

Disability Studies in Anthropology

– Concepts of Dis/Abled Otherness –

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Abstract

Disability studies, research on and by people with impairments, have developed within the last 30 years. Many academic disciplines have uniquely contributed to this subject. The different approaches all end in the perception that disability belongs to the social categorization of “the dis/abled other” or “dis/abled otherness”. In the last 30 years, ethnographies written by the dis/abled on the disabled and disability address the distance between “normalcy/the normal” and “otherness/the other” very well. They also determine the reciprocal (mis-)understanding of disabled and abled on each other as “the other” due to differing perspectives.

In this article I introduce the topic of otherness in ethnography by firstly presenting the theoretical and historical background of disability and disability studies. In a second step I will present its meaning and conception in ethnography and anthropology. I will consider and compare data about and from ethnographers and anthropologists on disability regarding their understanding and dealing with the subject(s). The context of research is on perceptions of the body, social malfunction and functional limitations as stigma, a scale of perception of disability as otherness and some general responses of society on disability.

Introduction

Disability has become a multi-faceted term in recent years.¹ In the past it was used to describe all sorts of bodily deficiencies in contrast to “the normal” or “the standard” body. Nowadays, due to social welfare, disability has been politicized describing those who expect special social care and assistance.² Modern thinking is concerned about the costs and the effort to handle disability, the rehabilitation or prevention. Only recently the discourse has turned to legal equality and the implications of inclusion that go with it. It is not long ago that the parties concerned, the disabled³, were solely objects to the abled, thus the disabled giving in to social paternalism. Social paternalism, as part of a hegemonic attitude, is basic to the notion of “dis/abled otherness/the dis/abled other” from both sides.⁴ A stable social balance between dis/abled was never given, but a clear-cut differentiation from both sides as “Them” and “Us”.

¹ There are various definitions of disability, but this is not the focus of this study, since every given definition expresses specific prejudices. It is more what a society labels as “abnorm, disabled, and handicapped” that covers the practical aspect of disability.

² The term covers mental, psychic, bodily and educational factors. Nowadays, heavily educable children, adults with sexual misbehavior, or social misfit are also categorized therein.

³ The WHO guesses that around 10% of the world population (~600- million) globally would fall into this category (World Health Assembly, Document A58/17: Disability, Including Prevention, Management, and Rehabilitation. April 15, 2005.).

⁴ Comaroff and Comaroff (1992:28-29) trace this Western attitude back to Colonialist times. They argue that social stratification, following the industrial revolution of the 18th century led to social classes that always were in competition with each other. As a comparative matrix they use a Marxist approach in anthropology. Hegemony they claim “consists of constructs and conventional practices that have come to permeate a political community”, thus it is in contrast to ideology (: *ibid*).

Thus, otherness is not an aim driven by ideology, but the basic notion of a perception, which aims to keep social balance between disparate members of a society.

The abled handle disability as carers, as observers (relatives, friends etc.), and as those taking part in the lucrative disability business, or on political or legal grounds (e.g. lawyers, judges, insurance clerks, etc.). A large group of abled ignores disability for cultural or social reasons (e.g. religiously conservative stances⁵), personal revulsion or political and social reasons (e.g. rightists, evolutionists, racists etc.). From the perspective of the abled, disability as a derivation from the “normal” is thus either ignored, supported (care, politics etc.) or controlled. The term disability can be defined much too widely such as calling “all people disabled” or not widely enough such as to include “only specific disabilities”. Creamer (2009:5) calls such attempts naive. An open and dynamic use balances both extremes and includes those that need to be included and those that want to be.

As disability crosses a whole society, so every academic discipline has uniquely contributed to this subject. I found that:

- social sciences and specifically anthropology entered the subject from the description of the mutual relationship of the disabled to the abled and vice versa (oppositional or comparative approach).
- medical sciences were interested in researching the cause and elimination of disability (defect approach),
- theology focused on ethics (moral approach) and
- missiology was until now little interested in disability as a part of the propagation of religion (religious approach).

During the development of disability studies it became an important and central issue that a strict divide of voices and research by “disabled” and “abled” people was neither helpful nor practicable (Dederich 2007:19). Since the 1980s disability studies are thus taken on by the “dis/abled” as well (Creamer 2009:4-5).⁶ The abbreviation “dis/abled” has become a brand of disability studies (DS) and so has the integrative/inclusive process – this time from the

⁵ The concept of sin against a monotheist “God” or polytheist “Gods” is argued (e.g. Matthew 9, Mark 2, Luke 5). In the Bible mainly a negative approach towards disability is found (McCloughry & Morris 2002:8-13; Yong 2011:57, 59). The Biblical text reflects ancient claims that disabled have to be healed that is restored to normality or to be regarded with pity or compassion (e.g. Mt 14:14; Mt 20:34). Another example is given in the Hebrew Bible by Job’s end: “as he died old and full of days” implying after all the physical trouble and hardtimes with disability and illnesses that Job experienced, which was presented as divine punishment, he was in need to be restored (Job 42:17; Yong 2011:37). Christian ethics of the Middle Ages are well reflected by Martin Luther, for an incident when “he recommends the drowning of a mentally retarded boy whom he alleged had no soul and therefore could only be an instrument of the demonic” (Reynolds 2008:38). We find the attitude of pity in the form of alms also in the Islamic teaching of *zakat*, the Jewish practice of *tsedaqa* and in some Buddhist directions, although the latter work as basic supply for monks.

⁶ The hereby used abbreviation dis/abled describes the disabled as well as the abled, which potentially can become disabled too. It symbolizes the wholeness of broken and normal society with fluent borders. The term dis/abled reads, abled and disabled (wholeness of society), disabled that are at the same time abled too (still humans and “productive” part of society), abled that can become disabled at any time (overcoming social paternalism or hegemony).

“disabled” allowing the “abled” to attend. In this sense, disability describes the advance towards social equality, towards full integration into all social institutions. A summary of disabilities would be far too ambitious. The entangled areas of life reach from sensory, motoric, physical, psychological and mental to learning and innovative disabilities. Disability is entered congenitally, by accident or illness, or by getting old and losing psychic or physical capacities. Disability can be temporary (short- or long-term) or life-long. However, during a lifetime one or another impairment somehow confronts everybody, thus everyone crosses from normalcy to otherness.

