

# Western Constructions of Disability and Local Systems of Knowledge: A Look at the Problematic Aspects of Intercultural Work

Sophie Schönfeld

## I Definitions of Disability: An Introduction

In the globalized world we inhabit today, disability has come to be seen and worked with in an international context, with support programmes that reach into the most remote areas of the planet no longer being an extraordinary occurrence. These new circumstances, however, give rise to unique cultural problems, some of which I hope to be able to illustrate in this essay, especially for all those who are not deeply involved in disability studies. Much of what is presented in the first two sections, dealing with the way concepts of disability and processes of othering come into existence, is based on my own observations and conclusions compiled over the course of seven semesters of studying special education. An extremely useful work for anyone who wishes to explore the connections of culture and disability within an international framework is *Disability in Different Cultures: Reflections on Local Concepts* (1999), a collection that emerged from the symposium “Local Concepts and Beliefs of Disability in Different Cultures,” which took place at the Gustav Stresemann Institute of Bonn in 1998.<sup>1</sup> Reading the various essays compiled in this book has sparked many of my following observations, which will highlight the troubles that accompany the clashes of differing cultural notions of disability.

In order to be able to fully grasp the tensions that come along with putting disability into an intercultural context, a firm understanding of what disability actually is and how it is rooted within the dynamics of culture is necessary. The longer one ponders the concept of disability, the more arbitrary and constructed it appears. Additionally, ever more aspects come to mind that make remarkably little sense for something that seems so reasonable at a first glance. For instance, legal definitions vary greatly. While section nine of the German Code of Social Law (*Sozialgesetzbuch*) states that an impairment must last for six months or longer to be labelled

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<sup>1</sup> Brigitte Holzer, Arthur Vreede, and Gabriele Weigt (editors), *Disability in Different Cultures: Reflections on Local Concepts* (Bielefeld: transcript, 1999).

as a disability,<sup>2</sup> the British Equality Act speaks of twelve months.<sup>3</sup> An individual who has been unwell for eight months is then, at least from an official point of view, a chimera of disabled and able-bodied. Someone who has been unwell for five months and three weeks is effectively disregarded altogether, caught in a limbo where neither realm appears accessible. This description might appear somewhat exaggerated at first glance, but it serves to show that when we observe the concept of disability, we are looking at a construction rather than a natural fact. The matter can be made yet more obvious by looking at the bigger picture: “Disability” serves as an umbrella term for an extremely wide range of impairments, grouping together individuals who experience challenges that vary fundamentally from person to person and who have highly individual needs. Assigning the same label to individuals with quadriplegia, hearing loss, and severe mental illness does not necessarily make for a useful way of thinking of these persons, communicating with them, or supporting them. The inclusion movement, made up largely of people who fall under the disability categorization, articulates highly ambivalent feelings regarding the term, with a clear tendency towards its eventual abandonment.

In her 2017 essay “Theorien der Inklusion: Eine Übersicht” (“Theories of Inclusion: An Overview”), German disability studies scholar Mai-Anh Boger impressively illustrates the various and often paradoxical perspectives on disability through a system of basic approaches to inclusion and, more specifically, otherness. Having a look at three key terms taken from this text may convey an impression of the theoretical complexity behind inclusion efforts and concepts of disability, as well as of the arbitrariness of such concepts: “the right not to be othered”; “resistant fundamental otherness”; “the right of the other to participation in a normality.”<sup>4</sup> These short excerpts already make plain the markedly different approaches in rejecting the category, the demand to have a right to exist with a difference in our society, and the acceptance of being different in order to affirm one’s right to participation. The concepts *other*, *othering*, and *otherness* deserve our special attention, for this trinity carries in it much of what characterizes the Western concept of disability that dominates global discourses on the subject as well as many associated concerns.

Disability in the modern global framework is most often considered within the bio-medical discourse. This puts educators, other professionals and, unfortunately, in many cases also those affected as well as their families and immediate social circle (i.e., those who have the direct and intense experience of what it means to be disabled), into a secondary, passive position at best. Simultaneously, a nearly mystified and extremely powerful status is attributed to doctors. After all, the medical professional, usually pictured as an older, exceptionally educated White man, has been the prime example of reason and knowledge ever since the Enlightenment. The doctor is, in society’s perception, the sole lord over life and death, for religion and folk magic (practices which granted to their practitioners a sense of empowerment) went

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<sup>2</sup> “§ 2 SGB IX Begriffsbestimmungen.” *Sozialgesetzbuch (SGB)*, 2021, web.

<sup>3</sup> “Definition of Disability under the Equality Act 2010,” *Government Digital Service*, 2015, web.

