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## **De-pathologizing Disability: Politics, Culture and Identity**

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# De-pathologizing Disability: Politics, Culture and Identity

Disability is a rather new field of research for the humanities. It raises important questions in relation to the term itself but also to its usage in political and cultural contexts. This review essay sheds light on various branches of research in social sciences and history. It focusses on the history of state and disability as well as the lack of research on representation and self-representation of disability and disabled people. In doing so, the article pleads for a wider approach to ethical questions surrounding disability.

The emergence of the field disability studies and its contemporary status in academia

Approximately 10%–20% of the world's population is estimated to be disabled and this number is expected to rise in the decades to come – fuelled by population aging, environmental degradation and social violence.<sup>1</sup> A more precise estimate would prove difficult because the definition of disability remains elusive as it constantly changes over time and space. Moreover, it is a particularly unstable category: as the saying goes: everyone is just one accident away from disability. Some people are born with it, while others acquire the condition during their life course. It may be permanent or temporary. It can manifest as a physical or cognitive condition, arising from a range of factors – genetics, accident, external circumstances, or advancing age. Some people who appear to have disabilities may argue that in fact they do not. It is for these reasons that a comprehensive definition of disability has proven particularly challenging.<sup>2</sup>

The condition affects not only the individuals concerned, but has consequences for their families and their environment and for the states in which they live; it is a human and social issue that affects us all. It requires intervention by welfare states and it has implications for human rights. As such, it has become a concern of global governance and an issue of policy- and lawmaking for international organizations. Moreover, in the last few decades, a social movement revolving around disability has emerged in several countries, which targeted attitudinal, environmental and institutional barriers and fought for a greater degree of autonomy and independence for disabled people. The movement has also demonstrated that disability can manifest itself as social and cultural identity which can be a source of pride and of a vibrant subculture. People in different cultural settings give different meanings to disability; its repercussions are both culturally contingent and universal. Thus, its study requires analysis on different scales.

Before the emergence of the new interdisciplinary field of *disability studies* in the 1980s, approaches to the subject had been dominated either by a medical view, which associated the situation with an individual pathology, or by a traditional sociological approach according to which it was a form of deviance. In both cases it was considered an undesired and undesirable individual condition in the need of remedy. Apart from its medical aspect, the study of this topic was usually excluded from academic research and that neglect – implicitly or

- 1 The author acknowledges the support of the ERC Grant *Rethinking Disability*, Contract Nr. 648115 for writing this article.
- 2 Jaeger, Paul T./Bowman, Cynthia Ann: *Understanding Disability. Inclusion, Access, Diversity and Civil Rights*, Praeger, Westport, CT 2005, p. 6.

explicitly – contributed to the reinforcement of the social inclusion of disabled people. This started to gradually change from the 1970s onwards, partly as the consequence of growing political activism on the part of disabled citizens. As a result, the concept became reconfigured from a medical into a socio-political category. This had the consequence that the earlier, *medical model* of disability, which focused on the dysfunctional, individual body, was replaced by *the social model* which viewed disability as a social construct and saw the cause of impairment not in the individual body but in discriminating social attitude.<sup>3</sup>

This development contributed to the challenging of an old perception which had until then relegated the study of disability to the unglamorous backwaters of scholarship which was expected to be of interest primarily to people in rehabilitation, special education, and other applied professional fields.<sup>4</sup> The increasing self-advocacy resulted in new policy measures and new legislation. Political engagement and academic research had mutually reinforced one another – as it had happened in the case of other previously excluded groups such as women, racial and ethnic minorities, gay and lesbian people – and this led to the challenging and transforming of the outmoded interpretative paradigms rooted in paternalism and prejudice.<sup>5</sup> The epistemological and ontological status of numerous taken-for granted categories also became questioned. Altogether, it has become evident that the field has potentials to contribute to fundamental discussions in the humanities, for example about what we understand under the notions of normality, difference and variety; how we define health and illness across time and space, and what constitutes dependence, independence and interdependence.<sup>6</sup>

An early account which demonstrated the broader significance of the subject was a seminal book by French philosopher Henri-Jacques Stiker published in 1983, which started to receive more widespread publicity when its English translation, “A History of Disability”, appeared fifteen years later.<sup>7</sup> Inspired by Michel Foucault’s ideas, Stiker provided an account spanning chronologically from biblical times to the present. In doing so he demonstrated how the construction of the notion of disability had been tied to the moral principles of Western cultures. One of the great values of Stiker’s approach was that it did neither provide a reassuring progressive trajectory nor did he approach narratives about disability along the positive-negative binary divides. Instead, he demonstrated how the exclusion of people with disabilities from society had been characterized by the desire for sameness and the rejection of difference, something in which he detected totalitarian tendencies.<sup>8</sup> All in all, Stiker called attention to the unexpected or undesired consequences which the socially desired processes of assimilation, inclusion and integration might bring about.

Stiker’s contribution was exceptional in the sense that it came from continental Europe, because it was in the Anglo-Saxon academic world that the field of disability studies first

3 For a reflection on the meaning and impact of the social model see Oliver, Mike: The Social Model of Disability Thirty Years On, in: *Disability and Society* 28 (2013), I. 7, pp. 1.024–1.026.

4 Kudlick, Catherine J.: Disability History. Why We Need Another “Other”, in: *The American Historical Review* 108 (2003), I. 3, pp. 763–793, here p. 765.

5 Poore, Carol: *Disability History in Twentieth-Century German Culture*, Michigan UP, Ann Arbor, MI 2007, p. XVI.

6 Addlakha, Renu (ed.): *Disability Studies in India. Global Discourses, Local Realities*, Routledge, London/New York 2013, p. 2.

7 Mitchell, David T.: Foreword, in: Stiker, Henri-Jacques: *A History of Disability*, Michigan UP, Ann Arbor, MI 1999, p. VII.

8 Stiker: *History* (see footnote 7), p. 13.

started to make its mark. This was particularly the case in the United States where vibrant disability activism in the period, culminated in the groundbreaking “Americans with Disabilities Act” (ADA) legislation in 1990. Disabled citizens came to position themselves as a minority group and formulated their demands not only in terms of welfare support, but also in terms of civil rights. Additionally, they pioneered the concept of *independent living*.<sup>9</sup> In the rest of the world, the field evolved at a much slower pace and in many academic environments it still occupies a marginal position. An important landmark in placing disability onto the agenda of mainstream historical scholarship was the publication of Catherine J. Kudlick’s article “Disability History. Why We Need Another ‘Other’” in “The American Historical Review” in 2003.<sup>10</sup> The fact that one of the world’s most prestigious and *the* most widely read historical journal showed interest in the subject was an indication that more and more people had started to take the subject seriously. Kudlick’s title made direct reference to a seminal article by Joan Scott: ‘Gender. A Useful Category of Analysis’ which had been published seventeen years earlier in “The American Historical Review”.<sup>11</sup> In that context, Kudlick’s article convincingly demonstrated that the concept, if understood not as an undesired apolitical and asocial bodily condition, but as a key defining social category, had scholarly potentials comparable to the much more widely employed notions of class, race, gender and sexuality. Intersectional research, revealing the intricate relationships and overlaps between those categories has remained an important desideratum in the field until the present day. To that end, an early seminal volume by Paul K. Longmore and Lauri Umansky, “The New Disability History. American Perspectives” pointed to the intersections between disability and working class consciousness by reminding their readers that occupational injury and illness occurred particularly frequently with workers. They also emphasized another intersection by showing that since colonial times American immigration law increasingly excluded aliens with all sorts of disabilities.<sup>12</sup>

In addition to the pioneering work undertaken by American scholars, their British colleagues can be credited with generating the shift from the medical to the social understanding of disability which refocused attitudes away from the body and onto social attitudes. Under the influence of Marxist ideas, they identified the social barriers that prevented disabled people from participating fully in the community and demanded an end to this oppression.<sup>13</sup> The pivotal nature of Anglo-Saxon scholarship in shaping the agendas of the new field has been fully recognized. Yet, there also exists consensus that it provides an inadequate framework when trying to capture experiences in other parts of Europe, let alone in a global context. For example, British scholarship, flavoured with neo-Marxist tendencies, criticized capitalist relations for subjugating disabled people and excluding them from society. However, disabled people’s experiences in Eastern Europe under state socialism revealed that non-capitalist forms of economic organizations could be equally harsh and repressive towards bodily and mental difference. It also needs to be taken into account that in authoritarian regimes

9 See Crewe, Nancy M./Zola, Irving Kenneth: *Independent Living for Physically Disabled People*, Jossey-Bass, San Francisco, CA 1983.