I define the terms “otherness” or “the other” concerning disability studies below (section 2.3). When it comes to disability, the term describes social stigmatization. Thereby it presents margins of societies that,

1. need extra vigor to be crossed, or
2. are never crossed because they mark the realm of taboo (“they” contrasting with “normal”), or
3. finally, in a positive sense, to indicate home, belonging or national identity as part of a peer group.

Ethnography follows an inclusive approach of the dis/abled to study the disabled and disability. Not to mention that disabled are also investigating all areas of social life. Thus important studies by dis/abled persons focus on the topic of disability and the social stigma of “dis/abled otherness” that goes with it. The social studies described below demonstrate what constitutes disability and how it is perceived from an etic and emic stance.

I am writing this paper from the perspective of a Middle-European with a Christian education who has direct experience of disability. This includes daily life encounters between disabled and non-disabled, which are based on the separation of people with mental, social or bodily impairments, caused by the social welfare systems in the West and a paternalist and hegemonic attitude. This article is reflecting the history and those daily life encounters from an insider who takes part in the disabled movements. I draw on my experience and my observations regarding the subject and give examples of encounters between different dis/abled and abled.

1. Toward Disability Studies - The Dis/abled Other in Anthropology

1.1 Historical examples of Disability in Societies

Although disability has always been part of humankind, there was little written until the 20th century with a focus on the disabled or their handicap, besides being mentioned as a social

reality. The Greek philosophers, as well as the Jewish or Hebrew Bible (Christian Old Testament) shows an awareness of disability. Patriarch Jacob was hurt and became disabled in a fight with an angel. Afterwards he was renamed Israel (Gen 32:25⁷). While fleeing from persecution the nurse dropped five-year-old Mephibosheth, who was paralyzed thereafter (2Sam 4:4). Few other Biblical protagonists are stigmatized by a handicap (e.g. Moses with a language issue; Job with illness and disability). Disabled people in the Qur'an are described in the context of religious jihad, and as such they get an exception from participating in the strive to expand Islam (Surah 4:95). In the Mishna we find discussions about the source of disability, often sin and God being the initiators (Rispler-Chaim 2007:6). The same is true in the Hadith and the Qur'an, although sin is not mentioned directly rather unbelief is a cause (Surah 47:23; 2007:8-9).

Looking into history leaves only hints, since individual cases contrast with the general descriptions. Thus, handicapped kings, queens, rulers and clerics could have been very influential. It is assumed that Emperor Claudius (10 BCE-54 CE) and his later successor Emperor Nero (37-68 CE) had psychological disabilities. Other rulers such as Emperor Alexander the Great (356-323 BCE), Emperor Julius Cesar (100 BCE-44 BCE), Emperor Napoleon Bonaparte (1769-1821 CE), Saxonian King Friedrich Christian (1722-1763), besides many others, are reported to have had epilepsy.⁸ These people present the few historical exceptions from the standard procedures to hide handicapped relatives from the public or to the fact that disabled were social outsiders, damned to poverty and fully dependent on the abled to survive. Disabled belonged always to that part of society living on pity and care by their relatives or people with a heart to support others. The effects of humanism and the Enlightenment led to a new public perception of the disabled as “the other” in contrast to “the normal” or abled (Goffman 1963:9-11).

With the changing social structures that resulted from industrialism, disabled people fell under the custody of special care centers and organizations. With it their self-esteem and dignity was raised on the one hand, but at the same time laid in the hands of the caring individuals or institutions. I cannot describe this very complex process here in detail but its results are summed up in written and oral reflections about the disabled in the 19th century (e.g. in *Oliver Twist* by Charles Dickens 1838). By then the disabled fell under limited public and social welfare run by religious or humanity-oriented pockets of society. The 20th century with its two World Wars generated so many disabled people that social care and welfare were necessary to deal with just a part of the enormous social and personal wounds. At least that is

⁷ I give Biblical, Qur'anic and other references for further studies.

⁸ The mainly used term “s/he suffered from ...” persuades the audience that “they” – the disabled – never came to deal with, or even further, accept their handicap, which would be astonishing given “their” success in world politics.

what happened in North-American and European societies. The aim of the social welfare by then was to rehabilitate the disabled so that they were able to work and contribute to their own living. In these times, due to limited auxiliary tools and medical options, the severely disabled got little chance to survive and were left to die.

Through the development of disability studies, disabled people on the one hand spoke out for themselves, on the other hand disabilities and their bearers became objects of wider scientific and public interest (e.g. Down syndrome; Asperger syndrome, cystic fibrosis). Before this, they were not heard, and others, if at all, spoke in their name. Two early advocates of the disability movement were Erving Goffman (1963) and Michel Foucault (1967; both presented in Renggli 2004).⁹ In the US, the veterans of World War I during the 1930s and of World War II in the 1940s-1950s fought for self-determination and independence. President Roosevelt (1882-1945), disabled by polio himself, became an important supporter of rehabilitation, still under the dictate of the medical model.¹⁰ Political movements by the disabled advocated their independence by moving away from social patronization in the 1960s, thus taking part in the liberation movements of that decade.¹¹ Parents of disabled children petitioned their children out of institutions and asylums into the schools of the normal. By the end of the 1960s and early 1970s the Independent Living Movement in Berkeley formed the slogan “Nothing about US without US” (Creamer 2009:26). As in feminism¹², the gay and lesbian movement¹³, the black¹⁴ and many other minority liberation movements, the “disability

⁹ Goffman made the public aware that disability is socially stigmatized because of the out- and unspoken prejudice of “abnormal nature” that nondisabled load on disabled people (1963). Freidson builds on Goffmans findings and comes to the assumption that societies require disabled people to become “normal”. Rehabilitation, social integration endeavors and legislation tempt to stigmatize disability to the effort to “bring them back” to “standard” (Creamer 2009:24).