<sup>4</sup> Mai-Anh Boger, “Theorien der Inklusion: Eine Übersicht,” *Zeitschrift für Inklusion* 1 (2017), n.p., web. Unless otherwise indicated, all translations are my own.

into decline around the same time. The doctor is the master of the bio-medical discourse. Little time is spent together, and all encounters occur within the same setting, that of the treatment room. Measures such as therapies are conducted by different specialists in a different place, and these visits usually follow a steadier rhythm, increasing the familiarity of the client with the situation, and therefore reducing the possible level of stress and discomfort which may be experienced in a doctor's office (especially for individuals with manifold health issues, this environment can quickly become associated with bad news as well as with potentially painful medical procedures).

The actual day-to-day life with the disabled person, their abilities, personality, and the challenges they face, are only witnessed by whoever they spend the most time with. In the United States as well as Western Europe, there is a chance of these people being professionals in their own right, in the form of personal assistants or as the staff of a care facility.<sup>5</sup> By far the most common form of accommodation, however, especially in developing countries where other options are often not readily available, is within the family, who, despite spending more time around the person in question than anyone else, are not considered to possess professional knowledge. Even when living alone and independently, the routines and daily life of an individual with disabilities are likely to be much more intimately known to friends and relatives than to the health professional in the treatment room. The doctor has no comprehensive image of the client, in whose personal experience of being othered medical issues are only one of many factors anyway. The expert status is furthered by the manner in which medicine is divided up into subdisciplines. This specialization creates the impression that there is supply for every possible demand, a solution for every problem, offered by medical professionals. The issue here is, of course, not to be attributed to medical staff personally. Knowledge regarding the biological factors of disability is important and extremely valuable. However, the prevalent structures within a Eurocentric cultural framework appear to make it the only knowledge that is considered truly valid.

Both medicine and psychology are marked by a focus on normative, comparative evaluation. This characteristic, since the bio-medical discourse is so dominant in constructions of disability, makes the concept un-questionable by rooting it in science. After all, disability can supposedly be measured and must therefore be an objective fact, from grades in school to measurements of the body to the percentage of disability (or grade of disability given in percentages) stated on one's handicapped identification card in Germany.<sup>6</sup> Through its claim to science and objectivity,

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<sup>5</sup> According to ADA-PARC, a research project conducted by seven ADA (i.e., Americans with Disabilities Act) regional centres between 2012 and 2016, an average of just under 7% of disabled US-Americans lived in specialized institutions or other group quarters. See "Community Living Indicators," *Center on Disability at the Public Health Institute*, n.d., web.

<sup>6</sup> The German handicapped identification card is an official document that can be obtained by disabled individuals. It states the degree and category of their impairment and is a necessary prerequisite for requesting compensations for disadvantages. The degree is given in increments of 10, ranging from 0 to 100. A person is considered disabled at a degree of impairment of 20 or higher, with severe

medicine stabilizes the knowledge it produces, allowing change to only arise from within the strict borders of the discipline and therefore becoming largely immune to outside factors, may they be corroding or actually beneficial in nature. Sociocultural influences in the construction of disability are pushed to the background, clouding our view of the actual inner workings of the concept, as well as of the actual factors making international cooperation so problematic. Framing disability purely as a biological fact legitimizes discrimination and segregation instead of encouraging a questioning of the prevalent structures within our society; little room is given to alternative perspectives, let alone alternative modes of knowledge. It seems that the dominant position of medicine is only ever questioned once it (physically or morally) affects a great number of people or is represented as doing so. Examples of such questioning include matters such as abortion, genetic engineering, and assisted suicide.

Writing in 2022, the extensive protests in major US cities against the tightening of legal regulations regarding abortions unto *de facto* bans on abortion access in the states constitute a prime example of this circumstance. Matters of disability, it might seem, simply do not affect enough people directly in order to create a sufficient popular reaction. Since disability is a largely arbitrary umbrella term that necessarily groups together people with vastly different needs, interests are fragmented even among the “disabled community.” Is that all there is to it, though? Is inclusion, defined by the *Cambridge Dictionary* as “the idea that everyone should be able to use the same facilities, take part in the same activities, and enjoy the same experiences, including people who have a disability or other disadvantage,”<sup>7</sup> only prevented by a lack of focused interest? Taking into account the (very real) possibility of becoming disabled is something the vast majority of people appear to avoid, perhaps precisely due to its being a realistic and frightening scenario. In reality, everyone is constantly in danger of becoming directly impacted. On an emotional level, this topic may then be comparable to death; something most people are highly uncomfortable discussing, let alone diving into more deeply. The concerns and problems of individuals with disabilities are, in a way, a smouldering fire. They have been an issue for ages, with palpable progress made here and there, but a large-scale collective public outcry usually fails to materialize. Some of the most recent disability-related events that made headlines in Germany are the deaths of twelve residents in a care facility in the course of the severe floods in the Ahr valley in 2021,<sup>8</sup> and the murder trial of a caretaker who was found guilty of killing four people with disabilities in Potsdam.<sup>9</sup> Both incidences did receive a fair amount of media attention. However, after the initial wave of outrage, demands for action

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disability beginning at 50. The assessment is carried out by medical examiners based on a legally established set of criteria.