10 Kudlick: *Disability History* (see footnote 4).

11 Scott, Joan Wallach: *Gender. A Useful Category of Analysis*, in: *The American Historical Review* 91 (1986), I. 5, pp. 1.053–1.075.

12 Longmore, Paul K./Umansky Lauri (eds.): *The New Disability History, American Perspectives*, NYU, New York 2001, pp. 2–3.

13 Campbell, Jane/Oliver, Mike: *Disability Politics. Understanding our Past, Changing our Future*, Routledge, London/New York 1996, p. 240.

alternative viewpoints were silenced and independent organizations were not permitted.<sup>14</sup> Furthermore, the Anglo-Saxon framework, in which non-governmental organisations play a significant role in the welfare provision, has limited applicability for Nordic countries where the state provided exemplary services for disabled people and the role of charities was much more restricted.<sup>15</sup> Its applicability to Southern Europe, where traditionally the families were expected to look after their disabled members, is likewise questionable. Lastly, the need to find an adequate framework for capturing the global implications of disability pose enormous challenges and some of these will be discussed in a separate section below.

As these accounts reveal, in the last three decades an increasing number of scholars have risen to the challenge and proved that far from being a 'grim' subject only relevant for a very restricted audience, disability studies can offer a new prism through which to analyze and shed new light on several societal problems. Moreover, as an outstanding representative of the field, Simi Linton has argued, it has the capacity to question false dichotomies by introducing contradiction into polarized categories such as 'weak' and 'strong', 'normal' and 'abnormal', 'dependent' and 'independent'. It also contests splits between the binary opposites of public and private, personal and political, mind and body, biological and social. As Linton put it: "Disability studies demonstrates how such compartmentalization often serves some groups better than others but ultimately serves no one well"<sup>16</sup>.

Moreover, she also convincingly tackled the challenge of proposing a convincing definition of the field of disability studies:

"Disability studies takes for its subject matter not simply the variations that exist in human behaviour, appearance and functioning, sensory acuity, and cognitive processing but, more crucially, the meaning we make of those variations. The field explores the critical divisions our society makes in creating the normal versus the pathological, the insider versus the outsider, or the competent citizen versus the ward of the state. It is an interdisciplinary field based on a sociopolitical analysis of disability and informed both by the knowledge base and methodologies used in the traditional liberal arts, and by conceptualizations and approaches developed in areas of new scholarship. Disability studies has emerged as a logical base for examination of the constructions and function of 'disability'. These scholarly explorations and initiatives undertaken by the disability rights movement have resulted in new paradigms used to understand disability as a social, political and cultural phenomenon"<sup>17</sup>.

## Disability and the welfare state

Undertaking research into the welfare state through the lens of disability demonstrates that the concept is paramount for our understanding of how cultures treat their vulnerable members, how they maintain social order and how they define progress. People with disabilities belong to some of the most exposed citizens in any state, and at times of financial crisis they typically become even more exposed to the deteriorating conditions than their able-bodied counterparts. Because working capacity and the ability to pay taxes is central to the concept

14 See McCagg, William O./Siegelbaum, Lewis H. (eds.): *The Disabled in the Soviet Union. Past and Present, Theory and Practice*, Pittsburgh UP, Pittsburgh, PA 1989; and Rasell, Michael/Smirnova, Elena (eds.): *Disability in Eastern Europe and the Former Soviet Union. History, Policy and Everyday Life*, Routledge, London/New York 2013.

15 Tøssebro, Jan: Introduction to the Special Issue: Understanding Disability, in: *Scandinavian Journal of Disability Research* 6 (2004), I. 1, Special Issue: Understanding Disability, pp. 3–7; Goodley, Dan, *Disability Studies. An Interdisciplinary Introduction*, Sage, Los Angeles, CA/London, 2011.

16 Linton, Simi: *Claiming Disability. Knowledge and Identity*, NYU, New York 1998, pp. 185–186.

17 Ibid., p. 2.

of the welfare state, the needs of disabled people who are not in the position to work – either because of their condition or because of the lack of opportunities for rehabilitation to enable them to join the workforce – have often remained ignored in the welfare provision. Recent scholarship has focused on the peculiarities in the evolvement of disability policies in different types of welfare states. In the case of Britain, such new work could build on an earlier account by Anne Borsay, “Disability and Social Policy Since 1750”.<sup>18</sup> In her book she pointed out that the so-called Beveridge Plan, the scheme that laid down the foundations of the welfare state in postwar Britain, operated with an ideal concept of social citizenship which stigmatized disabled people who were marginal to the workforce and it provided insufficient provisions for them.

Adopting a more focused perspective, Jameel Hampton’s recent “Disability and the Welfare State in Britain. Changes in Perception and Policy 1948–1979”<sup>19</sup>, scrutinizes the evolvement of disability policy over three decades in the United Kingdom. He pays particular attention to so-called non-statutory agencies such as the Trade Union Congress (TUC) and Disablement Income Group (DIG). He detects some improvement in status, particularly as traditionally marginalized groups were no longer considered ‘moral failures’ and the old distinction between the ‘deserving poor’ and ‘undeserving poor’ were being questioned. His analysis reveals that in the 1970s, partly as a result of disabled people’s campaigns, new reforms were introduced. However, his overall verdict is that the state’s expectation to provide universal welfare, as testified by the services of the National Health Service, was not met in the case of disabled people. In the longer run, instead of enjoying the much desired ‘cradle to grave’ welfare provision, they experienced pauperization and social marginalization and ever increasing inequality between their status and that of their able-bodied counterparts. As one of the chapters in the book tellingly reveals: disabled people were the ‘Cinderella’ of the welfare state in the sense that they belonged its most neglected citizens.<sup>20</sup> Moreover, when pointing to future developments, the author notes that the situation further deteriorated due to an ongoing economic crisis from the mid-1970s onwards as well as the actions of the government of Margaret Thatcher. The neoliberal state was now openly committed to inequality through its rejection of the collectivist consensus of the welfare state. The marginalization and impoverishment of those groups who were not able to compete in the ‘free market’ was in this sense considered an achievement and not a failure.

An interesting contrast to British developments is provided by Paul van Trig in his book “Blinden in een gidsland” (“Blind People in a Model Country”) which covers the period between 1920–1990 and as such has the merit of *longue durée* analysis transcending the pre-war/post-war division.<sup>21</sup> The book’s specific focus lies on the situation of blind people in the Dutch welfare state, and its case study revolves around a blind welfare institution, the Institute Bartiméus Sonneheerdt. The author uses this case study as a point of departure for asking broader questions about welfare. One of them relates to the relationship between the church and the state, both of which were involved in the welfare provision. In this context, a

18 Borsay, Anne: *Disability and Social Policy Since 1750*, Palgrave Macmillan, Basingstoke/New York 2005.

19 Hampton, Jameel: *Disability and the Welfare State in Britain. Changes in Perception and Policy 1948–1979*, Policy, Bristol 2016.

20 See Chapter Five „Cinderella of the Welfare State. Legislation for Disabled People 1970–1972, in: *ibid.*, pp. 133–180.

21 Van Trig, Paul: *Blinden in een gidsland, Over de bejegening van mensen met een visuele beperking in de Nederlandse verzorgingsmaatschappij, 1920–1990*, Hilversum, Verloren 2013.



Dutch particularity receives treatment in the book: the system of pillarization, the denominational segregation of social institutions.