¹⁰ President Roosevelt funded a recreation center at Warm springs in Georgia and the research on Polio vaccine.

¹¹ Overview under URL: http://archive.adl.org/education/curriculum_connections/fall_2005/fall_2005_lesson5_history.html accessed 2016-09-30]. Also Fleischer Zames, Doris & Zames, Freida 2001. *The Disability Rights Movement: From Charity to Confrontation*. Philadelphia: Temple University Press.

¹² Friedan wrote about the normal life of a housewife in the 1950s in the US. Her description exemplified the refusal of women to well paid jobs in politics, economy and journalism. She became an early advocate of the feminist movement. Friedan, Betty 1963. *The Feminin Mystique*. New York: W. W. Norton and Co.

¹³ Sigmund Freud (1856-1939) and Magnus Hirschfield (1868-1935) opened the venue for homosexual or bisexual orientation studies by assuming that it occurs naturally in an identifiable segment of humankind. Both let go of the then predominant idea of crime or illness. Donald Webster Cory published *The Homosexual in America* (Cory 1951), asserting that gay men and lesbians were a legitimate minority group. Dr. Evelyn Hooker won a grant from the National Institute of Mental Health (NIMH) to study gay men (1953). Her groundbreaking paper, presented in 1956, demonstrated that gay men were adjusted as well as heterosexual men, often more so. Regular raids of the Stonewall bar (New York Greenwich; June 1969) led to political action, which exploded through the National Gay and Lesbian Task Force, the Human Rights Campaign, the election of openly gay and lesbian representatives like Elaine Noble and Barney Frank, and, in 1979, the first march on Washington for gay rights.

¹⁴ In 1955 Rosa Parks (1913-2005) became a symbol for the black rights movement because she denied giving up her seat in the colored section to a white, after the white section was filled. She was not the first one, others did so in 1942, 1946, 1952, but she worked close with the avocates of the African-American Civil Rights Movement, namely Edgar Nixon (1899-1987), Ralph Abernathy (1926-1990) and Martin Luther King, Jr. (1929-1968). This was part of the well-known Montgomery Bus Boycott, a planned nonviolent boycott of public busses to make the public aware of the provocations given by segregation.

liberation movement” became a self-runner, mobilizing the disabled to ask for self-determination. The orientation was from objects of care to subjects of the own fate.

The political run for Washington of the equal rights movement (e.g. Martin Luther King) in the late 1960s and early 1970s encouraged also disabled people and their supporters to plea for legal recognition, which did in the Rehabilitation Act (1973). Globally unique, the Americans with Disabilities Act (ADA), initiated under the influence of disabled, passed in 1990 and ensured the equal treatment and equal access of people with disabilities to employment and public accommodations. In the UK the declaration of independent ways of living and self-support of the disabled in the 1970s, and the resistance to paternalism and infantilizing in the 1980s in Germany, became thriving empowerments of unions (e.g. associations, work groups, communal task forces) built up by disabled and abled alike. The difference therein was an initiative in these unions taken by the disabled, inviting the abled to join in. As an example, the so-called German “Krüppelbewegung” (cripple movement) in the 1980s started from a legal court decision on compensation for a tourist who felt offended by a family with a disabled child in the same hotel. In this case the Disabled controlled the movement but in a way that the Abled could join in.¹⁵

It has to be noted that the early political liberation movement focusing on disabled was initiated by a mix of disabled and abled persons (e.g. Ed Roberts 1960 in Beates 2012:109), but was run mostly by abled. The groups of people involved recognized the injustice, which was, without even being noticed, handed down to the voiceless disabled. Examples of this development are Joan Ablon’s contribution on dwarfism in the US (1981, 1984, Shuttleworth, Russel & Kasnitz 2004), Nancy Eiesland’s input on theology (1994), Ed Roberts’ proposal on Independent Living (Beates 2012:109) and others.

As disability is part of human embodiment, it is obvious that abled and disabled share the same body features, the experience of being hurt, losing abilities through illness, accident or age. Contrary to the other above named liberation movements, this makes the disabled aware that their call for changes was possible only together with the abled. Their own mental, psychological and physical limitations always demand some sort of support and dependency and hinder full independence. The dependency phenomenon – physically, mentally and socially – of the disabled from the abled is one of the less researched areas. “Dependency” is taken as a given, a “natural” outcome of disablement and regarded as “special needs” or “additional support”, thus hindering an “inclusive design approach to creating social environments to fulfil the everyday needs of all members of their society” (Fjord & Manderson

¹⁵ An extensive documentation regarding the US can be found in *A Disability History of the United States. ReVisioning American History* (Nielsen 2013).

2009:2). Dependency marginalizes or challenges the demand of self-ruling while full inclusion is less considered.

The dependency conflict is quite visible in the *Olympic Games* run by the International Olympic Committee (IOC). Nowadays they split them up in three events. Founded in 1894 the IOC is now based in Lausanne. The *Special Olympics World Games* for intellectual disabled, initiated by the IOC in 1968, the *Olympic Games* (since 1894 by the IOC) and the *Paralympic Games* as an extra event the week after the Olympic Games. The International Paralympic Committee (IPC), which is since 1989 located in Bonn, initiated in 1988 the *Paralympic Games*. IOC organizes the little known *Special Olympics World Games* for the intellectual disabled as an extra event. They proceed in between the years of the Olympic Games, including people with intellectual impairments in the organization as best as possible. The *Paralympic Games* came out of an initiative of Dr. Ludwig Guttman (1899-1980), who had to flee Nazi-Germany and worked with spinal cord injured people. The IPC employs dis/abled as well. With the case of Oscar Pistorius (400 and 4 x 400 m; Olympic Games 2012/London), the discussion arose whether disabled people should be included in the *Olympic Games*. Whereas race, sexuality, or nationality is not a reason for exclusion, quite contrary, the IOC is proactively promoting the inclusiveness and positive social effects of international sports.¹⁶ However, obviously in recent practice of IOC athletes with disabilities are excluded or need to go through great bureaucratic efforts to take part in the Olympic Games.¹⁷ Vice versa the IPC pays careful attention to split the different levels of handicap aiming at fairness and equality. However, non-disabled are excluded.¹⁸

1.2 Ethnography and The dis/abled Other - Terminology

Nowadays the terms “the other/ otherness” are discussed in anthropology, because the task of subjectivism is obvious. Clifford (1986:23) states: “It has become clear that every version of an ‘other’, wherever found, is also the construction of a ‘self’. Otherness, so it seems becomes arbitrary when studying cultures through participation. Who then defines who and what the other or otherness is? I will follow Johannes Fabian (1983), whose groundbreaking study on the topic *Time and the Other: How Anthropology Makes its Object* provides a framework. He

¹⁶ The IOC promotes global social development, peace and youth engagement (<https://www.olympic.org/public-affairs-and-social-development-through-sport> [accessed 2016-09-20].).