<sup>7</sup> “Inclusion,” *Cambridge Dictionary*, n.d., web.

<sup>8</sup> “Zwölf Menschen in Wohnheim für Behinderte ertrunken,” *Tagesspiegel*, 16 Juli 2021, web.

<sup>9</sup> Alena Kammer, “15 Jahre Haft für vierfachen Mord in Behinderteneinrichtung,” *Zeit Online*, 22 December 2021, web.

have remained limited to the disabled community and some particularly interested individuals.

There is more to this topic. So far, we have looked at processes of direct othering directly, without, however, taking into consideration its integration into larger cultural processes. We must question not only factors within the process of othering itself, but also its function within our society.

## II

### Discrimination in Practice:

### How Oppressive Definitions of Disability Manifest Themselves

It might be useful to remind ourselves of a simple societal truth: Norms are always constructed. They are naturalized and universalized over time, conveying the impression of being in some way logical and justified; but in the end, they are just as arbitrary as disability, which is characterized as deviation from norms and what is perceived as normality by definition. The division between being “normal” and being “disabled” is a self-referential and paradoxical one. Oscar Thomas-Olalde, a political scientist and researcher of education in intercultural settings, and Astride Velho, a professor of social work, describe the paradox as follows:

[The discursive] construction of difference makes the radical distinction between inside and outside of the social system a plausible part of the repertoire of normality. Only by constructing social antagonisms, cultural antitheses and epistemic dualities, it is possible to achieve discursive stability and thus stability of power.<sup>10</sup>

The perceived deviations, produced by the construct, prove their supposedly objective character by showing that people labelled as disabled are indeed unable to participate fully in our society. The fact that the structures we live in, from architecture to education, are themselves based on our conception of normality and must therefore be seen as part of this self-referential system, is conveniently ignored. In the duality into which society is being split, centre and periphery support and justify each other, but they also stabilise the identities of those who inhabit these realms by offering a point of orientation through the perception of fundamental difference. The periphery is therefore a particularly important spot within the system, and it needs to be inhabited in order to offer a point of reference for the organization of social and cultural life. This, of course, immediately raises questions about the possibility of true inclusion: will not the periphery always find a new mode of existing, no matter the number of measures taken? For a better understanding of how deeply

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<sup>10</sup> Oscar Thomas-Olalde and Astride Velho, “Othering and Its Effects: Exploring the Concept,” in *Writing Postcolonial Histories of Intercultural Education*, edited by Heike Niedrig and Christian Ydesen (Frankfurt am Main: Peter Lang, 2011), 35.

ingrained the duality described above is in all areas of our lives, a few examples may be beneficial.

First, the process of othering and the periphery's immense will to survive are especially obvious within the system of education, where inclusive schooling is being opposed by parents on grounds of potentially affecting their children's learning progress adversely. This discussion has been documented in a variety of articles, interviews, and other media texts. For instance, a 2013 article in the German newspaper *Westdeutsche Zeitung* illustrates the manifold anxieties surrounding a switch towards more inclusive education.<sup>11</sup> Parents doubt that the ideal of inclusive education, which would fundamentally change the existing education system, is feasible. They fear that the approach may be overly idealistic, a concern which is shared by many teachers, who are worried that the new classroom situation may become overwhelming. The process which is currently (supposed to be) taking place in Germany is effectively a transition from segregation (children with and without disabilities are often taught in separate schools) to inclusion (all children learning together). Various models exist in which a sort of "in-between" is created, e.g., through "partner classes," where separate groups of children (usually belonging to different school types) with and without special needs are partially taught together.<sup>12</sup> In these classes, phases of separate instruction are also included to the degree deemed necessary.

Meanwhile, the parents' worries do not seem to be exclusively tied to the idea that their children's learning progress may be compromised in an inclusive model. It appears, additionally, that a system in which children are not judged based on what a supposedly normal student is expected to achieve is viewed by those who consider themselves to be part of the realm of normality to be unfair or inefficient, lacking a common standard for comparison. Clearly, a form of organization which perpetuates division by causing a certain percentage of children to fail, creating the much-needed periphery, is met with more agreement (from those who are comfortably positioned in the centre). The parents alone may not be blamed, however. Their thought pattern is simply symptomatic of patterns of othering within society at large – whoever can be part of the social centre, the in-group, tends to seize that opportunity. Clearly, a restructuring of the education system (which in itself is no easy task) is not sufficient. The issue persists on a much larger scale and is much more deeply ingrained in people's minds.