Van Trigt asks why the social movements – for example the women's and the gay liberation movement – gained strong impetus in the Netherlands from the 1960s onwards, earning the country the 'progressive' label and why this kind of emancipatory process could not be observed in the case of disabled citizens. Of the various reasons the author provides one is that the Netherlands was a non-combatant country in World War I and therefore it did not have to face the need of integration of disabled veterans into the workplace. Another reason may be that the living conditions and satisfaction levels of disabled people in post-World War II Netherlands were better than in the Anglo-Saxon and many other countries. In that context, van Trigt makes a particularly useful point about the role of the state which is often considered an 'oppressive' power and its services are viewed in terms of paternalism. However, why should it necessarily be a problem if a welfare state provides citizens with extensive services?<sup>22</sup>

The volume edited by Gabriele Lingelbach and Anne Waldschmidt, "Kontinuitäten, Zäsuren, Brüche? Lebenslagen von Menschen mit Behinderungen in der deutschen Zeitgeschichte" has launched the series of Campus's Disability History, and is as such an indication of the gradual institutionalization of the field in Germany.<sup>23</sup> One of the numerous innovative features of this volume is that in addition to providing specific case studies, it also takes an interest in conceptual problems. To that end, it asks the question if the continuities, turning points and ruptures of 'disability' history in West Germany followed the trajectory of mainstream history, or rather, if they were manifestations of different temporalities. While the milestones in postwar German history are typically defined as the end of the war in 1945, the emergence of the student movements in 1968 and the fall of the Wall in 1989, in the case of disability such templates may not be the most convincing. Yet, there exists no general consensus about whether a 'breakthrough' took place in the long 1960s, when the self-organization and advocacy of people with disabilities started to gain ground, or in the early 1980s, when the UN International Year of Disabled Persons in 1981 provided a strong impetus. Or, alternatively, did a major shift happen only as late as in 2006 when the UN Convention on the Rights of Persons with Disabilities (CRPD) was adopted? It is certain, however, that from 1979, under chancellor Willy Brandt, the societal participation of disabled people became a political goal for the first time. Nevertheless, calls for rehabilitation were not motivated by the intention to contribute to societal integration, but merely by the incentive to integrate disabled people into the workforce.<sup>24</sup>

Of the ten articles that follow the comprehensive introductory chapter, the contribution by Anne Helen Günther focuses on the repercussions of the Contergan-case for the representation of disabled children in the media and for the political role of the media in the 1960s.<sup>25</sup> The widespread use of Contergan, a medicine containing thalidomide and offered for expecting women to combat nausea, led to the birth of thousands of children with serious disabilities. The author shows how the media, by constructing the notion of the 'Contergan child', brought for the first time the images of disabled children to the centre of the public's

22 Ibid., p. 19.

23 Lingelbach, Gabriele/Waldschmidt, Anne (eds.): *Kontinuitäten, Zäsuren, Brüche? Lebenslagen von Menschen mit Behinderungen in der deutschen Zeitgeschichte*, Campus, Frankfurt a. M./New York 2016.

24 See Lingelbach, Gabriele/Waldschmidt, Anne: *Einleitung. Kontinuitäten, Zäsuren, Brüche in der deutschen Disability History nach 1945*, in: *ibid.*, pp. 7–27.

25 Günther, Anne Helen: *Der Contergan-Fall als Zäsur in den 1960er Jahren? Eine mediengeschichtliche Analyse*, in: *ibid.*, pp. 142–165.

view. At the same time, she also notes that the increased attention on this specific group resulted in even less attention paid to groups with other types of disabilities. The article's central argument revolves around the transformation in the contribution of the press as a result of the scandal: while earlier on it saw itself as merely a provider of information, in the Contergan-case the press became an active agent by bringing to the light issues suppressed by the government and by embarking, if necessary, on political confrontation.

The relatively generous nature of European welfare states becomes evident when contrasted to the much more limited provision in United States. Here, many of the needs of disabled citizens are expected to be met in alternative ways. "Telethons. Spectacle, Disability, and the Business of Charity" by the late Paul K. Longmore (edited by Catherine J. Kudlick) addresses the history of fundraising and charitable giving.<sup>26</sup> The first telethon (a word coined by fusing 'television' and 'marathon') took place in the US in the 1950s, as a fundraising means for disability-related charities. Initially lasting for only a few hours, the shows gradually became longer and longer, sometimes stretching to nearly two days. As such they exerted a profound influence on Americans' vision of generosity, corporations, healthcare, and disability. The book acknowledges the improvement which the raised funds provided for thousands of citizens. It also points to the 'usefulness' of drawing the hitherto 'hidden' disabled people into the focus of publicity, all the more so, because it also allowed for the emergence of a bond between them: for the first time, they discovered that they were not alone.<sup>27</sup> At the same time the book argues that the collateral damage might have been greater than the benefits. In order to be successful at a fiercely competitive fundraising market, the image of disabled people as pathetic and pitiable had to be perpetuated. Two prototypical templates of disability emerged, one of them was the 'heroic overcomer' whose main virtue was in fact not being really disabled. The other was the 'tragic victim'. Further, the author discusses a paradox: while the emphasis on medical research proved useful for raising funds, it also reinforced an understanding of disability as a condition to be eliminated. The fact that people with disabilities can have happy lives and the condition will always remain an integral part of societies never received consideration.

While the majority of recently published volumes consider disability in European and North American contexts, "Disability in Japan" by Carolyn S. Stevens focuses on policy and lawmaking in the postwar period in a society which has had its markedly distinct historical, societal and cultural traditions.<sup>28</sup> Stevens is particularly interested in the tension between individual responsibility and state intervention, especially as it relates to caregiving, a crucial concern in light of Japan's ever increasing elderly population. Adopting an anthropological approach, she points to disabled people's exposure to societal and economic oppression, while she emphasizes that the needs of the individual at the micro-level also require attention. Some of the author's conclusions, at least to a certain extent, also apply to 'Western' contexts, for example the 'prolonged childhood', which many people with disabilities are being forced into. The degree of infantilization increases in proportion with the severity of disability. Stevens also engages with the paradox inherent in the neoliberal rhetoric of normalization: the emphasis on 'empowerment' by giving individuals the responsibility for making their own choices can at best be an empty phrase and at worst a harmful agenda if

26 Longmore, Paul K.: *Telethons. Spectacle, Disability, and the Business of Charity*, Oxford UP, Oxford 2016.

27 *Ibid.*, p. 12.

28 Stevens, Carolyn S.: *Disability in Japan*, Routledge, London/New York 2013.



the necessary support for exercising such agency is not provided.<sup>29</sup> In that context, Stevens notes that in Japan independence of disabled people through marriage and employment is discouraged. She also warns that care for the body is a for-profit business that both benefits and exploits people with high care needs: “dependence is reality and independence is grandiose thinking”<sup>30</sup>. Last but not least, she considers the consequences of the rise of the nuclear family in Japan in light of the traditional view of Japanese society as representing an unchanging ‘tradition’ through generations.

## Disability as social and cultural identity

In the first half of the twentieth century, in most countries attitudes to disabled people were characterized by the assumption that unless their condition can be fully ‘cured’, their dependence is a ‘given’ factor and cannot (or does not need to be) changed. From this followed that they need looking after. Decisions affecting their lives also needed to be made by others on their behalf. After all, if disability was an individual health deficit, then the authority to speak about the condition belonged exclusively to professionals. From the 1960s onwards, partly as a result of the escalating emancipatory movement, especially in the Anglo-Saxon world, a radically new attitude emerged. Protests, which occasionally attracted thousands of people (including able-bodied ones) took place with the motto ‘nothing about us without us’ and demanded that disabled citizens should be consulted when decisions would be taken about their lives. Protesters sought to facilitate the integration of disabled people into the mainstream of society. The disability movement was interrelated with other social movements, such as women’s movement, gay liberation, the youth- and the environmental movement. Although it never acquired a broad basis, it revealed disabled people’s agency, the ‘power of the powerless’, in new and unexpected ways. As they were routinely associated with dependence and passivity, their ability to bring the traffic to a complete halt in big cities in the course of their protests was a rather surprising sight for many viewers.