¹⁷ On June 14, 2016 the IOC and the IPC signed an agreement to partner closely. There is no mentioning of any inclusion: “The IOC and IPC share the same goal of making the world a better place through sport, and I look forward to our two organisations working closely together to achieve this. The IPC’s focus on sport for all and on high-level performance will enable it to reach more and more people around the world, and to ensure the organisation’s long-term success.” (IOC President Thomas Bach. <https://www.olympic.org/news/ioc-and-ipc-sign-long-term-agreement-supporting-the-paralympic-movement> [accessed 2017-01-20].). Adding to the given argument it would be interesting to know how the mentioned people with disability are represented within the 95 members of the IOC itself.

¹⁸ It is interesting to note that of the 15 IPC members at least a majority represents different disabilities.

claims that recognizing the other or otherness “is a condition of communication and interaction, hence of participating in social-cultural practices (or whatever sociological categories, from group to society, apply); or of sharing a *Lebenswelt*” (emphasis in original. EW. Fabian 2006:147). His keyterm coevalness describes the ethnographer and the people he studies as coevals, at the same time the production of an ethnography is descriptive and as such backward oriented. This mismatch leads to “allochronic” studies (:143), obviously subjective by leaving objectivism. However, intersubjectivism (see below) bridges the gap. Regarding The dis/abled Other, as mentioned in the example of the Olympic Games it is the disabled *and the* abled that raise the dichotomy of The dis/abled Other as a given.

I find that the terminology of “The dis/abled Other” wanders around “Difference”, “Otherness”, “Not of us”, “They – we” and so on (Kasnitz & Swizer 2001:2). Such terminology leads to an exclusive perception of the disabled by the abled, emphasized in the terms “The Other” or “Otherness”. It is sometimes not the term as such but the concept behind it, which is used by abled that discriminates and excludes.

Small-scale societies tend to be linguistically distinguished from “normal” or “standard” cultural perceptions by the majority language group. In effect this goes both ways, defining social margins as well as the realm of “Them” and “Us”. The social and cultural conception and construction of The dis/abled Other comes from a sort of stepping back and reflecting on the main mutual differences of “monstrosity” (e.g. Aristotle in his *Generation of Animals* cited in Caspary 2012:25) and “abnormalities” in contrast to “normality” or “the norm”. For the “abnormal” or “disabled” the linguistic category of The Other goes two ways. There is on the one hand the distinction and at the same time the emphasis and proclamation of the own appearance, which is often aesthetically rejected by the abled (e.g. a hunchback). On the other hand, it is about the realization of overcoming socially constructed perceptions of difference, leading to paternalism or infantilizing by the abled. The stigma of otherness does mean sticking to a socially constructed box, which for cognitive and linguistic reasons does not allow for transition (Reid-Cunningham 2009:99-100).¹⁹ Through this process disabled feel the effects of stigmatization, a topic that I will now investigate.

1.3 Ethnography and The dis/abled Other as Stigmatization - Group Dynamics

Examples of stigmatization are plentiful in the literature. Stigmatization of people with impairment is also evidenced in the exclusion from the public sphere (e.g. accessibility), disqualification in the work area (e.g. ineptitude in a specific job; Lischer & Lischer 1985) and daily discrimination based on physical or psychological otherness. Violent encounters of

¹⁹ In this context, proposals to name the disabled political correct are interesting. “Differently abled” is one suggestion aiming at humankind as a common ground (Reynolds 2008:106), “people with impairment”, and other constructs have been considered.

rejection, mocking and physical or emotional force are typical experiences of disabled. Whenever there is a conflictual situation in daily life, accusations are directly oriented towards the perceptible handicap. I observed that in traffic, when a wheelchair user crossed the street, still on the street the pedestrian traffic light changed to red and it was “the ugly cripple” who was blamed by the abled car driver whilst he had to wait for two seconds.²⁰ The real-life experiences that go beyond the reality of abled have to be kept in mind when researching disability or persons with impairments.

Social cohesion determines different processes. One of them is stigmatization. A social group process of claiming someone as The Other is part of normal group dynamics. To strengthen one’s own group identity everyone outside has to be stigmatized to some level. It is the “us” versus “them” paradigm, which addresses social cohesion or differentiation. The Third Reich propaganda was built on such practices, along with many other political, religious, or social attempts (Apartheid, racism, nationalism, dictatorship, world religions claims etc.). In disability studies The Other is constructed for two reasons: on the one hand to distinguish the disabled from the abled; on the other hand, to overcome the distinction and to find common ground in The Other. The later concept addresses The Other as (extra) part of humankind or a society. This is important due to the obvious need of the disabled to get to some degree support by the abled (care, accessibility, political voice etc.). In this sense “stigmatization” becomes a leading antipode to the normal life of people with impairment. Something that is fought against, always recognizing that it could only be softened but never overcome. To most people with impairment it is the “thorn in the flesh” as the Apostle Paul calls it (cf. 1 Corinthians 12:7). The aim of ethnography, as well as of the anthropological researcher, is not to overcome the gap between both parties, but to raise awareness that the category of The Other carries a huge cultural and social-functional load. With this in mind, the concept of The Other is helpful to understand the means and functions of social categorization. Social categories are useful to define socio-cultural areas of life. Due to language and culture shift such life-areas are always developing. Thus, when talking about “inclusion”, “integration” or “equality”, there needs to be clarification about the direction of change: *who to whom, from where and into what*. In other words, those demanding change, from whatever side such demands are raised, need to clarify *their own position* and *what the targeted solutions* look like. Ethnography is one (but by far not the only) practical tool for anthropologists to describe and relate to social phenomenon. Ethnography focuses on the complete social environment of persons or people groups.²¹

²⁰ The normal reaction would have been to say “idiot”. Although, it was not obvious to me if the person was really an abled, since using a car changes also the mind of disabled people and has its own psychological absurdness.

