions, a definition directly paralleling those of mental and intellectual disability. “Idiots”, “lunatics” and “persons non compos mentis” were said to have ‘nothing which the law recognizes as a mind

and thereby denied civil rights (ibid. 39). Moreover, persons with mental and intellectual disabilities historically were denied access to rights on the basis of ‘dependence’. This has its origin *inter alia* in the difficulties that arise for persons that are classified as having a ‘disability of the mind’.

For often the very terms used to name persons with mental disability have explicitly foreclosed our status as persons. Aristotle’s famous declaration that man is a rational animal gave rise to centuries of insistence that to be named mad was to lose one’s personhood (Price 2013, 298).

Persons with disabilities were often dependent upon a family, community, or the nation for economic and social support. In exchange for this support, ‘dependents’ were expected to forfeit their civil rights in exchange for care. The concept of self-advocacy opposes such exchanges and is, therefore, appealing for persons with intellectual disabilities, who began to organize in self-advocacy groups and thereby joined the emerging DRM. But this involvement remained rather difficult for many persons with intellectual disabilities, as they faced barriers to the formation of such groups. As Bonnie Shoultz, a self-advocate points out in an online publication that is meant to characterize the movement:

People with mental retardation who wish to form a Self-advocacy group face many barriers. They need recognition of their aspirations, information about Self-advocacy, and support to accomplish the initial tasks. They must identify a meeting place, find ways of communicating with other potential members, and deal with transportation problems. Typically, they need allies to help them overcome these barriers, but these allies may be difficult to find (Shoultz 1982).

The strategy persons with intellectual disabilities followed for organizational purposes was to rely on ‘allies’, which were persons without intellectual disability. This strategy involved persons ‘without disabilities’ that were not included in the movement of persons with physical disabilities (UPIAS 1976). However, within the movement of persons with intellectual disabilities these were regarded as, persons “who speak for ‘them’” (Carey 2009). This approach, embedded in the concept of self-advocacy, represents the sole tenet within the DRM that actively took up questions of intellectually disabled persons. The growth of the self-advocacy movement occurred as part of a larger international phenomenon in which people with ‘mental retardation’ around the world, particularly in Sweden, Britain, and Canada, were organizing (Cochrane 1991).

Self-advocacy has been most prominently taken up by the People First movement, which represents the largest movement of persons with intellectual disabilities within the emerging DRM. Its emergence has to be situated close to IL but put a special emphasis on self-advocacy. The movement has especially focused on issues surrounding questions of rights for persons

with learning disabilities. This category held the most potential to include most persons of the intellectual disabilities spectrum.

A basic assumption of the self-advocacy movement highlights that people with learning difficulties “want to and are able to learn” (Chappell, Goodley, and Lawthom 2001, 46). At the same time, it also implies that some are better at it than others and recognizes that all people have a learning difficulty one way or another:

A man couldn't do woman's work... I said, “You want to come and see some of them working in the centre and I bet they'd have to teach you how to do it.” Come and try and do our work and you'll soon find out if you've got a learning difficulty or not (Kershaw, as cited in *ibid.* 46).

In this quote, Joyce Kershaw, a Self-advocate rejects a deficit approach to learning difficulties, emphasizing competence and the capacity to change instead. The capacity for change is central to the concept of learning difficulties. This feature bears the possibility and chance to highlight the capability of learning instead of, a diagnosis, that underestimates the abilities of these persons. A self-advocate reaffirms: “If you put ‘people with learning difficulties’ then they know that people want to learn and to be taught how to do things” (Sutcliffe and Simons 1993, 23).

This ‘feature of change’ is also entailed in the foundation of the initiative *Project Two*, a Nebraskan based self-advocacy group formed as a “political force as well as a support system, encouraging former institutional residents to share their experiences with the public and to work to close Nebraska’s institutions” (Carey 2009, 155). Interestingly the founder of the organization, Ray Loomis, conceptualized the organization in what he referred to as a “brainstorm” (*ibid.* 155). Because of his own difficulties making the transition to community living, he thought there should be a group of people with disabilities that provided support to individuals as they left institutions and established their lives in the community. Although neither Loomis nor the organizations with which he worked had heard of the term “Self-advocacy,” Loomis “knew instinctively that the group must be self-directing” (Williams and Shultz 1982, as cited in Carey 2009, 156). Although diverse, early self-advocacy groups typically shared several key goals, the most basic was the goal of self-advocacy itself. In 1978, a *Project Two* resolution explained the philosophy behind self-advocacy:

1. We believe that we are people first, and our handicaps are second. We wish people would recognize this and not give us a tag like “handicapped” or “retarded.”
2. We believe that we have to fight for our own rights, and unless we do we won't get them.
3. We believe that people shouldn't just stay at home and feel sorry for themselves and ask for pity; there's a beautiful world out there, and we want to be part of it.
4. We believe that we should work to destroy the physical and mental restrictions on everybody, not just on ourselves.
5. We believe that it is important to get people out on their own.
6. We believe that it is wrong for the public to run us down and treat us badly.
7. We believe that we can win this fight, if we work together. (Williams and Shultz 1982, 223–224)

If a movement for persons with intellectual disabilities can be identified in the emerging phase of the DRM, one must regard the People First movement and the manifold expressions of the tenet of self-advocacy. Although the emerging phase holds ready only the first seeds of the tenets of such an understanding of disability, one must trace them to contextualize the place intellectual disability within the DRM.

To revoke the objective of this, I will further concentrate on the relationship between intellectual disability and the DRM in the following chapter.