Second, special needs education itself, although on the surface advocating for inclusion, is crucial in maintaining division and can, in its current state, only exist based on continued separation. It is hard to believe that any discipline would sincerely and actively advocate for its own abolition. The name itself, "Special Needs Education," still stands for segregation and stresses difference, no matter its outwardly shown support for the ideal of an inclusive world. The Institute for Special Education at the Julius-Maximilians-Universität Würzburg (JMU) states the following on its website: "Inclusion is understood to be a task of society at large; special

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<sup>11</sup> Thomas Lekies, "Inklusion verunsichert Eltern," *Westdeutsche Zeitung*, 17 April 2013, web.

<sup>12</sup> "Partnerklassen," *Inklusion und Schule Bayern*, n.d., web.

needs education here plays the role of a mediator and interlocutor, providing scientifically based applicable knowledge and functioning as an advocate for those affected – with their participation, of course.”<sup>13</sup> This shows that, naturally, like any other department, that of special education seeks to maintain itself. The disappearance of special education as a discipline would mean an aggravation of the already existing lack of professionals who are needed to make inclusion work, if it can work.<sup>14</sup> The situation is somewhat paradoxical: Inclusion calls for an abolition of divisive factors within society, and especially in education; this would, strictly speaking, leave no room for the discipline in its current form, which focuses on students who are, after all, perceived as different on a cognitive, physical, and/or behavioural level, and structures its subdisciplines accordingly. At the same time, the specialized knowledge and skills conveyed to future professionals are indispensable, as is the institutionalized advocacy for the concerns of disabled individuals – for, as we have learned by now, the larger public tends to avoid the topic, and non-professionals often remain unheard – although this latter position has been contested by disability studies for some time. However, within the framework of inclusion, new sets of tasks emerge, creating new spaces for special needs education to operate in. The discipline thus appears to be in need of redefining itself. Such a renegotiation may be laborious, but it, which transcends all such discussions about ideals and possibilities rigidly maintaining the divide. For a student at the institute, encounters and exchanges with people with disabilities are remarkably rare. And as if to open the eyes of the last, most oblivious individual to the irony of this situation, students who rely on a wheelchair are required to use the side entrances at the Institute for Special Education. The grand main entrance, whose broad stairs also serve as one of the main meeting spots for students and are, therefore, of great social significance, is not wheelchair-accessible.

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<sup>13</sup> Kollegiale Leitung des Instituts für Sonderpädagogik der Julius-Maximilians-Universität Würzburg, “Positionierung Inklusion,” *Institut für Sonderpädagogik*, May 2018/January 2021, web.

<sup>14</sup> Florentine Anders, “Lehrermangel verschärft sich weiter – Was die Länder dagegen tun,” *Das Deutsche Schulportal*, 10 August 2021, web.



Figure 1. The non-wheelchair-accessible front door of the Institute of Special Education at the Julius-Maximilians-Universität Würzburg (JMU), Main Building at Wittelsbacherplatz (photo: Sophie Schönfeld).



This leads us to my final example of structures that serve to maintain centre-versus-periphery divisions: that of architecture. Nora Ellen Groce, director of the Disability Research Centre at University College London, focuses on matters of disability and health in a global framework. She stresses the importance of ideas regarding aetiology (the presumed origin or cause of a disease) and social expectations as the main factors that determine how difference is dealt with in a society.<sup>15</sup> Interactionist models that touch on societal and environmental contexts – e.g., the World Health Organization’s International Classification of Functioning, Disability and Health (ICF) framework – are widespread today within the professional discourse, but not within the minds of the general non-professional public that, as previously discussed, tends to locate the source of disability exclusively in the realm of the bodily, since the implicit (non-professional) definition is that of some type of physical aberration. While interactionist models may be seen as a step in the right direction, they too need to be viewed critically, for they suggest that there is a hard, essential reality or a natural state of things not shaped by cultural factors whatsoever, which does not make disability appear as a construct, but rather as a necessary, although unfortunate, consequence of said reality.