²¹ “While it is clear that all societies change, there is no universal law governing the direction of that change. Instead anthropologists today seek explanations for societal change in complex historical and environmental factors” (Mascia-Lees & Black 2000:25). Methodologically, ethnographic approaches are presented by “participant observation” (Spradley 1980), “participant listening”

2. Disability Studies in Anthropology

2.1 *An interdisciplinary Overview*

Introductions and overviews to disability studies take a disciplinary preference. The examples given here are not final. Dederich gives such an introduction from social sciences (2007), Reid-Cunningham comes from anthropology (2009), as do Davis and Corker (2000). Olive looks at disability studies from social science and its closeness to politics (1990 and 1996). In theology we learn about the “disabled God” (Eiesland 2009), we hear from a theologically initiated liberation movement (Chopp 1987), or a theology grounded on broken and needy leadership (Beates 2012:138-140). Based on his experiences with his disabled brother with Down’s syndrome Yong presents a theology of disability centered on weakness (2011). In anthropology we learn from a *Venus on Wheels: The Life History of a Congenital Amputee* (Frank 1981); the same author presents also feminist study on “congenital limb deficiency” (1988a). Robert Murphy introduced his own emic experience of disability by a slow-growing spinal tumor ([1987] 2001). In linguistics and anthropology, we find social coherence of disabled persons (Longmore 1985). In medical anthropology, rehabilitation became a big topic in disability studies (Zola 1982). Driedger (1989) and Hahn (1987) discuss the advocacy of disability as a civil or human right from the perspective of social sciences. Scotch (1984) develops the civil rights agenda on the handicapped by engaging those who implemented “civil rights for disabled” out of good will. In addition, there are *historical overviews* of disability studies that draw on anthropology, such as Bösl (2010), who argues that disability is a constructed social perception. Such historical reviews are part of the social sciences too as shown by Renggli (2004).

2.2 *Three Models of Disability within Disability Studies*

The main discussion about the understanding of disability is whether it is a concrete absolute rather than a socially constructed category. The following three main models of disability studies swing between these two assumptions (Kasnitz & Swizer 2001:2).

The basic model in disability studies is the *medical* model of disability (see President Roosevelt above). It builds on the assumption that a pathological finding is what defines disability. Followers of this model consider mobility, mental, communicative, aural or visual impairments as disablement. It is restricted to the individual body and its correction or rehabilitation is based on medical diagnosis. It falls short considering the fact that some handicapped people do not consider themselves handicapped, because “we are the way we

(Forsey 2010), the “ethnographic interview” (Spradley 1979), as well as qualitative research out of rehabilitation counselling (Hershenson 2000).

are”); just as some handicaps are not considered disablement (e.g. one-eyed, wearing glasses, stutter, getting older and slower). In addition, the larger social or cultural structures are not discussed in the medical approach.

Here the *social* and *cultural* models come into play. Based on social experience, such as race, gender and sexuality, they understand disability as a social construct (Moss & Schipper 2011:2). Whereas the social model is widely used by British scholars, the cultural model is more established in North American scholarship. The difference lies in the understanding of a disability. The social model grounds on the medical model and disability is an impairment, which has to be located and defined as such. In the social model, disability refers to social and structural discrimination against persons with impairments (2011:2).²² The cultural model understands disability as a social invention of the ways that cultures use physical and cognitive differences to narrate, organize, and interpret their worlds. Thus, descriptions of disability become one way by which we create or shape culture (:4). The impact of the cultural model is obvious. It focuses on insiders as well as outsiders and it aims at the anthropological outcomes of disability on society. It is within these perceptions of the world that people build up their dichotomy of The Normal/normality and The dis/abled Other/otherness.

An unsolved problem of all these models is represented by the categorization of disability. It is not just the person with impairments, and the society, that define disability. Sometimes other issues also lead to a perception of disability. For instance, different aesthetics generate different perceptions. A 2.2 meter square-shouldered giant can be perceived as disabled (e.g. a frightening bully in Japan), but in basketball he would be a hero. Another example is a woman with an excessively large bust: the perception ranges from impairment (e.g. combined with a short torso) to sexual attractiveness. Every variation from the physical and behavioral “norm” offers the prospect of being considered a disability. In addition, it includes the notion of risk, due to negative social attitudes against the understanding of disability in a society. For instance some societies in the Near East disqualify men without beards as eunuchs (sexual disability), nasty or worse (e.g. Lemos 2011:48-49).

Approaches based on the social and cultural models need to keep other different aspects in mind when claiming disability. Before we go deeper into this, we will now look at some historical developments concerning the make-up of people with impairments as The Other.

2.3 The Dis/abled Other, Otherness - Aspects of Disability

The concept of “The dis/abled Other” goes back to the notion of the “broken” or “functionally deficient” person (Brock 2012:2). Social categorization follows social characteristics of

²² For instance, Tom Shakespeare calls the social model a dead end (2006). He promotes a pluralist, engaged and nuanced approach to disability.

individuals or groups. Innate properties such as race, gender, age, bodily features as well as acquired features such as property, reputation or social power management determine such categories. In every ethnic group, society and microculture, a division of the non-normal just by their sheer existence determines the norm and vice versa. Disabled people present a contrast, and thus define the margins of “normality”.²³ Yet, they are considered monsters, abnormal, disabled, they, The Other, not to mention the many bad local nicknames they are given. As a subgroup within every human structure they constitute an additional or contrary social element to the group of normal, both groups constituting the society as a whole.