6. The Disability Rights Movement and intellectual disability

As has been collated in the preceding chapter, the varying alignments of the emerging DRM (1960–1981) are rooted in ‘its’ diverging tenets. These tenets are characterized on the one hand by a certain commonality of shared resistance against a ‘politics of disablement’ that problematized prevailing practices of ‘treating’ persons with disabilities. On the other hand, a variation has been identified that clearly differentiated between a movement specifically addressing persons with physical disabilities and a movement which addressed persons with intellectual disabilities. It is necessary to analytically depict this variety in order to grasp the differences of perceptions of disability and examine this divide further.

Intellectual disability takes a ‘special role’ within the emerging DRM. This role stems from the difficult relation of the DRM towards intellectual disability. This relation is embedded in the overall questions, that the emerging DRM as one entity (without the differentiation between movements of physical and intellectual disabled persons) has been confronted with. How are disability rights established and sustained in light of prevailing theories regarding the function and justification of rights that make it difficult to justify disability rights claims?

Proponents of civil rights usually claim that to be regarded as a “rights holder,” one must have agency and rationality (Sabatello in Adams, Reiss, and Serlin 2015, 448). This situation made it difficult for persons with intellectual disabilities to find a platform within the emerging DRM and to demand rights. Persons with disabilities were in general often viewed as objects, and persons with “cognitive and mental disabilities” were all the more viewed as especially lacking the qualifications for personhood (ibid. 448). However, as has been cited before, persons mainly

with physical disabilities have managed to establish the social model of disability. It constitutes a tool to communicate about the understanding of disability that is capable of transforming some of these prejudices that persons with disabilities were historically confronted with. But most importantly it aims at a shift of responsibilities regarding the rights of persons with disabilities within the societies they live in. I have defined this model in chapter 3 and encountered its evolvement and dissemination further within the British disability movement and IL.

In this chapter, I will first depict the role of this most influential ‘understanding of disability of the DRM’ in relation to the DRM and intellectual disability. By researching the ‘role of the social model of disability’, I aim at condensing certain shortcomings of the model regarding intellectual disability. Thus, I proceed by identifying ideas or concepts that could fuel an understanding of disability, that explicitly takes up the challenge to regard persons with intellectual disabilities. Such an approach has been termed an “inclusive social model of disability” (Goodley 2000, 44). By asking if and how such a model could be characterized, I will first look at criticisms that have been formulated regarding the social model of disability. To forego a unidirectional approach towards the issue, I will depict what an inclusive model of disability would entail, by outlining fundamental research questions of self-advocacy and possible interests of research regarding this model.

In its last section, this chapter will depict and discuss the ‘product’ that the disability rights discourse, which has set off with the emerging DRM has led to. This development is depicted in examining the ‘transformation’ from the emerging DRM to more institutionalized forms of advocating for disability rights with the instruments of law.

6.1. The role of the social model of disability

The movement of persons with physical disabilities played a central part in advocating the rights of persons with disabilities. The arguments brought forward by this movement were based on the ‘impairment distinction’ which has been established within social oppression theory. This distinction between ‘impairment’ and ‘disability’ was a fundamentally new approach, that made it possible to rally for demands and rights of persons with disabilities. However, the ‘impairment distinction’ also posed a problem, as the incapacity to reflect intellectual disability sufficiently within the main argumentation line of the social model highlights the fact that it has been centered around physical disability:

[...] just as people with physical impairments have written about disability from their own perspectives, so the accounts of people with 'learning difficulties' have clarified the socially contested nature of disability. However, while the social model of disability is not reserved for people with physical impairments, it may often seem that way (Watson, as cited in Goodley 2001, 212).

Writers committed to the social model have applied it with great enthusiasm to physical and sensory impairment, but they have often neglected people with learning difficulties. Thus, Mike Oliver, as one of the key academics associated with the social model, made only scant reference to people with learning difficulties (Oliver 1990 and 1996). However, the influence of the social model of disability has been enormous for the DRM. It has been used as a powerful tool for the communication of pressing issues of persons with disabilities and has created a political platform for persons with disabilities. In this way, it has demonstrated success for the DRM. In challenging discrimination and marginalization, linking civil rights and political activism and enabling disabled people to claim their rightful place in society (Owens 2015). Another example of this is the adoption of the definition of disability by DPI, as exemplified in the next paragraph.

The British Council of Organizations of Disabled People (BCODP), the successor of UPIAS, who was set up as a coalition of disabled-led groups in 1981, adopted the 'UPIAS approach' to disability. Vic Finkelstein and the other BCODP delegates to the first DPIs *World Congress* in Singapore later that year, worked hard to have their definitions of disability adopted on the global stage (Shakespeare 2006). Is there a depiction of intellectual disability in the social model of disability and if not, is there a contrast that arises with this finding? The 'impairment differentiation' that mainly rests on the differentiation between 'impairment' and disability, does not specifically entail intellectual disabilities. Thus, the definition of disability often aims at referring to 'all forms of disabilities (including intellectual disabilities). An example for this is a comment by Julie Mulvany, who traces the thin lines between disability, impairment or illness and references an incapability to conceptualize 'serious mental distress' by the social model:

Sociologists working in the area of mental health have been loath to confront the possibility that a range of mental impairments exists which make the performance of certain activities difficult for people who suffer from these impairments. Traditionally, sociologists have avoided the dilemmas of confronting the implications that may flow from an acknowledgment that some people experience severe pain and discomfort as a result of disorganized thinking, racing thoughts, fixed paranoid delusions, inability to control thought processes or perceptions of external thought control. This makes their work increasingly irrelevant for many people experiencing serious mental distress. Barnes and Shardlow (1996: 130) provide a succinct summary of this failure when they argue that the sociology of mental health has not been able to develop an alternative model (equivalent to the social model of disability) which can provide the basis for both understanding the origin and nature of distress and providing enabling and empowering assistance to those experiencing such distress (Mulvany 2000, 588).