Buildings, for example, are not just a product of architectural necessity and aesthetics, but also an integral part of the structures that reinforce the aforementioned self-referential system. Dick Hebdige elaborates on the connection between culture and architecture in *Subculture: The Meaning of Style* (1979). Here, cultural studies can add a useful dimension to the way we theorize disability, a train of thought which appears to have been largely neglected in special education so far. What the ICF model usually refers to as “environmental factors” is not random, let alone natural; and the description as simply “environmental” does not do the actual character and function of these barriers justice.<sup>16</sup> Our surroundings are fundamentally shaped by cultural norms and notions of power, or, in short, the way we think about the world. This becomes visible in architecture and the interior design of buildings as well as other human constructions (e.g., playgrounds), for here the realm of the cultural, rather difficult to grasp otherwise, is expressed in material terms. As Hebdige expresses it: “[T]he frames of our thinking have been translated into actual bricks and mortar.”<sup>17</sup> The division of people into belonging and not belonging is manifested in such a blatantly literal manner in built environments that one cannot help but feel uncomfortable upon being confronted with the matter. Something about the wheelchair user who is not able to participate in a work meeting because it is upstairs, seems too un-metaphoric, too palpable to be comfortably ignored for the sake of stable norms. Indeed, in recent years attempts have been made to make public and commercial architecture more accessible in Germany, although that

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<sup>15</sup> Nora Ellen Groce, “General Issues in Research on Local Concepts and Beliefs about Disability,” in *Disability in Different Cultures*, edited by Brigitte Holze, Arthur Vreede, and Gabriele Weigt (Bielefeld: transcript, 1999), 287.

<sup>16</sup> See “The Integrative Bio-Psycho-Social Model of Functioning, Disability and Health,” *ICF Case Studies*, n.d., web.

<sup>17</sup> Dick Hebdige, *Subculture: The Meaning of Style* (London: Routledge, 1997), 13.

certainly does not mean that there will be an end to exclusion.<sup>18</sup> Additionally, initiatives that aim at increasing the accessibility of public spaces based on improvised solutions are becoming more and more common these days. One of the most well-known of these campaigns involves the construction of wheelchair ramps out of LEGO bricks,<sup>19</sup> while in another one, people are asked to knit or crochet colourful covers for bollards and barrier posts in order to increase their visibility.<sup>20</sup> Changes, slow and partial as they may be, are being effected; yet critics may claim that such effort is being made to make ignoring inequality comfortable again, by allowing those responsible to claim that they have at least shown good will. A wheelchair ramp in front of an office building is largely useless if no wheelchair user finds employment in the edifice, and improvised solutions such as the ones mentioned above are just that: improvised rather than suitable for permanent use.

### III

## Intercultural Conceptions of Disability: A Clash of Ideologies, not Facts

Even based on my necessarily incomplete selection of examples, it has become obvious that there are a variety of systems in place to perpetuate division within our society. Ray McDermott and Hervé Varenne, both professors of education, sum this up by stating that “people in all cultures can use established cultural forms to disable each other.”<sup>21</sup> What, then, happens when culturally specific norms and notions that were established within a unique local and historical framework are transferred to a new locality with different cultural, social, and environmental conditions, becoming dominant within the work that is done there in support of individuals with disabilities? Problems are guaranteed wherever this kind of intercultural work takes place.

If we are all, as Clifford Geertz claims, “suspended in webs of significance” that we have spun ourselves and if culture indeed shapes our entire existence, it appears extremely insensitive to carry a cultural construct as complex as that of disability over into a different context and simply expect things to work out.<sup>22</sup> Our professional behaviour is saturated with culture, as is everything else we do.<sup>23</sup> Acquiring

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<sup>18</sup> Svenja Heinecke, “Barrierefreiheit in Deutschland: Was hat sich in den letzten 5 Jahren getan?” *IGPmagazin: Ihre Gesundheitsprofis*, 2 July 2019, web.

<sup>19</sup> “Bunte Legorampen begeistern Deutschland,” *Aktion Mensch*, n.d., web.

<sup>20</sup> “Bitte ran an die Nadeln: Stricken und Häkeln für mehr Sicherheit auf Deutschlands Gehwegen!” *Deutscher Blinden- und Sehbehindertenverband e. V.*, 14 April 2021, web.

<sup>21</sup> Ray McDermott and Hervé Varenne, “Culture ‘as’ Disability,” *Anthropology & Education Quarterly* 26.3 (1995): 332.

<sup>22</sup> Clifford Geertz, *The Interpretation of Cultures: Selected Essays* (New York: Basic Books, 1973), 5.

<sup>23</sup> Patrick Harris, *Culturally Competent Disability Support: Putting It into Practice: A Review of the International and Australian Literature on Cultural Competence* (Harris Park: Multicultural Disability Advocacy Association of New South Wales, 2004), 24.

some superficial information on customs and traditions in a foreign country is not an effective way to bridge the gap. Culture does not work like the vocabulary of a foreign tongue. Holding on to the language metaphor, one can indeed acquire a limited range of vocabulary and thereby gain a rudimentary understanding of what is said fairly quickly, as long as the sentence structure is simple. However, one missed word or an unnoticed undertone is already enough to destroy the entire operation. Failing to understand the larger structure and logic that connects everything, as grammar does in language, will result in misunderstandings and in limitations to communicative complexity.