In academic life, these developments gained reflection in the intention to shift away from traditional narratives written ‘from above’. These usually focused on the history of social policies, rehabilitation and segregated institutions. Instead, new histories sought to address lived experiences. Instead of rendering disabled people as *objects* of studies, they considered them as *subjects* and self-conscious actors. They sought to find out how the struggles and protests against discrimination led to the emergence of a new collective identity and to societal change through self-empowerment. The recent special volume of the journal “Moving the Social. Journal of Social History and the History of Social Movements” “Disability Movements. National Policies and Translational Perspectives” (53 (2015)) places emphasis on the transnational entanglements of the disability movement in the 20<sup>th</sup> century. As we have seen, the close ties of disability to the traditions, definitions, sanctions and entitlements of national social policies does not make it an ideal subject for transnational research when it comes to researching the welfare state. By contrast, studying the emergence of a new social movement requires the tracing of networks across borders and between likeminded people. It also invites questions about the ways in which know-how and strategies were transferred and adjusted to often highly divergent local circumstances.

29 Ibid., p. 92.

30 Ibid., p. 93.

The volume contains case studies on West Germany, the Netherlands and Hungary and it identifies some parallel tendencies which occurred irrespective of ideological differences during the Cold War on either side of the Iron Curtain. One of such instances is the impact of the United Nation's International Year of Disabled Persons (1981) in the raising of awareness and de-pathologization. Activities during this year were organized at the international, national and regional levels by experts, disabled people, parents of disabled children and by the supportive able-bodied public. Numerous protests called attention to the yawning gap between ideals and everyday realities. The articles in the volume demonstrate that protesters were well aware of what was happening in other countries and drew inspirations from those developments.

The article by Anne Waldschmidt, Anemari Karacic, Andreas Sturm and Timo Dins "Nothing About Us Without US, Disability Rights Activism in European Countries. A Comparative Analysis"<sup>31</sup>, explores disability rights activism as a form of collective political participation. By providing a comparative analysis of national bodies in the German, British, Italian, Irish, Norwegian, Swedish contexts it seeks to add new dimensions to the study of political citizenship of disabled people; a topic which has been overlooked both in welfare research and political science research. This type of organized civil society has been and continues to be vital in promoting and implementing social and political change in European societies. Yet, upon the assessment of self-help groups based on reciprocity most mainstream political scientists consider them either as politically irrelevant forms of collective action that support the fragmentation of societal problems by means of individualization, or as forms of exercising practical critique of patronizing social services. By contrast, the authors of the article show that in the context of disability such groups can raise group consciousness and provide positive experiences of collective action. They also acknowledge the significance of national assemblies representing disability organizations. They conclude that these vary widely from country to country, but are important forms of political participation.

Cultural representations and particularly self-representations of disabled people have yet to receive sufficient attention in scholarship. Nevertheless, the limited literature that exists on the subject testifies the crucial significance of studying disability as part of a larger cultural system which forges bodies into hierarchies and then distributes power and privilege according to arbitrary distinctions. A groundbreaking study in this subject from two decades ago, "Extraordinary Bodies. Figuring Physical Disability in American Culture and Literature" (1996) by Rosemary Garland Thomson, argued that "the physically extraordinary figure [...] is as essential to the American project of self-making as the varied throng of gendered, racial, ethnic and sexual figures of otherness that support the privileged norm"<sup>32</sup> and that disability is a product of cultural rules about what bodies should be or do. One of the pioneering aspects of Garland Thomson's work has been the integration of disability within the remit of feminism in such a way which not only deepened or broadened, but also challenged fundamental norms of feminist theory.

31 Waldschmidt, Anne et al.: Nothing About Us Without US, Disability Rights Activism in European Countries. A Comparative Analysis, in: *Moving the Social. Journal of Social History and the History of Social Movements* 53 (2015), Special Issue: Disability Movements. National Policies and Translational Perspectives, pp. 103–137.

32 Garland Thomson, Rosemary: *Extraordinary Bodies. Figuring Physical Disability in American Culture and Literature*, Columbia UP, New York 2016 (anniversary edition, orig. 1996), p. 6.

More recently, Carol Poore's book "Disability History in Twentieth-Century German Culture" convincingly demonstrated the centrality of disability to modern German culture through exploring it as a concept, a symbol and a lived experience. As she put it:

"My book can be described as an extended exercise in seeing disability when its broader significance as an important cultural phenomenon has previously been overlooked. First, awareness of disability as an important sociocultural category makes it possible to reinterpret many well-known art and literary works, films and media depictions as texts that are also about disability, although scholars have generally not emphasized this before. Second, I focus on the intense debates that erupted over the proper places for disabled people in the public sphere"<sup>33</sup>.

Poore explores the contradictions inherent in German culture and society. On the one hand, it has offered some exemplary programs for certain groups of disabled citizens. On the other hand, it has a contested history of compulsory sterilisation and eugenic dogma. Covering the period from the Weimar Republic through National Socialism and the post-war (West and East) Germanies, the author traces the marginalization and emancipation of disabled citizens by using sources of history, art, literature, film and her own personal experiences in the 1980s. By venturing into the history of the GDR the author provides useful comparative points by concluding that the conditions of disabled people in East Germany were (even) worse than in the West, mainly because of material reasons.

Through their refusal of standard pathological accounts, disabled citizens created a cultural community which seeks to be based on respect and affirmation. This ambition to overturn traditional hierarchies and distinctions was marked by a phenomenon which could also be observed in other formerly marginalized groups: just as the gay movement turned the word 'queer' and civil rights movement the expression 'black pride' into a celebratory re-appropriation; disabled communities reclaimed the hitherto pejorative word 'cripple' in English and some other languages. Yet, the forging of a distinct cultural identity was not necessarily a universally desired aim. As Vic Finkelstein, one of the most influential and visionary disabled scholar-activists argued:

"There is a great deal of uncertainty amongst disabled whether we do want 'our own culture'. After all, we all have had experiences of resisting being treated as different, as inferior to the rest of society. So why now, when there is much greater awareness of our desire to be fully integrated into society, do we suddenly want to go off to a tangent and start trying to promote our differences, our separate identity? Secondly, at this time, even if we do want to promote our own identity, our own culture, there has been precious little opportunity to develop a cultural life"<sup>34</sup>.

Nevertheless, Finkelstein's view was not shared by all of his colleagues. For example, Rosemary Garland Thomson proposed that:

"Disability studies should become a universalizing discourse. Disability [...] would then be recognized as structuring a wide range of thought, language and perception that might not be explicitly articulated as 'disability'. I am proposing then a universalizing view of disability by showing how a concept of disability informs such national ideologies as American liberal individualism and sentimentalism, as well as African American and lesbian identities"<sup>35</sup>.

Such differences in opinion within scholarship and activism indicate the extreme heterogeneity and the often divergent and even clashing desires and needs of various groups with disabilities. For example, ever since *sign* has been accepted as *language*, many representatives of the deaf community have argued that they were a linguistic minority and not a group with disabilities. Hence, they insist that the universalizing logic of phonocentric society

33 Poore: Disability History (see footnote 5), p. XVIII.

34 Campbell/Oliver: Disability Politics (see footnote 13), pp. 111–112.

35 Garland Thomson: Bodies (see footnote 32), p. 22.

contradicts their needs. This is evident from the evolution of the separate field of Deaf Studies which differentiates itself from the realm of Disability Studies. The clashing interests are also manifest in the matter of education: while generally for people with disabilities inclusion and mainstreaming is a crucial goal; some members of the deaf community endorse these objectives, while others wish themselves supportive and separate schools for deaf children. These are just a few indications of the multifaceted nature of deaf culture which are addressed in a recent, accessible survey by Thomas K. Holcomb's "Introduction to American Deaf Culture"<sup>36</sup>. Being deaf comes with different options: for some, this may include the acceptance of prosthetic devices such as cochlear implants, while others would reject these implants on the grounds that they are impositions of audism – the attribution of superiority to individuals who can hear. The book engages with deaf art and it may come as surprise to an unseasoned reader that this not about a lonely painter setting down the images of his/her immediate environment. Two distinct forms of art presented in the book: resistance art and affirmation art. In addition, deaf theatre and films in ASL also receive attention, as does the provocative question if music forms part of deaf culture or not. By way of conclusion, noting the huge investment into medical attempts trying to cure deafness, the author ponders what future is awaiting the deaf community: is it going to thrive or vanish?<sup>37</sup>