A contrast arises out of a certain ‘avoidance’ of the social model regarding intellectual disability. This contrast brings up an inconsistency between the seeming theoretical conjunction (especially in rights questions) between people with physical impairments and people with intellectual disabilities and affirms the notion of avoidance of the group of persons with intellectual disabilities by the proponents of the social model of disability:

For the past fifteen years, the social model of disability has been the foundation upon which disabled people have chosen to organize themselves collectively. This has resulted in unparalleled success in changing the discourses around disability, in promoting disability as a civil rights issue and in developing schemes to give disabled people autonomy and control in their own lives. Despite these successes, in recent years the social model has come under increasing scrutiny both from disabled people and from others working in the field of chronic illness (Oliver in Barnes and Mercer 1996, 29).

Simone Aspis, a founding member of ‘People First London’ who held the position of a campaigns officer at the organization notes a similar observation by stating that:

People with ‘learning difficulties’ face discrimination in the disability movement. People without ‘learning difficulties’ use the medical model when dealing with us. We are always asked to talk about advocacy and our impairments as though our barriers aren’t disabling in the same way as disabled people without ‘learning difficulties’. We want concentration on our access needs in the mainstream disability movements (Campbell, Oliver, and Oliver 1996, 97).

The DRM has recognized this lack of inclusion of the issues of persons with intellectual disabilities in some cases. One of the references, that reads like a self-critique of the IL movement is the following:

If all these services are open to all disabled people, people with intellectual disabilities are strongly underrepresented as clients. This is particularly related to the more intellectually oriented counseling service, which is geared to self-determination and self-responsibility (Theunissen 2001, 17).

Additionally, the WHO, in its *World Report on Disabilities* chapter *Understanding Disability* references that:

People who experience mental health conditions or intellectual impairments appear to be more disadvantaged in many settings than those who experience physical or sensory impairments (World Health Organization 2011, 8).

The social model of disability has been very influential in establishing a doctrine-like argument that is easy to understand and yet somehow excludes persons with intellectual disabilities.

However, the social model of disability never claimed to have the explanatory power of a social theory. It can be understood as a springboard for an analysis of the economic and social barriers experienced by the collectivity of disabled people. Nevertheless, ‘learning difficulty’ has been tagged on only as an afterthought within much of the literature generated by the social model (Chappell, Goodley, and Lawthom 2001, 46).

As these three researchers, who are one of the few dedicated researching this issue, notice, there is a divide between people with physical and sensory impairments and those with intellectual disability (as exemplified by “learning difficulties” in the article): “As yet, the social model and its supporters have been unable to overcome this division” (ibid. 46). This sets the stage to examine an inclusive social model of disability, that treats the model from the viewpoint of persons with intellectual disabilities: the possible ‘supporters’ of an “inclusive social model of disability” (ibid.).

6.2. An inclusive social model of disability

One People First organization (in depicting the movement of persons with intellectual disabilities) has argued, that whilst the DRM has fought the colonizers of disability (e.g. the medical and its allied professions) for the right to define disability on their own terms, the fight against the colonizers of learning difficulty is of a different order, it is a fight against the denial of humanity itself (People First Scotland, as cited in Chappell, Goodley, and Lawthom 2001, 48). While this might be a very drastic claim, the need to establish a theory of disability, that is not solely dependent on accounting the social model of disability has become apparent in the preceding chapter. Dan Goodley formulates the call that the theoretical draft of an inclusive social model of disability demands:

The aim now is to move from the social model of disability to mutually inclusive social theories of disability and impairment that are open and inclusive to people who have been labeled as having ‘learning difficulties’ (Goodley 2001, 225).

It is important to reiterate that the Self-advocacy movement is the only movement that succeeded in representing people with learning disabilities, which is part of the definition of intellectual disabilities. It has proven to provide participants with a collective voice, has encouraged resilience and is founded on an assumption of the competence of people with learning difficulties. The Self-advocacy movement has brought the views and actions of people with learning difficulties into the public domain to illuminate the components of a social model, that could be called an inclusive social model of disability (Goodley 2000, 44). Hereby, addressing learning difficulties has been the most effective strategy in establishing a platform for persons with intellectual disabilities in the DRM. Centering issues around the term ‘people with learning difficulties’ made it possible for the movement to find a voice through the international Self-advocacy movement: notably People First and its affiliated groups (Williams and Shoults 1982; Sutcliffe and Simons 1993; Goodley 2000).

The self-advocacy movement stands out as the only movement, that depicts intellectual disability and the self-advocacy tenet as central for describing the role of intellectual disability in the emerging DRM. Evaluating the experiences of this movement could be of use for describing a ‘wider’ theoretical framework that takes into account the criticisms that the social model of disability has had to endure, as it has been used as the dominant model for researching disability. However, some argue that normalization principles continue to influence the Self-advocacy movement. In explaining the oppression of people with learning difficulties, Jan Walmsley notes that the Self-advocacy movement tends to emphasize issues associated with negative labeling (drawing on normalization) rather than the consideration of disabling social and economic structures as set out by supporters of the social model (Walmsley in Atkinson et al. 1997). Dan Goodley, in response to this, argues for a reconsideration of impairment in relation to ‘learning difficulties’ to challenge “pervasive ideas” that are often projected on issues that accompany the issues of persons who identify with having learning difficulties (Goodley 2001, 1). The BCODP’s strong emphasis on being ‘disabled and proud’ and its affirmation to reclaim the term ‘disability’ to develop a new collective definition can be interpreted as a congruent move (ibid. 1).