Thinking of culture as a grammar of life may prove useful in preventing important matters from getting lost in translation. This may not give us culturally specific knowledge, whose importance is so often (over)stressed, but potentially something more valuable: awareness of and openness to fundamental cultural difference. As Australian public health researcher Patrick Harris expresses it: “[W]hat is required is not familiarity with every culturally specific belief and behaviour, but a general approach to culture that respects the diversity of cultural perspectives that influence the health of individuals and communities.”<sup>24</sup> Openness and flexibility are necessary conditions for intercultural work: It is simply not feasible to familiarize oneself with every aspect of a foreign lifestyle prior to getting involved in an international project. Mindfulness may therefore be our best bet when it comes to recognizing and letting go of hindering stereotypes that are rooted in various othering processes – which, on an international scale, include many more levels than just disabled versus able-bodied. In a context that allows for such a broad range of tensions, cultural awareness and, equally importantly, self-awareness (in terms of professional self-reflection) can make the difference between mutual understanding and mutual frustration.

It is just as vital to recognize local knowledge(s) as useful. This, however, poses a special challenge that goes well beyond simple cultural openness, and which must be analysed within the context of power as well as within the context of the real-life structures supporting the respective relief organizations. The global discourse on health in general, and therefore also on disability, prioritizes Western forms of knowledge. Interestingly, this issue has not really received widespread attention in the context of disability, but only became relevant to a wider public after the outbreak of the Covid-19 pandemic, when internationally coordinated disease control emerged as a topic of focus within the media. An article published on the *Bill of Health* website, a page maintained by the Harvard University Law School, states that “despite having the institutional competence to do so, the WHO failed to address the holistic determinants of health affecting the enjoyment of the right to health during the pandemic, predominantly determinants affecting those in the Global South.”<sup>25</sup> The World Health Organization (WHO) being, as its name suggests, the officially recognized, worldwide main authority on the subject, while operating

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<sup>24</sup> Harris, *Culturally Competent Disability Support*, 29–30.

<sup>25</sup> “A Critical Analysis of the Eurocentric Response to Covid-19: Western Ideas of Health,” *Bill of Health*, 11 June 2021, web.

primarily based on Western, Eurocentric modes of theorizing health, also publishes international standards for relating to diagnostics and disability, thereby shaping the global discourse. Non-compliance with its immanent rules and systems of logic results in reduced possibilities of participation in international dialogue. Alternative modes of knowledge, which are often connected to regional spiritual beliefs (such as the thought of ancestor intervention as a possible cause of disability) are framed as literal non-sense clashing with Western, globalized ideas, which are usually centred around the bio-medical, strictly scientific discourse, explaining disability through genetics and other physical causes.<sup>26</sup>

This is not to say that there is a full-fledged consensus over all aspects of disability present even within the West, but there is a certain amount of common ground that enables a smooth exchange of information, as well as rather uncomplicated cooperation. The wallpaper might look different, but the foundational walls are the same, insofar as medical knowledge tends to be prioritized and “un-scientific” ideas rigorously excluded. Upon encountering communities whose understanding of disability is based primarily on local knowledge, the common ground tends to shrink from a seemingly world-spanning dimension to what appears to be scarcely enough to take a first step in one’s endeavour to support people with disabilities: From assigned roles to concepts of disability and from the origins of disability to its medicalization, local ideas may be vastly different from the globalized norm in public health and may not immediately make sense to outsiders. They are embedded in a specific cultural, historical, and material framework, are limited to certain regions, and oftentimes tie into religious and spiritual beliefs. Where Western countries value the ability to lead a self-determined lifestyle as well as being economically independent, setting up interventions accordingly, a community which relies primarily on indigenous knowledge and cultural practices may prioritize marriage and the ability to start a family.<sup>27</sup> The vast majority of disability professionals have come to naturalize their notions of what constitutes a fulfilling life, and it may come as a surprise just how starkly different the opinions of those they plan to support can turn out to be. What makes local knowledge valuable and useful is precisely its local character: It is not a one-size-fits-all approach, but a system adapted to its unique setting, following a more holistic approach, and therefore possessing a quality globalized knowledge alone cannot offer. Besides being practically useful by inherently taking into account the specific conditions of its environment, local knowledges also serve as “sources of identity and pride.”<sup>28</sup> These two aspects alone should be reason

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<sup>26</sup> Friedrich Albrecht, “The Use of Non-Western Approaches,” in *Disability in Different Cultures*, edited by Brigitte Holzer, Arthur Vreede, and Gabriele Weigt (Bielefeld: transcript, 1999), 125.