### Disability and human rights

One of the most notable international developments in the recent four decades has been the integration of disability into the framework of human rights, which culminated in the adoption of the United Nations Convention on the Rights of Persons with Disabilities in 2006 (although not every country has ratified it). This was a historic moment, as it officially recognized the rights of what has often been referred to as *the world's largest minority*. Merely two decades earlier, when governments relied either on charity or welfare measures – such as employment quotas – in order to improve the conditions of disabled citizens, such an idea would still have been unthinkable. The new, rights-based approach required an entirely new way of thinking: rather than just ensuring the mere survival of disabled people, it acknowledges that they are entitled to a quality of life. The milestones that paved the way for the convention are documented and interpreted in an earlier, decisive account by Theresia Degener (ed.) "Human Rights and Disabled Persons. Essays and Relevant Legal Instruments"<sup>38</sup>. Although the intended primary readership of this voluminous book is a narrower group of legal experts, it still demands attention because no comparable volume has offered such a systematic collection and analysis of the documents which had been produced with the aim to protect the rights of disabled people to dignity and equality, such as the UN Declaration on the Rights of Mentally Retarded Persons (1971), on the Rights of Disabled Persons (1975), the UN's World Programme of Action (1982) and the UN Standard Rules on the Equalization of Opportunities for Persons with Disabilities (1993), all of which represented steps towards the enforceable Convention of 2006.

36 Holcomb, Thomas K. *Introduction to American Deaf Culture*, Oxford UP, Oxford, 2013.

37 Ibid, p. 304.

38 Degener, Theresia (ed.): *Human Rights and Disabled Persons. Essays and Relevant Rights Instruments*, Springer, Haarlem 1994.

More recently, the volume edited by Edurne García Iriarte, Roy McConkey and Robbie Gilligan, "Disability and Human Rights. Global Perspectives"<sup>39</sup>, has taken a useful thematic approach in its exploration of the global dimension of disability and in its critical review of the progress of the implementation of the United Nations Convention on the Rights of Persons with Disabilities. This publication, which can also serve as a textbook, is particularly useful in familiarizing readers with the components that constitute integral parts of the human-rights based approach. In addition to the better-known aspects of the right to education, work and rehabilitation; they also entail rights to having a family, independent living and access, and enjoying opportunities of recreation. The book dedicates separate chapters to the specific problems arising from poverty, war and social exclusion and also pays attention to the rights of disabled children and to the perspectives of caregivers. It also points to the significance of lobbying and advocacy by reminding the readers that the Convention itself is not the conclusion of a long process, rather, an important milestone in the achievement of full and equal participation through the life course. Summaries organized around key points, conclusions, study points and a list of resources at the end of each chapter make this book an excellent educational tool.

Comparative works on any aspect of disability, and particularly the kind of research which requires proficiency in various languages, are rare. One notable exception is "Rights Enabled. The Disability Revolution from the US, Germany and Japan, to the United Nations" by Katharina C. Heyer<sup>40</sup>, which combines fieldwork with the analysis of socio-legal literature in tracing the transformation toward a global model of disability law and politics. A special virtue of the book is that it avoids the pitfall of a teleological narrative. Instead, it emphasizes that like every paradigm shift, the rapid transplantation of right-based approach to disability following a long tradition of treating it as a welfare issue has brought about with gains and losses.

The author traces the uniquely American origins of this disability rights model which led to the adoption of the ground-breaking Americans with Disabilities Act (ADA) in 1990. It shows how German and Japanese activists imported this model to their own countries in which radically different disability laws and policies had prevailed. In Germany, the individualized rights model collided with labour and welfare traditions which posit the state as the provider of basic social rights. In Japan, where family interdependence is highly valued, the individualizing effect of a rights-based paradigm reduced the importance attributed to community integration. Simultaneous to the discussion of developments at the nation-state level, the book traces the process of rights globalization within the framework of the UN and shows that this requires the harmonization of often divergent definitions of disability. It shows that both in Japan and Germany international norms have become a powerful source of activism as they provided means for 'shaming the state'.<sup>41</sup>

With her study the author contests two typical convictions inherent in American political culture: one which tends to see the country as an entity insulated from global developments and another one which tends to see it as the provider of a global model for legal reform. To that end, she puts forward the proposal that tracing the different reinterpretations of the

39 García Iriarte, Edurne/McConkey, Roy/Gilligan, Robbie (eds.): *Disability and Human Rights. Global Perspectives*, Palgrave Macmillan, Basingstoke/New York 2015.

40 Heyer, Katharina C.: *Rights Enabled. The Disability Revolution from the US, Germany and Japan, to the United Nations*, Michigan UP, Ann Arbor, MI 2015.

41 *Ibid.*, p. 207.



American disability law rights model in foreign countries may help American scholars to detect the limitations of the original.<sup>42</sup> Lastly, the book points to the tension between the civil-rights based approach in which the question of financial costs should ideally not play a role and neoliberal ideology in which the centrality of cost-effectiveness may lead to the violation of rights.

A particularly significant aspect of the right-based approach of disability, one which is becoming even more crucial in light of the world's aging population is the right to access. If disabled citizens are not able to leave their house because of the inaccessible environment, then the human rights discourse has very little meaning. In a broader context, the practical implications of access can be studied in terms of translating the ideals of human rights into practice. Marie-Theres Modes „Raum und Behinderung. Wahrnehmung und Konstruktion aus raumsoziologischer Perspektive“<sup>43</sup> offers a refreshing sociological account on this topic. It utilizes the spatial turn in studying the meanings of disability. Her fieldwork takes place in a hotel which employs people both with and without disabilities. It shows the enrichment which such integrative approach can bring into the analysis of perceptions of the public and private spheres, space, difference and integration. It also reveals that the notion of *interdependence* may often be more serviceable than the notion of independence when studying the relationship between disabled and able bodied worlds.

One of the fundamental rights of disabled citizens, *education* is at the centre of “Inclusive Education Twenty Years After Salamanca”, a volume edited by Florian Kiuppis and Rune Sarromaa Hausstaetter.<sup>44</sup> The book's point of departure is a seminal document which is familiar only to the narrowest circle of experts: the so-called Salamanca Declaration. The declaration was the result of UNESCO's World Conference on Special Education held in Salamanca in 1994, and was subsequently reinforced by normative instruments. It marked the first focused international recognition of the right of each child to achieve his or her full potential from birth onward. It emphasized the importance of inclusive education for children with developmental delays and inclusive education. The essays in the volume reveal that the concept of inclusive education was not devoid of conceptual confusions and its implementation resulted in different practices. One of these is the focus on the inclusion of disabled children in 'schools for all', while a second one extends the approach to other groups with vulnerabilities such as working children, indigenous groups, children affected with AIDS, and those living in rural remote areas and in urban slums. Lastly, a third approach to inclusion, practiced especially in the UK, focuses on the heterogeneity of learners, by taking diversity as a starting point for educational theory and practice. An added value of the volume is that the discussion of legal and educational developments and national particularities of implementation also includes personal accounts, for example by Lenah Saleh, whose work at the UNESCO is unanimously considered one of the most distinguished contributions to inclusive education.<sup>45</sup>

42 Ibid., p. 212.

43 Modes, Marie-Theres: Raum und Behinderung. Wahrnehmung und Konstruktion aus raumsoziologischer Perspektive, transcript, Bielefeld 2016.

44 Kiuppis, Florian/Hausstaetter, Runa Sarromaa (eds.): Inclusive Education Twenty Years After Salamanca, Lang, Frankfurt a. M. 2014.