But research strategies that examine a more diverse picture of the DRM could also be utilized to depict an inclusive social model of disability, as other forms of interpreting disability have existed. One example for such a network is the *Liberation Network of People with Disabilities*, which has existed next to the UPIAS in the context of the British disability movement. Tom Shakespeare (2006, 215) takes up the organization’s approach towards a definition of disability. Their draft *Liberation Policy*, which was published in 1981, argued that while the basis of social divisions in society was economic, these divisions were sustained by psychological beliefs in inherent superiority or inferiority. Crucially, the *Liberation Network of People with Disabilities* argued that people with disabilities, unlike other groups, suffered inherent problems because of their disabilities. Their strategy for liberation included:

Developing connections with other disabled people and creating an inclusive disability community for mutual support; exploring social conditioning and positive self-awareness; the abolition of all segregation; seeking control over media representation; working out a just economic policy; encouraging the formation of groups of people with disabilities (ibid. 215).

However, the organization is hardly mentioned in the literature regarding the issue of disability rights. The organization which dominated and set the tone for the subsequent development of the British disability movement, and of disability studies in Britain, was UPIAS. “Where the Liberation Network of People with Disabilities was dialogic, inclusive and feminist, UPIAS

was hardline, male-dominated, and determined” (Shakespeare 2006). Researching such ‘supporting actors’ of the emerging DRM, just as the Liberation Network of People with Disabilities represents, might prove very fruitful for an inclusive social model of disability, that critically comprehends the roles of the dominant actors of the DRM.

The basis for such academic research thus lies in methodology, method, and analysis in researching self-advocacy for an inclusive social model of disability (Goodley 2000, 44).

Dan Goodley takes this seriously and has combined the social model with the sociology of learning difficulties. This approach may be termed an ‘inclusive’ social model of disability, embracing the ambitions of disabled people while being sensitive to the impact of a disabling society. It remains an indispensable necessity for the DRM to include the perspectives of persons with learning difficulties:

The resistance of people with learning difficulties and their experiences of being disabled (where naturalized views of impairment are at the core of oppression offer us lived examples that enable the socializing of impairment (Goodley and Moore 2000, 861).

This is also stressed by a criticism raised by the self-advocate Mitchell Levitz, who stresses a confusion between control (being one example for the commonality of the emerging DRM) and support:

Support does not mean control. In their efforts to shield us from harm, parents, friends, advocates, and service providers must be careful not to be over-protective. They should recognize our need for privacy and give us time for ourselves. [...] For those of us who need extra help, it is important that we have people in our lives that we can depend upon – not to do things for us, but rather to help us to do things for ourselves. A *circle of support* is a good example (Levitz, as cited in Herr et al. 2003, 455).

Also, the consideration of including other ‘forms of intellectual disability’ into research for such a model must be considered. The applicability of disability research to the survivors’ movement- those with experience of the psychiatric system could represent such an inclusion. However, not all survivors consider themselves ‘disabled’ despite the similarities in social disadvantage and social oppression. This in part explains why the survivors' movement has been far less united on its theoretical and research agenda (Herr et al. 2003, 455). Margaret Price reaffirms the possibilities, that lie in such research endeavors by stressing by highlighting that mental illness can be allied with the substantial — and sometimes contentious— intersections between illness and disability (Price 2013, 25). Susan Wendell also points out that activists in the DRM in the United States have often sought to “distinguish themselves from those who are ill.” This has led to a schism between those she calls the “healthy disabled,” whose impairments “are relatively stable and predictable for the foreseeable future”, and those who are chronically ill. Because those with chronic illnesses are often exhausted, in pain, or

experiencing mental confusion, their very identities as activists come into question (Wendell, as cited in Price 2013 2001, 26).

In this section, I touched upon issues that could serve as a basis for an inclusive social model of disability entail. An inclusive social model of disability contrasts the successful “big idea” of the DRM and thus stresses a commonality of disability (Hasler 1993). This commonality could be argumentatively used to challenge the politics of disablement:

The politics of disablement is about far more than disabled people; it is about challenging oppression in all its forms... Like racism, sexism, heterosexism and all other forms of social oppression, [disability] is a human creation. It is impossible, therefore, to confront one type of oppression without confronting them all and, of course, the cultural values that created and sustain them (Campbell, Oliver, and Oliver 1996, 1).

The social model, however, has been used to argumentatively underline the most effective form of defining disability in securing rights for persons with disabilities in treaties. In the next chapter, I will trace the development from disability rights to the HRMD. This is accounting the most recent developments, concerning the rights of persons with disabilities and takes into consideration the major shift that this “paradigm shift” represents. Thus, I will consider and reflect the question of intellectual disability within the central document of the HRMD: the CRPD.

6.3. From disability rights to the Human Rights Model of Disability

The rights discourse concerning persons with disabilities was introduced by the emerging DRM in the years 1960–1981 and it has also been at the forefront of international organizations that were committed to implementing the demands of rights for persons with disabilities. An important case for such a process that resembles a ‘translation’ from demands to rights is the close association of the DPI and the UN, as has been depicted in chapter 4.4. This translation took place in a transnational form of collaboration and treating issues of persons with disabilities and will be referenced in this chapter by depicting the transition from disability rights to the HRMD. Thus, this examination will assert particular attention towards the question of how intellectual disability, in particular, was referenced in these processes.