<sup>27</sup> Dee Burck, “Incorporation of Knowledge of Social and Cultural Factors in the Practice of Rehabilitation Projects,” in *Disability in Different Cultures*, edited by Brigitte Holzer, Arthur Vreede, and Gabriele Weigt (Bielefeld: transcript, 1999), 205.

<sup>28</sup> Patrick J. Devlieger, “Local Knowledge and International Collaboration,” in *Disability in Different Cultures*, edited by Brigitte Holzer, Arthur Vreede, and Gabriele Weigt (Bielefeld: transcript, 1999), 176.

enough to meet these alternative systems of understanding disability with a certain amount of respect, instead of insensitively attempting to replace them.

Effective communication and collaboration between globalized and local frameworks of knowledge are hindered by a certain arrogance, which carries with it the idea that people must be taught and convinced, to be led to the right path, for their approach is thought to be less valuable or even harmful. This arrogance, to be quite fair, is not “produced” by the individual workers whose intentions may very well be altruistic and who, on an individual level, may themselves possess the aforementioned awareness and mindfulness regarding cultural difference. After all, had they lacked humanitarian passion, they would have likely chosen a more comfortable occupation. Instead, this phenomenon appears to be rooted within society as a whole and concentrated by the administrative structures operating within public health organizations.

I have granted much room to an analysis of the dominant role of the bio-medical discourse, which serves to legitimize practices and hierarchies and is hardly questionable. This is problematic enough within the Western context, but even more so when encountering local systems of knowledge. We are, after all, talking about a perspective that includes a self-image of science as the only truly legitimate way of seeing disability and which is now up against ways of knowing that may appear radically unscientific, as is the case with some indigenous theories of aetiology which interpret disability as (among other things) signs from God or the ancestors, or as a consequence of witchcraft.<sup>29</sup> If the disability is seen as fated or as serving a spiritual purpose, it is highly unlikely that the family or the affected individual will actively seek treatment, and in many cases, offers to intervene by means of scientifically proven tools and procedures will end up being resolutely rejected. This, of course, is then quickly interpreted as “unreasonable” and “uncooperative.”

Positive aspects of local approaches, especially in what is considered the “Global South,” often are not only dismissed but concealed. Making use of a theory proposed by anthropologist Benedicte Ingstad, special needs educator Friedrich Albrecht explains the so-called “North-South Myth” as follows:

This myth has arisen as a result of supportive measures in the disability field between North and South. Here also concepts like shame, concealment and killing are emphasized in order to attract attention and to legitimate assistance measures. Let the developed societies teach the underdeveloped nations how to integrate people with disabilities is the message of this myth.<sup>30</sup>

The catchword in the quoted passage is *power*. Lending any sort of credibility to alternative modes of knowledge would inevitably compromise the position of what Albrecht calls “developed societies” by putting into question the narrative of bio-medical explanation as the singular reasonable approach. Local knowledge

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<sup>29</sup> Maya Kalyanpur, “Meanings of Disability for Culturally Diverse and Immigrant Families,” in *Disability in Different Cultures*, edited by Brigitte Holzer, Arthur Vreede, and Gabriele Weigt (Bielefeld: transcript, 1999), 141.

<sup>30</sup> Albrecht, “The Use of Non-Western Approaches,” 123–124.

therefore cannot be treated as equal. This is, of course, an uncomfortable and inconvenient truth, since the lending of a helping hand to supposedly “underdeveloped” communities and countries is presented as an altruistic, selfless act – not as an act of oppression with almost colonialist features. I use the term “colonialist” purposefully here. The British Empire, for example, justified its colonial activities by interpreting them as “the White man’s burden,” an expression that gained fame through Rudyard Kipling famous poem.<sup>31</sup> According to this interpretation, the Empire existed not for the benefit – economic or strategic or otherwise – of Britain itself, but in order to make sure that supposedly “primitive” peoples, would, with British guidance, eventually become civilized.<sup>32</sup>

Other cultures have, against all claims regarding the sole validity of the globalized approach, developed useful concepts and well-functioning techniques of coping with disability within their systems of local knowledge. This, of course, is not to say that such conceptions are inherently unproblematic and have no potential or need for further development. This would mean falling for another, equally blinding myth: that of “Better People in Other Places,” which is as much of an ignorant essentialism as the myth previously mentioned.<sup>33</sup>