One aspect of otherness as disablement needs to be emphasized. The reality of disability is open to all. It is not a fixed state of being but a state that all may enter, it is an intrinsic part of humanity. Not just a slip on the ladder, but growing old, getting ill or being handicapped short-term (e.g. broken leg, arm etc.) opens up the experience of impairment to everybody (Tataryn & Truchow-Tataryn 2013:13-14). From this point of view, the concept of The Other seems absurd to some extent. However, the life experiences of illness and short-term impairment differentiate the status quo of the normal – the abled – from the disabled. It is the ignorance or dispossession of impairment due to being pregnant or ill, getting old, or the widely and at some level accepted impairments like wearing glasses, teeth-braces, a hearing aid, or similar deterioration, which allows for addressing people with impairments as The Other. The constituents of such differences are embodiment, social malfunction, and limited self-awareness, which now come in focus.

2.3.1 Perceptions of the Body

Speaking about “brokenness” or “deficiency”, the concepts of the body, including embodiment is of interest here. The body, although physically manifested in an individual, functions also as a metaphor (Brock 2012:2). This goes two ways. The term “body” stands as a symbol for the idealization of physical perfection, its aesthetic and ethical aspect. Thus, body represents the manifold variations of humankind, such as race, gender, environmental adaptation, or disability. The body can also be understood as metaphor or symbol for larger social structures (Douglas cited in Abrams 1998:73). A “social body”, such as a political or clerical structure, reflects to some extent the body of an individual (e.g. 1 Corinthians 12:15-20). An individual’s “rejected” body mirrors the general attitude within a society to banish anything that this body

²³ In societies in which specific body malfunctions are decreasingly recognized a social location of these people can change over time. HIV (AIDS) was considered a deadly epidemic in the beginning (which it was); over course, it changed to a serious illness, which by now, due to the developed cure moved into one of many illnesses. Leprosy underwent the same change, looking into perceptions of the antique and today. In religious settings such as Islam “AIDS is believed to be God's punishment for homosexuality and adultery” (e.g. cited in Rispler-Chaim 2007:10). Other religious segments nowadays claim AIDS an illness and care the infected (<https://www.elca.org/Our-Work/Relief-and-Development/HIV-AIDS-Ministry> [accessed 2017-01-12].).

represents. In this sense body functions as a metric to define the boundaries of the social norm(s). Take for instance the priestly orders of the Hebrew Bible and the preconditions of their sacredness. Bodily perfection is a prerequisite to perform the bond between heaven and earth, thus the social group of the Jewish priests mirror the ideal human condition defined by the deity (Abrams 1998:61, 66).²⁴

In many religions, each of the faithful is to some extent part of the wider religious or priestly body. The inner circle of clericals or priests echo the expectation of sacrosanct perfection. In political structures, the elected (democracy), or those that are most powerful (dictatorship), represent the ideals of the social body temporarily. In the case of disability, people with impairment are marked as The Other, because “trust”²⁵ in their benefit for society is basically missing. This perception includes the thinking of human indignity based on the assumption that these people can take no responsibility for themselves (Reynolds 2008:30).²⁶ In the worst case, dehumanization of the degenerated body leads to euthanasia or the expulsion of the unwanted segments of The dis/abled Other (e.g. Third Reich euthanasia program T4/Tiergarten 4).

2.3.2 Social Malfunction – Orientation of Conscience

Another aspect of abled seeing disability as otherness is social malfunction. This term expresses the aspect of derivation, especially when the impairment comes to the foreground and the individual, as a character, a mind and a person is no longer recognized. Social malfunction describes the conflict that arises to keep relationships socially balanced. If the handicap makes up the individual, then rejection aims at the whole person. In Gen 1:26-27²⁷ mankind is asked to “rule, take charge” or “take care” of all the earth. The author of John chapter 9 describes a blind man as a poor (beggar) and the disciples of Jesus ask about his sin. During the whole discourse, Jesus, claiming to be the Messiah (John 4:26), makes explicit that sin is not a cause for blindness. However, he transfers (negatively connoted) real blindness to a negatively connoted spiritual blindness and this brings back the harmful public opinion given

²⁴ Leviticus 21 describes the purification laws for priests. A Jewish priest could be disabled, but that would exclude him from specific services (Abrams 1998:23-25, 28-29). Impurity goes here with specific impairments (dwarfism, blindness, paralysis etc.). “No one with a defect or imperfection is allowed to enter the Holy” (23: Vv. 17-21). How far these religious laws are merely human reflections and not inspired and divine words is a debate in Bible sciences.

²⁵ “Trust” refers to the benefit that people attribute to a social institution. E.g., a politician is elected because people assume he is able to fulfil the anticipated role. Such leading confidence of social benefit is missing in the case of disability.

²⁶ Reynolds takes on a Christian point of view on assumptions about human wholeness and normalcy: “Usually they are perceived as inverse reflections of God's purpose, a tragic mark of something gone wrong. Disability quickly becomes a sign of imperfection, a flaw in God's good order, something to be undone.” (Reynolds 2008:30).

²⁷ “Then God said, ‘Let Us make man in Our image, according to Our likeness; and let them rule over the fish of the sea and over the birds of the sky and over the cattle and over all the earth, and over every creeping thing that creeps on the earth.’ And God created man in His own image, in the image of God He created him; male and female He created them.” (Gen. 1:26-27 NAS)

to blindness. The circular reasoning is because blind people, representing all disabled, are not perceived to fulfill the instruction of Genesis 1:26-27.

Defining social malfunction of disability as an economic concept is a global attitude, but the reasoning seems different. In North-American and West-European cultures a problem-oriented approach, based on the medical model (see above), is grounded in individualism, capitalist economy and humanism. Cultures based on strong individualism follow more a guilt-orientation. In contrast, collectivistic cultures follow more a shame-orientation. In shame-oriented cultures, e.g. Asian, near and middle eastern, the social and cultural models fit better to understand the processes that lead to the different levels of rejection of persons with impairment. In those societies normalcy spans the social embedding in the nuclear and extended family, the wider social structures (e.g. small-scale societal structures) and mainly the ability to start and support a family. The economic pressure of North-American and European Western cultures contrasts with the social pressure of shame-oriented cultures. Economically a person or family should be able to support itself and provide for all its members. Social balance on different levels of society aims at stable and sustainable relationships following social rules.