45 Ibid., p. XIII.



## De-stigmatization or re-medicalization? The emergence of new medical symptoms

As has been demonstrated, disability is an enormously heterogeneous and constantly changing category. This also entails that certain conditions which had been identified as disability subsequently lose that identification. For example, whereas today homosexuality is considered an alternative form of sexual orientation and as a subculture, until 1975 the American Diagnostic and Statistic Manual of Mental Disorders (of which more below) listed it as a form of mental illness. Another telling example of the amorphous status of disability is short-sightedness: because nowadays it is so easy to correct it with glasses or contact lenses, short-sighted people are very unlikely to consider themselves disabled if they have access to those devices. On the other hand, recent decades have seen the emergence or proliferation of a plethora of new conditions, ones which had not necessarily been categorized in medical terms earlier on. These include autism, attention deficit hyperactivity disorder (ADHD) and depression. Moreover, certain conditions, such as dementia have become much more frequent because of the increase of the aging population in many parts of the world. This process of medicalization of numerous conditions is a somewhat paradoxical development in the light of the efforts to de-medicalize disability and to frame it in social, cultural and human rights contexts.

An earlier account by Peter Conrad, "The Medicalization of Society. On the Transformation of Human Conditions into Treatable Disorders" offers a powerful account of the process whereby conditions that had not been considered inherently medical have become pathologized in the last few decades.<sup>46</sup> For example, learning differences have been turned into deficiencies and labeled as ADHD, while divergences in sexual desires or performances are now categorized as sexual disfunctions. Conrad points to the huge role of the pharmaceutical industry in this expansion of medical control and surveillance and reveals that this has resulted in a rather narrow focus on the individual (the consumer at the medical market) at the expense of the social context. This is regrettable because the environmental and social context also constitute a factor in the emergence of these conditions. While Conrad convincingly demonstrates the 'dark' sides of the transformation of many human differences into pathologies, he also notes that some form of medicalization may help reduce stigma.<sup>47</sup>

A more recent book by Hanna Decker, "The Making of DSM-III®. A Diagnostic Manual's Conquest of American Psychiatry" focuses on the paradigm-changing role of the third version of the "American Diagnostic and Statistic Manual of Mental Disorders" which appeared in 1980.<sup>48</sup> Unlike its first two earlier versions (published in 1952 and 1968), which were intended for use in state hospitals and had little impact, DSM-III was aimed at private doctors and contained a radical revision of the earlier two versions. Decker convincingly demonstrates that the manual's publication corresponded with the crisis of American psychiatry and the emergence of the anti-psychiatric movement.<sup>49</sup> Psychoanalysis, the dominant form of American psychiatry, was losing its prestige. For one thing, it seemed to have failed in the case of serious mental illness. For another, the emerging drug remedies proved to be more attractive, as they promised faster and cheaper results. It was also at this time

46 Conrad, Peter: *The Medicalization of Society. On the Transformation of Human Conditions into Treatable Disorders*, JHUP, Baltimore, MD/London 2007.

47 Ibid., p. 147.

48 Decker, Hanna: *The Making of DSM-III®. A Diagnostic Manual's Conquest of American Psychiatry*, Oxford UP, Oxford 2013.

49 Ibid., p. 310.

that competitive effective psychotherapies, such as cognitive behavioural therapy, emerged. Under these new circumstances, insurance companies and government agencies started to demand accountability. They questioned the cost-effectiveness of long-term psychoanalytic practices. This led to the rejection of psychodynamic thinking and the invention of new symptoms as well as to the redefinition of a host of older ones. For example, up to that time Vietnam veterans had been diagnosed with the condition of 'gross stress disorder', whereas in the DSM-III replaced the old notion with the new terminology of 'anxiety disorder'.

Decker's conclusion is similar to Peter Conrad's reasoning: the global success of the DSM, which became the Bible of psychiatry with an immense impact that reverberates everywhere, contributed to the 'pathologization of normality'.<sup>50</sup> For example, in the manual, what formerly had been considered shyness became classified as the medical condition of social anxiety, and what earlier on had been routinely thought to be sadness was now called depressive disorder. Decker emphasizes the role of big pharmaceutical companies in this process of medicalization, but like Conrad, she also points to the stigma-reducing effect of the DSM by showing that previously disparaged conditions qualify as illnesses. In addition to the immense growth in mental illness-related diagnoses, another, nowadays extremely widespread condition, which had been either not recognized earlier on or carried the label of 'imbecility' is the focus of an earlier book by Adam Rafalovich, "Framing ADHD Children. A Critical Examination of the History, Discourse and Everyday Experience of Attention Deficit/Hyperactivity Disorder"<sup>51</sup>. The author assesses neurological, psychological and sociological theories and traces the process of the redefinition of earlier labels of idiocy and imbecility into a clinical condition. Unlike the majority of similar accounts that focus on the medical scene, it looks at three specific notions of the social realm: home, classroom, clinic and it gives equal consideration to the perspectives of doctors, teachers, parents and children.

While the process of the emergence of new medical symptoms has received relatively generous attention, its repercussions and alternatives to drug-based therapies have hardly been considered. The fifth edition of the "Disability Studies Reader", edited by Lennard J. Davies, focuses on the disability-normality-power nexus and contains a chapter by Bradley Lewis: "A Mad Fight. Psychiatry and Disability Activism" which is one of the few existing accounts that warn that extensive medicalization have led to the neglect of scholarly attention paid to the cultural and societal aspects of these conditions. Like the other books discussed in this section, it reminds its readers that the contemporary dominant model of biopsychiatry, with its preference for neuroscience and genetics, has been created with the generous support of the pharmaceutical industry.<sup>52</sup> The most striking example of this phenomenon is the unprecedented success of the antidepressant Prozac. As Lewis points out, between 1987 and 2002, when Prozac came off patent, more than 27 million new prescriptions for the drug were produced. But if we add to this number the prescription of new drugs which operate on a similar principle (they all are known as 'selective serotonin inhibitors' (SSRI), then in the US alone the total number is around 67,5 million. This means that nearly one in every four people in the US took Prozac-like drugs. Without questioning the validity of the biopsychiatric framework, Lewis nevertheless argues that many people who take these drugs would get better results from psychotherapy, peer-support groups or engagement in personal

50 Ibid., p. 328.

51 Rafalovich, Adam: Framing ADHD Children. A Critical Examination of the History, Discourse and Everyday Experience of Attention Deficit/Hyperactivity Disorder, Rowman & Littlefield, Lanham, MD 2004.

52 Lewis, Bradley: A Mad Fight. Psychiatry and Disability Activism (chap. 7), in: Davies, Lennard J. (ed.): The Disability Studies Reader, Routledge, London/New York 2016, p. 345.

and political activism, but these options have become overshadowed by the seemingly less complicated, more direct and much better marketed drug therapy.

The emergence of patient groups and health movements based on ‘illness identities’ which can instigate political mobilization has been receiving increasing attention by scholars lately. One of these phenomena is the embodied health movement, which focuses on the biological body and as such on the individual experience.<sup>53</sup> It is through the realization that others also share identical or similar bodily experiences that various communities are being forged. Interestingly, some of those groups seek to medicalize their bodies, for example those who identify themselves as sufferers of chronic fatigue syndrome. Others seek to de-medicalize their condition, such as the fat acceptance movement which contests that obesity is an ‘epidemic’ and that overweight and ill health are causally linked. Another new ideological phenomenon is new materialism, which attempts to bring *matter* – and when applied for the case of disability – this means the body in its materiality and substance into a relationship with representation and discourse.<sup>54</sup> This development may prove useful for theoreticians in the field of disability studies who have come to criticize the social model of disability for entirely neglecting the bodily experience, be it a suffering or a positive sensation.