A record to depict disability rights in international law is the *Declaration on the Rights of Disabled Persons* which was adopted by the General Assembly of the United Nations (GA) in 1975. The declaration asserts that persons with disabilities have the “same civil and political rights as other human beings.” Furthermore, such persons are “entitled to the measures designed

to enable them to become as self-reliant as possible” (Campbell, Oliver, and Oliver 1996). The UN’s *International Year of Disabled Persons* in 1981 also marks an important step of the organizations efforts to depict the rights of persons with disabilities: “It called for a plan of action at the national, regional and international levels, with an emphasis on equalization of opportunities, rehabilitation, and prevention of disabilities” (UN 1981). Furthermore, a major lesson of the ‘year’ was that “the image of persons with disabilities depends to an important extent on social attitudes; these were a major barrier to the realization of the goal of full participation and equality in society by persons with disabilities” (Verdugo et al. 2012, 1038). A major outcome of the International Year of Disabled Persons was the formulation of the *World Programme of Action Concerning Disabled Persons* adopted by the UN General Assembly in December 1982 which contains a “declaration of principles, policy options, and plans to enhance disability prevention, rehabilitation and equalization of opportunities of individuals with disabilities to further their full and effective participation at all levels of society” (Schalock et al. 2002, 464). How has intellectual disability been depicted within the disability rights of the UN?

It is striking, that in 1971 the General Assembly already adopted a resolution entitled *Declaration on the Rights of Mentally Retarded Persons*. Significantly, this resolution begins by stating that ‘such persons’ enjoy the same Human Rights as all other human beings (article 1). The resolution is conscious of the need to protect the interests of such persons and to appoint a “qualified guardian where necessary” (OHCHR, Declaration on the Rights of Mentally Retarded Persons, 1971). Significantly, it cautions against “taking the mere inability to exercise rights fully as a carte blanche for their complete withdrawal” (ibid.). A certain variability of the UN has to be noted in depicting persons with intellectual disabilities by first depicting intellectual disability solely and then broadening the scope of disability again in 1975.

Here, one organization that is concerned with the rights of intellectually disabled persons needs to be introduced: *Inclusion International*. This organization has evolved out of the International League of Societies for Persons with a Mental Handicap (Parmenter 2001, 283) and gives voice to persons with intellectual disabilities in the context of the Disability Rights model. *Inclusion International* represents the international network of people with intellectual disabilities and their families, advocating for the Human Rights of people with intellectual disabilities worldwide. It has evolved out of the International League of Societies for Persons with a Mental Handicap (ibid. 283).

Barb Goode, a Canadian self-advocate and at the time of the speak an elected member of the executive council of *Inclusion International* reflects the stance of the organization in a speech she gave in 1992. She declared in front of the full General Assembly of the UN in the session marking the end of the *Decade of Disabled Persons* in 1992:

I speak on behalf of all persons with mental handicap. We are people first and only secondly do we have a mental handicap.

We want to push our rights forward, and we want to let other people know that we are here. We want to explain to our fellow human beings that we can live and work in our communities. We want to show that we have rights and responsibilities.

Our voice might be a new one to many of you, but you had better get used to hearing it. Many of us still have to learn how to speak up. Many of you still have to learn how to listen to understand us. We need people who have faith in us. You have to understand, that we like you, do not want to live in institutions. We want to live and work in our communities. We count on your support to people with mental handicap and their families. [...]

Above all, we demand that you give us the right to make choices and decisions rewarding our own lives (Mittler, as cited in Herr et al. 2003, 31).

The use of the word ‘handicap’ in this quotation shows a difficulty, that has also been depicted in the preceding chapters. The term has been strongly rejected by proponents of the social model of disability following its first use in the ICIDH (See chapter: 3.2. Classifications of disability). However, it fits the purpose of the context of the depicted speech rather well, as Barb Goode is referring to the societal construction that is constituting disability. The *Statement of Unity* is a record of the organization’s vision. Here they state a particular commitment, which stands paradigmatic for the development of the demand for disability rights to the demand of the Human Rights of disability.

As members we fully commit to the United Nations Convention on the Rights of Persons with Disabilities (CRPD) as the Human Rights Framework to guide our work and as benchmark of the progress we are making towards our vision of a world where people with an intellectual disability and their families can participate on an equal basis and be valued in all aspects of community life (Inclusion International 2019).

The Human Rights of persons with disabilities were demanded by a broad coalition of DPOs, that was constituted within the processes of the emerging DRM and subsequently often rallied around the questions of Human Rights. As such also the BCODP, which has since its formation in 1981 insisted that disabled people are denied their basic Human Rights in British society (Foley and Pratt 1994). This followed up the development, that the treaties, which tried to re-affirm the rights of persons with disabilities in the 1970s never became international treaties and were not legally binding (Quinn, Degener, and Bruce 2002, 19).

The shift from disability rights to HRMD was marked in 1993 when the *Vienna Declaration and Programme of Action* were adopted at the *World conference on Human Rights*. This

declaration has marked the shift from the demand of disability rights to commonly frame the demands of persons with disabilities as HRMD.

The UN started to consider persons with disabilities more and more as a group who need support to become equal citizens and shifted from a rehabilitation-oriented perspective towards a Human Rights approach (Foley and Pratt 1994).

The starkest example of this shift is the adaption of the CRPD in 2006, when ‘disability rights’, became a subject of Human Rights. The CRPD was commissioned by the committee of the Office of the High Commissioner for Human Rights (OHCHR) and designed and adopted by a special committee concerned with the issue of establishing the convention, a ‘milestone’ for the effort to substantiate rights for disabled persons in legislation on a worldwide scale. The CRPD was the first treaty of Human Rights in the 21st century. It also resembles the first convention, that has been made on behalf of persons with disabilities. The form of communicating and definition of disability, has changed in international legal language and self-definition has become extremely important and the question of identity politics. The new platform of arguing for disability rights as a human right has been the basis for the convention, as Theresia Degener, a member of the CRPD Committee at that time, reiterates:

Human dignity is the anchor norm of Human Rights. Each individual is deemed to be of inestimable value and nobody is insignificant. People are to be valued not just because they are economically or otherwise useful but because of their inherent self-worth. ... The Human Rights model focuses on the inherent dignity of the human being and subsequently, but only if necessary, on the person’s medical characteristics. It places the individual center stage in all decisions affecting him/her and, most importantly, locates the main ‘problem’ outside the person and in society (Degener 2016, 2).