#### IV

### **Balancing Support and Sensitivity: An Analysis and Some Constructive Ideas**

At this point, the work of special needs educators, social workers, doctors, and all others involved in intercultural projects may seem like a tightrope act. These front-line workers act within an extreme tension, in which they can hardly be or remain neutral. They are the first ones to experience all the issues arising from the problematic aspects addressed, while in many cases also being the ones who must come up with solutions (which need to be set up in a way that does not violate certain guidelines). Even if they strive to proceed in a culturally sensitive manner, they are still likely to encounter cultural phenomena that they simply cannot agree with, because they seem detrimental to the well-being of their clients. Yet how can one legitimize global judgements and interventions when still judging from an inherently Western-aligned perspective, looking through a distorting lens of universalized “truths?” The cases in which support programmes that are rooted in a globalized but ultimately Eurocentric perspective work towards the culturally determined aspirations of the foreign clients are few; and if these aspirations are fulfilled, more often than not this is a mere side effect of having worked toward different goals, a lucky coincidence, so to speak. Dee Burck, a Dutch rehabilitation specialist who has

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<sup>31</sup> Rudyard Kipling, *Stories and Poems*, edited by Daniel Karlin (Oxford: Oxford University Press, 2015), 479.

<sup>32</sup> See David Cody, “The British Empire,” *The Victorian Web*, 1988, web.

<sup>33</sup> See Albrecht, “The Use of Non-Western Approaches,” 124.

worked extensively within various cultural settings, recounts the following experience:

There is an example of a project in Africa some years ago, which was quite successful in assisting blind men to become economically independent. The men were involved in various handicraft activities and when I visited their centre, I noticed that the handicrafts they produced did not sell much. Nevertheless, virtually all the men left the vocational rehabilitation centre after their training period, settled independently in the village and managed to sustain themselves thereafter. Finally, it was revealed to me that, while at the training centre, virtually all the men were married off to women who had been divorced or widowed and who had been working in the centre as cleaners. This aspect of the project had never been revealed to the donors however, as they might have opposed this marriage broker role of a rehabilitation project.<sup>34</sup>

More frequent than stories of obvious success, however, are instances of mutual frustration of all those involved: The Western workers feel that their work is not being fully respected, and the clients feel that their individual concerns are not being taken seriously. This poses a serious risk: In cultures where cause and effect of disabilities are interpreted in religious or spiritual ways, seen as fated and therefore as serving an important purpose, unwanted and insensitive involvement has the potential to throw a whole community off balance, actually worsening the situation of the clients.

It is within the system of administration and financing that the full extent of organized cultural insensitivity operates largely unnoticed, which is also indicated by the events described by Burck above. People who run the charities from afar and rarely see themselves confronted with the reality on site, must work out the financial support the organization needs to function. This support is gained by showing off successes, which are being judged within the realm of certain cultural standards. "This man got married" is simply not as impressive as "this man is now supporting himself through his employment in a small workshop." Most sponsors would not donate money to help people in some foreign country get married, be they disabled or not. The current, intrusive models cannot be fully successful because they cannot and are not allowed to work in a culturally sensitive manner. What matters to the business of disability organizations is not primarily the satisfaction of the individual client, but the judgement of the wider public and the sponsors.<sup>35</sup>

How, then, can people with disabilities be supported in a culturally sensitive manner? The answer is rather obvious: They themselves can take initiative in the form of self-advocacy. Employees of aid programmes should be recruited locally or should ideally have a bicultural background, allowing them to reliably navigate the winding paths of culture. Clinical psychologist and multicultural studies scholar Stanley Sue concludes from his own research that culture-specific experts "are effective in their own cultures because they know the cultures and have the skills to

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<sup>34</sup> Burck, "Incorporation of Knowledge of Social and Cultural Factors in the Practice of Rehabilitation Projects," 205.

<sup>35</sup> *Ibid.*, 206.

translate this knowledge into effective interventions.”<sup>36</sup> It would then appear to be the duty of those who are in charge of organizing aid systems to support local actors and ensure the free distribution of information, while standing back from getting otherwise involved. This, however, would necessarily mean both a loss of control and severe damage to the carefully constructed self-image. There is little enthusiasm about playing second fiddle, especially since our image of the *other* has been equally meticulously fabricated. In painting the picture of the primitive, indigenous barbarian as well as that of the helpless, victimized individual *suffering* from a disability, we have concluded in advance that individuals are not to be trusted with taking their fate into their own hands. The same patronizing attitudes we have against people with disabilities within our own culture are here amplified through several additional layers of othering, maintaining the strained status of intercultural relationships for the sake of maintaining the dominant position of the West.

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<sup>36</sup> Stanley Sue, “In Search of Cultural Competence in Psychotherapy and Counselling,” *The American Psychologist* 53.4 (1998): 446.