## Disability studies goes global

Although the majority of the world’s disabled population resides in the global South, until very recently the study of disability – its theoretical underpinnings, its methodology and its geographical coverage – has remained dominated by scholarship in the global North. Most legal documents operate with a ‘prototypical person with disability’ which has continued to reflect the circumstances of citizens in well-resourced democratic countries and at best those of the urban elite of activists in developing countries. Moreover, often the superiority of ‘Western’ medical tradition is taken for granted, which may appear somewhat paradoxical, given that in recent decades non-Western alternative medicine has enjoyed huge popularity in the ‘developed’ world. This Western-style commercialization has even been called the McDonaldization of traditional medicine. Indigenous traditions were in the core of the volume edited by Waltraud Ernst, “Plural Medicine, Tradition and Modernity, 1800–2000” which reflects on the historical, medical and ethical issues that have arisen with the increasing popularity of alternative medicine. The contributions in this book challenge Western history’s claim to epistemological and therapeutic superiority and emphasize that the allegedly unchanging medical traditions such as Ayurveda (Hindi) or Unani (Islamic), and Chinese practices are not only made up of a number of schools, but have also dynamically adopted to changing circumstances, like the cultures and societies in which they evolved.<sup>55</sup> At times, they did not only coexist, but also competed with each other. The chapters also point to the ethical dilemmas involved in the professional regulation of pluralist, alternative medicine – while the imposition of supposedly superior, scientific criteria of biomedicine should be prevented; the exposure of the public to potentially unethical or simply ineffective but fashionable practices is likewise to be avoided.

53 See Epstein, Steven: The Politics of Mobilization in the United States. The Promise and Pitfalls of ‘Disease Constituencies’, in: Social Science & Medicine 165 (2016), pp. 246–254.

54 For the first edited book on the subject, with interviews see Dolphijn Rick/Van der Tuin, Iris: New Materialism. Interviews & Cartographies, Michigan UP, Ann Arbor, MI 2012.

55 Ernst, Waltraud: Plural Medicine, Tradition and Modernity, 1800–2000 Routledge, London/New York 2002, p. 10.

Scholarly engagements with disability on a global scale must also take into account that concepts of 'personhood' vary widely across the globe. Especially the work undertaken by anthropologists and special education experts has emphasized that the mainstream notions of agency, independence and ability may not be universally serviceable. In that context, two volumes edited by Benedicte Ingstad and Susan Reynolds Whyte, "Disability and Culture" and "Disability in Local and Global Words" respectively, called attention to the different cosmologies and the often fundamentally different societal and family structures in the global South.<sup>56</sup> The contributors to these volumes assessed some important programs, for example Benedict Ingstad examines the impact of community based rehabilitation (CBR), a practice which was developed by WHO in order to integrate rehabilitation services into local-level health care. Ingstad avoided the pitfall of adopting a simplifying framework by either considering this practice as a 'Western invention' or as a universal remedy brought about by 'civilized' countries. She did not deny that these programs had potentials, and showed that in many cases their failure had to do with practical issues such as their short lifetime and their prematurely terminated funding rather than their 'imposed' nature. Moreover, she pointed to the potentially damaging effect of the fundraising practices: in order to create sympathy, not only a picture of disabled people in this region living in a state of utter misery was presented to the world, but myths, such as that developing countries hid or even killed their disabled members, were invented and have been perpetuated by prestigious international forums until the present day.<sup>57</sup>

Another valuable pioneering account, Julie Livingston's "Debility and the Moral Imagination in Botswana"<sup>58</sup>, showed how closely the escalating experiences of chronic illness, debilitating disease and accidents were related to the transformations in the political and social domain. These included the traumas of colonialism and the often abrupt changes after Botswana had acquired independence, for example the rapid process of industrialization. Livingston demonstrated how indigenous Tswana medical thought and practice had become intertwined with Western bio-medical ideas and techniques. Like the essays in "Plural Medicine, Tradition and Modernity, 1800–2000", it points out that 'traditional' medical knowledge is often erroneously perceived and portrayed by Westerners as static and ahistorical.<sup>59</sup> Livingston's second, more recent book "Improvising Medicine. An African Oncology Ward in an Emerging Cancer Epidemic" is based on fieldwork undertaken in the only cancer ward in sub-Saharan Africa in Botswana where a German oncologist, local nurses and caretakers are constantly confronted with unpredictability as a fundamental experience and where improvisation is the organizing principle of treatment.<sup>60</sup> Livingston's main interest lies in the body as a moral condition and in cancer as a *social* experience, which happens 'between people'. Because most patients get admitted into the ward in the final stadium and often with serious disfigurements, a fundamental question is how it is possible to retain one's dignity in disturbing and deeply uncomfortable situations. Apart from treating an 'emerging epidemic' which will make a fundamental impact on public health in Africa, the author is interested in

56 Ingstad, Benedicte/Reynolds Whyte, Susan: Introduction. Disability Connection, in: *ibid.* (eds.): *Disability in Local and Global Words*, California UP, Berkeley, CA 2007, p. 2; *ibid.* (eds.): *Disability and Culture*, California UP, Berkeley, CA 1995.

57 Ingstad, Benedicte: Seeing Disability and Human Rights in the Local Context. Botswana Revisited, in: *ibid.*/Reynolds Whyte: *Global Words* (see footnote 56), p. 237–286.

58 Livingston, Julie: *Debility and the Moral Imagination in Botswana*, Indiana UP, Bloomington, IN 2005.

59 *Ibid.*, p. 163.

60 Livingston, Julie: *Improvising Medicine. An African Oncology Ward in an Emerging Cancer Epidemic*, Duke UP, Durham, NC/London 2012.

the question as to how universal (or not) cancer is, and what difference does it make to have to experience having cancer in New York and in Gaborone (Botswana's capital).

Caregiving constitutes one of the major themes in the volume edited by Renu Addlakha "Disability Studies in India. Global Discourses, Local Realities" which powerfully demonstrates the intersections between gender and disability.<sup>61</sup> In addition to shedding light on how the concepts of human rights, disability movement, inclusion and disability art can be interpreted in the Indian context, it offers a nuanced overview of gendered concepts of disability in the work-, home- and community setting and in urban and rural backgrounds. It reveals that men with disabilities become 'emasculated' because of their condition, while women with disabilities are often considered asexual and incapable of taking on sexual, reproductive and maternal roles. However, the expulsion from traditional gender roles has not protected women from the threat of male violence.<sup>62</sup>

As some of the case studies on India reveal, it has proven a particular challenge to 'translate' human rights discourses into the circumstances of people experiencing extreme poverty, displacement and living in repressing regimes. Self-empowerment and living an independent life can sound very futile when families face chronic poverty and states lack resources to provide even basic education and healthcare. In that context the question has been asked if human rights in the context of disability represent an universal or rather, an *universalizing* discourse. Several researchers either coming from or representing the Global South have levelled criticism at what they consider 'scholarly colonialism': the imposition of theoretical frameworks on the region which ignore its particular social experiences.<sup>63</sup>

A critical point relates to the research which has been typically accommodated within the 'development paradigm', and as such has continued to be fundamentally grounded within traditional epistemologies: these imply that the South, as a backward region is constantly lagging behind, but is given the chance to improve thanks to generous foreign aid provided by affluent Northern countries. Although the authentic voices of disabled people are not easy to retrieve even in well-resourced countries, this problem is even more acute in the context of the Global South. While in some regions and under certain circumstances people believe disability is a condition worth cherishing and celebrating, in the South it is typically associated with injustice and suffering and is therefore presented as something that needs to be prevented and eradicated. In order to redress this shortcoming with the motto 'another knowledge is possible' scholars have called for the elaboration of Southern epistemologies that would challenge the imperial historicity and the teleological perspective.<sup>64</sup> These initiatives are often characterized by an activist tinge, and as such they reveal parallels with other global movements, including labor internationalism which emerged in the late 1970s.

In "Disability and Poverty in the Global South. Renegotiating Development in Guatemala" Shaun Grech's self-declared mission is "to call for a debate that dislodges fixities, that is inclusive and that never stops short of the ultimate goal – to challenge and disrupt oppression

61 Addlakha: Disability Studies (see footnote 6).

62 Ibid., p. 17.

63 See the article of Meekosha, Helen: Decolonizing Disability. Thinking and Acting Globally, in: Disability & Society 26 (2011), I. 6, pp. 667–682.