The term ‘Human Rights model of Disability’ appeared for the first time in an article by Theresia Degener and Michael Quinn (2002) where they state:

The Human Rights model focuses on inherent dignity of the human being and subsequently, but only if necessary, on the person’s medical characteristics. It places the individual Centre stage in all decisions affecting him/her and, most importantly, locates the main ‘problem’ outside the person and in society. According to Degener, the UN CRPD indeed goes beyond the social model of disability and codifies the Human Rights model of disability (Quinn, Degener, and Bruce 2002, 10).

The adoption of the CRPD marks a step in the direction of a social rights-based approach concept of disability. It is also seen as an expression of the recognition that the social aspects of the concept of disability should be incorporated into a legal context (Aichele 2013).

The most important argument was the social model of disability. It was the “most successful dictum” during the negotiations of the CRPD. If there is one single phrase which summarizes the success story of the CRPD, it is that it manifests the paradigm shift from the medical to the social model of disability in international disability policy. This special emphasis was also noted by Theresia Degener, when she complies with Rosemary Kayess and Phillip French

(2008). They stated in their analysis of the drafting process of the CRPD that the enormous influence the social model had during the negotiations has come from a “populist conceptualization of the social model as a disability rights manifesto and its tendency towards a radical social constructionist view of disability, rather than from its contemporary expression as a critical theory of disability” (Degener, as cited in Blanck and Flynn 2016, paragraph 2). Theresia Degener highlights the necessity of this reductionism by given the fact that the drafting of international Human Rights norms is always a highly political undertaking. “The social model of disability had become the motto of the international disability movement and it served as a powerful tool to demand legal reform” (ibid.).

However, the Human Rights model of disability does not enjoy undivided support from all actors of the disability movement. Rachel Hurst, for instance, argues in a conference that the term “Human Rights model” is rather confusing and turns Human Rights inaccurately into an analysis of a relationship instead of considering it as an agreed code to ensure social cohesion. She suggests that there should be a clear understanding “between the analytical nature of the social model and the actions needed for social change inherent in Human Rights” (Hurst 2000). The social model of disability has been of great help for the establishment of HRMD, as it served as the “philosophical basis” of the CRPD (Sabatello and Schulze 2013, 26). Herein a broad definition of disability is given, that does not address differences between persons with physical and/or intellectual disabilities. It seems, that somehow the difference of persons with physical and intellectual disabilities is circumvented. A good example is the preamble of the CRPD, which is referring to the interaction between the individual and society, through which disability arises. The phenomenon is seen as part of human diversity rather than categorizing disability as a defective deviation from anthropologically based humanity (Degener 2009, 275).

The purpose of the present Convention is to promote, protect and ensure the full and equal enjoyment of all Human Rights and fundamental freedoms by all persons with disabilities, and to promote respect for their inherent dignity. 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 (Convention on the Rights of Persons with Disabilities 2006, Article 1).

The depiction of persons with disabilities as having “impairments” (Article 1 of the CRPD 2006) is emphasizing the social model of disability. It thus frames the depiction of intellectual disability as “mental, intellectual impairment” points to the social model’s ‘impairment-distinction’ that we have encountered often in this thesis.

I will turn to some comments about the drafting process of the CRPD to expand upon the question, how intellectual disability was framed within the process of setting up this convention. The organization *Inclusion International*, as noted above, represents an important voice for the rights of persons with intellectual disabilities in the HRMD approach. During the drafting and/or negotiation process of the CRPD it has represented the ‘stance of intellectual disability’ by its council members, families, self-advocates, and experts from its member organizations. *Inclusion International* was present at all major CRPD events from the *Working Group* meeting through all the sessions and the signing ceremony (Sabatello and Schulze 2013, 26). One comment, that is oft-cited when referring to persons with intellectual disabilities is the following:

This Convention can’t just be about those of us here today. It has to be meaningful for the people who aren’t in the room; to my friends who aren’t always seen or heard by others because they don’t communicate in the same way as us here. It has to protect their rights and speak about their lives as well (MacQuarrie and Laurin-Bowie 2014, 25).

This comment by Robert Martin, a member of the Council of Inclusion International and a self-advocate from New Zealand is cited by MacQuarrie and Larin-Bowie (2014, 25), who further stress the general interest of persons with intellectual disabilities within the draft of the CRPD were to “have state parties and other groups recognize that the Convention includes and must protect the rights of people who cannot always speak for themselves.” The subsequent election of Robert Martin, who is a former *Inclusion International* Council member, to sit on the UN Committee to monitor the CRPD can be seen as an expression that these demands were partially met. He is the first person with an intellectual disability to sit on a UN Committee (Inclusion International 2016). This shows the tendency, that there is a willingness to include persons with intellectual disabilities within the process of further implementation of the CRPD. But as a clear reference of persons with intellectual disabilities within CRPD has not become apparent in this examination further research activity is needed. Furthermore, a general criticism of the “moral language of rights” concerning persons with intellectual disabilities has to be also considered. Heinz Reinders (1999) points to some of the limitations of the rights discourse concerning intellectual disability in general. He argues that:

The moral language of rights is neither sufficient nor necessary to ground moral responsibility for disabled people. His essential argument is that the contemporary rights discourse is deficient in accounting for the moral features of caring practices—practices that are committed to the wellbeing of people who are dependent on the support of others. Without people who have sufficient moral character to care, rights can do little to sustain the mentally disabled and their families. People can be forced to comply, but they cannot be forced to care (Reinders, as cited in Parmenter 2001, 286).