In sum, economic inability of independent living of dis/abled persons leads to a social malfunction. The social need behind is universal, but is given different levels of public attention in different settings such as e.g. a personal budget, daily assistance or care. People with impairments have a harder time keeping this social balance out of financial and interhuman reasons. Therefore, they are always on the edge of social malfunction.

2.3.3 Functional Limitations - Paternalism

“Disability exists when people experience discrimination on the basis of perceived functional limitations” (Kasnitz & Swizer 2001:2). Extreme outcomes of discrimination are easy to define, but what about ignoring somebody unconsciously, giving preference to someone else or just feeling uncomfortable in the presence of “The dis/abled Other”? Interestingly the latter is also often observable when people with impairments unknown to each other meet in specific tight situations. This is also the case for nurses or carers attending a person with impairments. As I personally observed, for example, a group of people with mobility and mental impairments went out riding horses led by caregivers. They met an unknown person with a wheelchair on a small path. There was confusion as to how the carers and the disabled should handle that situation. The caregivers and some disabled (maybe just following their approach?) asked the unknown wheelchair driver to leave the path until the group went by with the comment that the path is far too small to drive a wheelchair along (!). In this strange situation “The Others” (group with horses) become paternalist toward “The dis/abled Other” (wheelchair user). They

passed on the same dominant attitude that they experience to the seemingly weaker party. This paternalist approach toward dis/abled is deeply rooted in humankind. Inclusive approaches tend to balance the paternalist human tendency, to rule over or care for the weaker parts of society, against independence. This is also true concerning the protection of women, children and political or religious minorities, but it is less recognized for people with a handicap.

2.3.4 A Social Scale of Perception - From Minimal Acceptance to Full Rejection

Historically we find some disabilities that the abled reject socially less. In North-American and European Western cultures this includes mobility disabilities. On the other hand, there are those that the abled reject strongly, such as physical deformity and mental illness. Often these are combined and so it is difficult to reduce a disability to a specific group. The ability to communicate, to understand, to reflect, to see, to hear and so to participate in society leads the abled to ignore to some extent lesser mobility or deformative disabilities (e.g. walk with a limp, a stoop). Abrams reveals that for a person to function fully in Judaism one “has to have da'at (cognition or consciousness)” (1998:15). So, in this setting mental soundness of mind has highest priority for functioning religiously (:153). Another example is given in the inclusion of dwarfism as part of royal amusement or public disgrace (fair, circus) in the past.²⁸ However, these people groups still face the concept of dis/abled otherness.

The American film industry reflects at least the North-American and European Western levels of perception of disablement to some degree, aiming at an inclusive approach. For instance, actors with dwarfism are engaged as main actors or in minor roles (e.g. *Station Agent* 2003; *Mirror Mirror* 2012).²⁹ Bodily impairments are mainly related to people that “made their way” meaning became publicly know (e.g. *My left foot* 1989 – Christy Brown; *The theory of everything* 2014 – Stephen Hawking). On the other hand, mental disability is introduced cautiously. Autism (*Rain Man* 1988; *Mozart and the Whale* 2004) or developmental disability (*I am Sam* 2001) occurs in films in which all the main actors, nor supporting actors, do not share the disability. In the following examples, there are great arcs of tension between psychotic insanity (e.g. *Psycho* 1960; *The Silence of the Lambs* 1991; *Shutter Island* 2010), schizophrenia (e.g. *A Beautiful Mind* 2001) and mental disability (e.g. *Memento* 2000). Mainly because the actors are not disabled themselves, most movie attempts are highly criticised by those that are said to be represented by the abled. In between is the deaf and mute community, which is often highly isolated, but less acknowledged under the label disability (e.g. *Beyond*

²⁸ As a matter of fact it were the mentally impaired by which the court jester movement started during the Middle Age. They were encouraged to reflect the rulers by speaking out the “truth” that is the unconditioned perception of a behavior, a situation or a person. The mentally impaired were considered to speak Gods true thoughts due to the presumption that they cannot reflect (Lever 1992:19, 119).

²⁹ One has to decide whether this presents a follow up of dwarfism as court jesters, as in ancient Egypt to Medieval royalism.

Silence 1996). These examples show how sensitive society is when dealing with different disabilities but how little disabled are engaged to represent and play themselves.³⁰

As another example, there is the law of minimum wage in some European countries. People with impairments that live and work in special-care organizations of social welfare are one of the sole categories exempt from these rules. The exemption should lead employers to work with as many people with impairments as possible to lower costs, yet this seldom happens due to prejudices.³¹ If it were not for the microcultures of disabled people, the capitalist economic pressure would make prolific use of such legal exceptions.³² I am arguing here for enough assistance that people with impairments can earn the same money that everybody gets.

2.3.5 General social Recognitions of Disability as Otherness

Disability follows universal social responses to (negative) perceptions of societies. These contribute to the concept of The Other. There are three ways this happens.

1) Special public conscious attention is given to people with disability or impairment.

2) Different levels of social recognition are given to disability as otherness.

2.1) For example, care or help is the primary intention.

2.2) Some disabilities then generate different levels of rejection, from disinterested aversion to banning.

2.3) Some disabilities also lead to admiration, at least if the handicapped person shows that the handicap is not a reason to reach life goals.

3) Some disablement is not even recognized, although obvious. I now look at these observations with regard to universal implications.

In public, special cognitive attention (section 1) is obviously given to people with impairments. This is observed when children in North-American and European Western contexts are pointing very directly with their finger and asking questions like “What’s that?” (note the neutral!), “Why is (s)he so small?”, “Why is (s)he using a wheelchair?” etc. In cultures that are more shame oriented the same situation would attract a crowd and loud laughing would go with these questions and the attempt to touch the “object” (haptic or sensory society). Often adults have a hard time explaining the otherness of disability to their children.