64 De Sousa Santos, Boaventura: Another Knowledge is Possible. Beyond Northern Epistemologies, Verso, London 2007; Comaroff, Jean/Comaroff, John L.: Theory from the South. Or How Euro-America is Evolving Towards Africa, Routledge, London/New York 2012.



and to work in genuine partnership for social justice and transformative change”<sup>65</sup>. In his book Grech addresses the assumed relationship between disability and poverty, one often described as a mutually reinforcing cycle. He points out that ‘imported and fabricated discourses’ about architectural barriers and political representation may not serve disabled people who were often positioned in a policy and service vacuum, haunted by immediate needs that demand immediate solutions. Inclusion and empowerment remain abstract notions for people in extreme poverty whose main concerns are the most basic forms of survival: food, shelter, sanitation, medication. Moreover, he points out that in the particular case of Guatemala security is such a fundamental issue that by comparison disability-related considerations will always remain marginal.

The ambitious handbook “Disability in the Global South” goes a long way to address problems and themes that have often been ignored in mainstream discourses. It provides a critical assessment of virtually every aspect of disability from legal documents such as the United Nations Convention on the Rights of Persons with Disabilities (UNHRPD), and the World Report on Disability by the World Health Organization (WHO) and the World Bank. Its call to challenge Eurocentric dominances goes hand in hand with the critique of capitalism, colonialism and neocolonialism and neoliberalism which all consider disabled bodies as unproductive. The essays in the volume point to the continuities in conditions that can cause negative social stereotyping of physical anomalies and impairments, for example by challenging the usefulness of the early modern/modern divide in several regions of the Global South.<sup>66</sup> The book has an explicit political message: it encourages forms of resistance across the global South, so that global hegemonies could be subverted, making the emergence of Southern counter-narratives possible. For example, it proposes that a counterpart of global financialization may be the promise of participatory budgeting. Last but not least, the volume also reminds the readers of the biopolitical aspects of disablement especially related to digital network technologies. One powerful example is the harmful and disabling potential of e-waste that is routinely shipped to the South by Northern nation states and transnational corporations.

A recent, but rapidly evolving initiative in the field of global health has been the Global Mental Health Movement, which was launched in 2008 and which seeks to eliminate the so-called treatment gap (i.e. the lack or shortage of services and treatment options in comparison to better-resourced countries) for people living with mental disorders worldwide. In a broader context, it seeks to alter the landscape of global mental health. Its focus is on the low and middle income countries, where according to the advocates of this movement mental-health related discrimination appears to be particularly rampant. As the founders of the initiative explain in the book edited Vikram Patel, Harry Minas and others, “Global Mental Health: Principles and Practice”, the movement is framed in two terms: scientific evidence and human rights.<sup>67</sup> It considers mental health essential for the achievement of sustainable development and seeks to improve availability, accessibility and quality of services. Recognizing that the burden and impact of mental disorder is omnipresent, but not every country has the professional means to address it, one of the objectives of the movement has been to teach ordinary people to deliver psychiatric services. For this purpose, they produced

65 Introduction: Disability in the Global South, in: Grech, Shaun/Soldatic, Karen (eds.): Disability in the Global South. The Critical Handbook, Springer VS, Wiesbaden 2016, p. XV.

66 Grech/Soldatic: Disability (see footnote 65), p. XIII.

67 Prefaced to Patel, Vikram et al. (eds.): Global Mental Health. Principles and Practice, Oxford UP, Oxford 2014, p. XI.



open-access 'diagnostic manuals', such as "Where there is No Psychiatrist. A Mental Health Care Manual" authored by Vikram Patel (2003) and "Where there is No Child Psychiatrist. A Mental Health Care Manual" written by Valsamma Eapen, Philip Graham and Shoba Shrinath (2012). These contain numerous explanations of key features and symptoms and abundant visual illustrations of syndromes.

In her book "Decolonizing Global Mental Health. The Psychiatrization of the Majority World" China Mills critically engages with the rationale of the Global Mental Health Movement. Based on fieldwork undertaken in India, Mills contests the movement's mission by showing that its aim, to 'scale up' access to psychological and psychiatric treatments globally and particularly in low-and middle income countries, evokes colonial attitudes and practices. The author seeks to de-familiarize current 'Western' conceptions of psychology and psychiatry using postcolonial theory. She finds this phenomenon especially doubtful in light of the increasing criticism of chemical treatments in the global North (both by those who take such medication and those who prescribe it). Another often overlooked circumstance on which she sheds light is that funding for mental health usually comes from those with a vested interest in it – the pharmaceutical industry which has openly declared the developing world as an untapped market for psychiatric medication. Indigenous healing practices are overlooked and alternative support is non-existent. The book argues that it is imperative to explore what counts as evidence within Global Mental Health. It argues that normative policies advocated by Global Mental health exaggerate the prevalence of mental illness and they are typically drawn without consultation with the local communities, users and survivors. The author also asks whether the disabling circumstance that needs to be treated in the first place is the mental disturbance itself, or whether it is poverty which increases the chance of mental illness. Lastly, she argues that the movement routinely perpetuates images which give the impression as if in indigenous settings human rights violations were more likely to occur.<sup>68</sup>

## Epilogue. Future perspectives on bioethics

Fundamental ethical questions about the value and quality of human life have frequently revolved around issues related to disability. It may not be surprising that some of these have been voiced in the realm of science fiction, as the volume edited by Kathryn Allan, "Disability in Science Fiction. Representations of Technology as Cure" demonstrates.<sup>69</sup> Fiction in general, and science fiction in particular, offers us many alternative ways of imagining what it means to be human and of thinking about the boundaries between humans and technology. Human-alien and human-animal partnerships in science fiction can also illuminate the forms of 'otherness' which are often associated with disability. They also offer an unconventional platform to reflect on some fundamental ethical questions. One of these is enhancement utopianism, the idea that in the future technological innovations will make it possible to create a perfect, disability-free world.

One of the most contested ethical dilemmas is in the focus of "The Human Enhancement Debate in Disability. New Bodies for a Better Life" edited by Christoph Rehmann-Sutter and

68 Mills, China: Decolonizing Global Mental Health. The Psychiatrization of the Majority World, Routledge, London/New York 2014, p. 5.

69 Allan, Kathryn (ed.): Disability in Science Fiction. Representations of Technology as Cure, Palgrave Macmillan, Basingstoke/New York 2013.

others.<sup>70</sup> Its point of departure is that there is no single disability response to the enhancement debate. As the renowned disability activist and scholar, Tom Shakespeare argues in the foreword to the book, none of the enhancement technologies are intrinsically immoral or mistaken. But social justice is a crucial ethical factor; it therefore has to be examined whether the enhancement contributes to the narrowing or to the widening of inequalities. He points out that cutting-edge innovations often receive widespread publicity, but the majority of disabled people are neither in the need nor would ever be able to afford a futuristic power chair which masterfully negotiates obstacles and costs 25,000 dollars. Rather, they require a basic wheelchair, valued at 250 dollars.<sup>71</sup> Moreover, he also emphasizes that the lived experience of disability challenges the desire for perfection – subjective quality of life of many people with disabilities is often much higher than expected in an able-bodied world.

The enhancement debate involves not only prosthetic devices, but also other sources of enhancement via the most advanced means of neuroscience and genetics. These are expected to bring about (an even) higher degree of medicalization. Such a prospective development is likely to further increase the focus on the individual, at the expense of the attention paid to the social environment. Disorders are namely caused not by the genes themselves, but by the interaction between genetics and the environment.<sup>72</sup> All in all, the fundamental dilemma of these ethical debates is whether we should insist on biological mutability as a desired condition, or we should allow for the scenario that cutting-edge medical interventions and prosthetic devices may eliminate disability. Societal pressure certainly makes an impact on disabled individuals' desire for assimilation to the norm. It is yet to be seen whether the love of variety or the passion for similarity will form the main guiding principle of human societies in the future. A disability-free world may be a dream for some people, but a nightmare for others who insist that diversity is fundamental and indispensable to the human experience.

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<sup>70</sup> Rehmann-Sutter, Christoph/Eilers, Miriam/Grüber, Katrin (eds.): *The Human Enhancement Debate in Disability. New Bodies for a Better Life*, Palgrave Macmillan, Basingstoke/New York 2014.

<sup>71</sup> *Ibid.*, p. XII.

<sup>72</sup> Conrad: *Medicalization* (see footnote 46), p. 153.

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