It remains to be seen whether the HRMD is a 'tool' or an instrument (inspired by Vic Finkelstein's understanding of the social model of disability) that is capable of aiming at such goals, as Niels Erik Bank-Mikkelsen has formulated it in one of the first pleas of the normalization principle:

We hope that the philosophy will become strong enough to eliminate distinctions between the normal, the mentally retarded and other deviants (Bank-Mikkelsen, as cited in Nirje 1985).

7. Conclusion

The actions and demands of ‘the’ DRM have shaped the lives of many persons with disabilities in the course of the 20th century and brought about many political changes. These changes were incited and accompanied by the question of rights for persons with disabilities in their respective societies. In this thesis, I have set out to trace the roots of the DRM by examining the time frame, which constitutes the period of the beginning of these changes for some persons with disabilities: the time frame of the emerging DRM (1960–1981).

Before the DRM first demanded equal rights, most disabled people were not seen as part of the ‘public body’, but as people with separate and special needs. This thesis has depicted the ‘voice’ of persons with disabilities, that set out to change this condition. By including secondary literature, which comments upon the DRM and literature which was crafted by DPOs I have collated records of this social change brought about by persons with disabilities. The social change, that the DRM became known for later was furthered by DPOs, that were often organizing and analyzing the situation ‘they’ were exposed to in their respective societies. In depicting the documents and manifests produced by these organizations, I have analyzed the stage, that set the ‘birth’ of the DRM. This prologue of the DRM shows (in parts, as we only examined a limited scope) the fragmentation of this ‘new social movement’, that has united upon shared tenets with national (UK and US) differences.

This was on the one hand side referenced by highlighting organizations that were part of the British Disability movement (Disability Income Group Disability Alliance, Union of the Physically Impaired Against Segregation) relied on the tenet of Social oppression. The other main focus of this thesis was the depiction of the U.S. specific case of a disability movement, that has involved Independent Living, which has starkly relied on features of a minority group rights approach. In this regard, the examination of the case of the People First movement held much insight. This movement constitutes the only movement, that has included people with intellectual disabilities from the very beginning within their self-conception.

Subsuming the stances of these organizations I have identified the alignments of these DPOs. The variety of the stances of the main DPOs has made it necessary to distinguish the different movements by identifying different tenets, that the demands rested upon. In the observations encountered in this analysis, I have further asked whether the emerging DRM was capable of creating a singular voice for the needs and demands of disabled persons. This question

represents one basis of this examination. In asking who is the ‘us’ in the famous slogan of the DRM “Nothing about us without us” I have analyzed the most prominent cases of DPOs in regards of their alignment (Charlton 1998, 3). This thesis has complicated this catchy slogan of the DRM but did not to criticize the slogan *per se*. The rationale of this thesis was highlighting the potential of an inclusive social model of disability, nurtured by such insights. The analysis of the major organizations involved within the emerging DRM has shown manifold approaches towards the ‘issue of disability’. Because the tenets of these DPOs varied so widely, the depictions of disability were manifold.

The reasons for this have were shown this thesis: the different DPOs concentrated on different impairments groups and therefore developed different approaches towards their alignments of understanding disability. This led to a stark contrast between intellectual and physical disability. By analyzing the commonality and variety within the heterogeneous composition of the DRM in its emerging phase, I have examined the differences in the alignments of the DPOs that were part of the emerging DRM. This difference is constituted along the lines of a movement which has taken up issues of persons with *physical* and of persons with *intellectual* disability and justifies the claim that the emerging DRM itself has been divided upon these questions from the very beginning of the movement. As a contribution to disability studies approaches in the humanities, this work has raised the issue of a divide between intellectual and physical disability in the time frame of the emerging DRM.

I have continued the examination by placing the question of intellectual disability amidst the DRM. The role of the social model of disability was of key-interest for this undertaking, as the mobilization of the “politics of disability” (Mike Oliver 1984) was broadly based on this model. It conveyed a clear message, which was to differentiate between ‘impairment’ and disability. As has become clear in the research for this thesis, such an understanding of disability bears the potential to be communicated on a broad and well understandable argumentation.

However, there has been growing criticism which considers the social model of disability as incapable to reflect the social component of impairment (Goodley 2000). This thesis supports this criticism regarding intellectual disability in the light of the emerging DRM. The inclusive social model of disability stands for a concept that combines arrays of criticisms of the social model of disability and thus takes into consideration the social component of disability. The tenet of self-advocacy represents this approach best. Nevertheless, this thesis has shown that

the depiction of intellectual disability within the emerging DRM needs further analysis. The social model of disability was used in the negotiation process of the CRPD, as a “populist conceptualization” which bears a tendency towards “a radical social constructionist view of disability, rather than from its contemporary expression as a critical theory of disability.” (Degener 2014, 29). Taking up these discussions, the question of how to include persons with intellectual disabilities in such rights-based frameworks remains an important issue for the DRM in the present days. It is this relation describing the ‘Disability-rights-model’ and intellectual disability that has nurtured the analysis of this thesis.

This thesis intends to inspire further research in the context of intellectual disability and aims at sparking questions, such as: Is it desirable for persons with intellectual disabilities to establish a starker contrast between persons with intellectual and physical disabilities in rights-based discourses?

Taking into account manifold forms of how movements might have centered around political issues regarding their rights must be the imperative of such investigations and thus leave enough room to examine ‘other forms of resistance’ that might not be centered around rights of persons with disabilities. By placing the inclusive social model of disability in exactly such contexts, the question of a “commonality of disability” (Finkelstein 1993) can be reformulated to ask whether political activism for persons with physical and/or intellectual disabilities can possibly rest on common shoulders.

Where are the ‘common lines’ of the movements situated today? For future research, it would be of great use to include other geographical areas than the well documented cases of the movements situated within the UK and the US. This may put the concept of ‘care’ in a non-legal conceptualization in a different light and might also include the important challenge of “transnationalizing” such discussions. Such research would include approaches such as expressed by Shaun Grech and Karen Soldatic when criticizing Disability Studies research as reenacting certain forms of oppression by only depicting the stances of the “majority world” (Grech 2009).

This thesis does not question the importance or appropriateness of the social model of disability. However, it has been shown that the social model of disability has served a particular group within the emerging DRM best: persons with physical disabilities. Taking such an insight into

a productive account, the creation of synergies between persons with physical and intellectual disabilities stands on common grounds in researching disability as a “human condition” (Zola 2005, 21). The research of such a condition holds a promise, as Irving Zola reaffirms: “In short, what is done in the name of disability today will have meaning for all of society’s tomorrows” (ibid. 21).

8. Bibliography

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10. Figures

Figure 1.

Figure reprinted from M. Samaha, Adam M. 2007. “What Good Is the Social Model of Disability?” SSRN Scholarly Paper (Rochester, NY: Social Science Research Network.): 74.

Figure 2.

Figure reprinted from World Health Organization. 2001. “The International Classification of Function, Disability and Health (ICF).” Geneva, Switzerland: 18.

Figure 3.

Figure reprinted from M. Samaha, Adam M. 2007. “What Good Is the Social Model of Disability?” SSRN Scholarly Paper (Rochester, NY: Social Science Research Network.): 9.

Figure 4.

Figure reprinted from Magdolna, BIRTHA. 2014. “Making the New Space Created in the UN CRPD Real: Ensuring the Voice and Meaningful Participation of the Disability Movement in Policy-Making and National Monitoring.” PhD Thesis, School of Law, NUI Galway (Ireland): 54.

Abstract (English):

By using critical discourse analysis, this thesis analyses the Disability Rights Movement (DRM) in the period of 1960-1981. This time frame was chosen, as it constitutes the emerging phase of this 'new social movement, in which Disabled Peoples Organizations (DPOs) had a leading role in the developments surrounding the emerging DRM.

I have analyzed the central DPOs within the United Kingdom, the United States and an actor in the 'international sphere' concerning their conception of disability. The alignments of these DPOs are subsumed in identifying tenets of the most important organizations/movements of the emerging DRM. The analysis of the alignments of these organizations based on identifying specific tenets forms the basis of this thesis. The fact that the alignments of these actors of the emerging DRM were constituted along two lines is the central finding of this thesis. These lines were situated among organizations of persons with physical disabilities and of persons with intellectual disabilities.

This insight is taken as an incentive to discuss the role of intellectual disability in the wider DRM. In highlighting the role of the social model of disability, the most important conceptual tool of the DRM will be utilized to evaluate whether the possibilities of treating intellectual disability in an inclusive social model of disability are given.

The thesis concludes with a reference of the status quo of 'disability rights politics' concerning intellectual disability by examining the Convention on the Rights of Persons with Disabilities, which has been adopted by the United Nations in 2006.

Abstract (German):

In dieser Master-Arbeit werden die politischen Anfänge der Behinderten-Rechts-Bewegung in den Jahren 1960-1981 thematisiert. Dieser Zeitrahmen wurde gewählt, da er die aufkommende Phase dieser „neuen sozialen Bewegung“ darstellt. Von großer Wichtigkeit für die Entstehungsgeschichte der Behinderten-Rechts-Bewegung waren sogenannte Organisationen für Menschen mit Behinderung. Zentrale Sprachrohre dieser Bewegung habe ich in Großbritannien, den Vereinigten Staaten von Amerika und in der Sphäre ‚internationaler Zusammenarbeit‘ ausgemacht.

Meine Analyse thematisiert das grundsätzliche Verständnis von Behinderung dieser Organisationen und macht eines ersichtlich: dass das Verständnis (die Definition) von körperlichen und intellektuellen Beeinträchtigungen schon zu Beginn der Behinderten-Rechts-Bewegung nicht als einheitlich konzipiert zu verstehen sind. Folglich identifiziere ich zwei Richtungen der Behindertenrechtsbewegung. Eine, die sich vermehrt für Rechte von Menschen mit intellektueller Beeinträchtigung einsetzt und eine andere, die sich für die Rechte von körperlich beeinträchtigten Menschen einsetzt. Dieses Erkenntnis wird im Laufe der weitergehenden Arbeit verwendet, um die Rolle von ‘intellektueller Beeinträchtigung’ innerhalb der Behindertenrechtsbewegung zu diskutieren.

Von Relevanz ist dies vor allem im Hinblick auf die Rolle, die das soziale Modells von Behinderung als das wichtigste ‚konzeptionelle Instrument‘ der Behinderten-Rechts-Bewegung gespielt hat. Im Rahmen dieser Arbeit wird die Frage aufgeworfen, inwiefern intellektuelle Behinderungen in einem sozialen Modell von Behinderung mitgedacht werden können. Von diesem Diskussionspunkt ausgehend wird zum Ende der Arbeit hin auch ein inklusives soziales Modell von Behinderung miteinbezogen, welches einer weitergehenden Analyse des *Status quo* dienen soll. Sie bezieht unter anderem sich auf die Behindertenrechtskonvention (BRK), die 2006 von den Vereinten Nationen (VN) adaptiert wurde. Hierin wird untersucht, inwiefern das Thema intellektuelle Beeinträchtigung aufgegriffen, bearbeitet und mitberücksichtigt wurde.