³⁰ What are reasons for that? One main factor is about the extra effort that a handicap brings with it, for instance carers or auxiliary tools. Another, not openly discussed reason are the assumptions that people with impairments would not be able to perform their role or not be well received by the audience due to their handicap. It is one thing to look at a Hollywood star playing a handicapped or to watch a handicapped performing his reality.

³¹ It is interesting that in an economic system such as social capitalism (e.g. Germany), people with impairment are counted as non-employees, although they go to work. Here by legal sanction the valuation of a person based on his ability to work and serve society is reduced to sheer work occupation with as little reward as possible (<https://www.lebenshilfe.de/de/themen-recht/artikel/Keine-Auswirkungen-des-Mindestlohngesetzes-auf-WfbM.php?listLink=1> [accessed 2017-01-12]).

³² Another limitation are the laws of protection for people with impairments. It gets difficult for employers to prove that the working conditions are based on the needs of a disabled employee.

This tension declares the unbalanced bias towards “The dis/abled Other”. The observation by children in itself is a hint to any deviation from the “norm”. Thus, the use of medical and technical aids, the inability to use any or all of the five senses or an aesthetic distinction (physical mal- or deformation) leads to such perceptions. Whereas children on the one hand are stuck on the physical deviation, they adapt quickly to new concepts, if these are socially acceptable, like wheelchairs. Adults, on the other hand, deal more easily with any deviation but they are more eager to defend the social “norm”. In the long run the first response, by children, allows a widening of the perception of the “norm”, and thus bridges the gap to The dis/abled Other. The second response, by the adults, supports a social interaction within clearly set boundaries. However, in both attempts otherness is socially determined.³³

As a second universal social response we find different levels of recognition (section 2). First, there is a consideration to care for people with impairments. The so-called human maternal instinct grieves for the weak.³⁴ However, within this consideration disability as otherness is automatically defined as weakness. Typically, persons in wheelchairs or with sticks before a closed door are not asked if they need help but the door is automatically opened. It is only by the opportunity to self-supply as a productive member of society that people with impairments are coming out of long-term care. In many cases that would include a legal personal budget (on individual budget see below). From the point of view of the officials, the cost factor hereby is weighed against the utilization factor. Thus, the core family of the disabled is left alone to make a final decision also based on financial grounds. Sociologically, one does not have to go as far as Aristotle to find economic reasons to kill all such elements at the onset of the disablement (*Generation of Animals*; in Caspary 2012:25).

Different levels of social recognition are given to disabled people by care or help (section 2.1 above). It is a fact that people with impairments are asking for less individual but more general political recognition as a group. Because of their otherness they fall outside of “normalcy”, based on their dependency on care and social help. This leads to an unfortunate social imbalance for those in need, asking those for help who categorize them as economical beneficiaries, abnormal, The Other. Even worse, such dependency weighs heavily into the deviation from the “normal”. Fortunately, recent governmental attempts in some European countries are based on an individual budget that would give people with impairments the option

³³ Attempts to balance the gap of norm and otherness are found in sport events run by disabled. Often the audience is invited to use the sports wheelchairs too or to play during breaks with them. However, professional non-handicapped games are seldom open to invitations of handicapped. Besides reasons of piety (“we don’t want to compromise them”), rejection plays into this.

³⁴ Few, if any societies would exclude disabled children per se. However, the human maternal instinct could be oppressed by social pressure, based on economic, religious or ideological interests. The practice by medical staff that goes along pre-implantation diagnostics tends to hand over the “full responsibility” to the parents/ mother without giving social options, such as information on financial support or legal adjustments of state care for handicapped children (e.g. assistance, day care etc.).

to handle their needs on their own (e.g. in Germany: Personal Budget for people with impairments).

There is another main response regarding the level of recognition one gives to disabilities (section 2.1 above). There are disabilities that are either ignored (e.g. wearers of glasses, hearing impairments) and others, which are highly rejected by society (e.g. aesthetic anomalies, mental disabilities)³⁵. Universally, the moment the impairment is recognized it is clearly defined as a derivation from normalcy, otherwise it would not be a handicap, disability or impairment. Normalcy, from the aspect of ignored impairments, displays a grey zone in which disabilities are recognized under the surface but do not demand any social reaction. On the level of high rejection, the social response ranges from justified euthanasia, starting with abortion and sterilization, to ignorance and isolation of people with impairments (e.g. hospitalization; section 2.2). According to my observation, in this case, normalcy is defined by a negative boundary into which one is not to enter, close to the concept of taboo. Anything outside normalcy is considered abnormal, subhuman or non-human. Such attempts allow societies to treat those outside based on a specific ruling, sometimes legally, e.g. the Nuremberg Laws from 1935, sometimes interpersonal.

Some disabilities lead to admiration; at least if the handicapped person shows that s/he can reach life goals despite a handicap (2.3). In this case the ethical foundation of a society generates a path for the dis/abled Other. Dis/abled outsiders, “they”, are able to participate in society as potentially full members. However, extra recognition is necessary to earn acceptance, going along with pressure of performance to reach out to normalcy. For instance, in sports (e.g. the Paralympics), in arts, in politics or as influential leaders, people with impairments are admired, sometimes welcomed, and at least not (only) reduced to their handicap.

3. Ethnography in Disability Studies

I want to give an overview of anthropological research on disability studies to understand their social impact. As already mentioned, methods of ethnography are many.³⁶ I will only focus on ethnography about disability. Kasnitz and Swizer (2001) claim that anthropology is ideally suited to address disability studies because

anthropologists seek the other to find themselves, the newly identified concept of otherness of disability attracts established ethnographers looking for a renewal of their experience of other in a known field site and disability attracts anthropologists because it is a socially and

³⁵ The examples are from North-American and European Western socio-cultural backgrounds.

³⁶ See section 1 Introduction last paragraph and FN 21.

culturally constructed category with important implications about how societies differentially distribute power (Kasnitz & Swizer 2001:2).

Reid-Cunningham argues similarly about the differential power distribution regarding dis/abled as The Other or otherness by following the paradigm of stigma/stigmatization (2009:99-100). It is in the natural interest of anthropologists to research dis/abled otherness or The dis/abled Other, including the microcultures of people with impairments. The aim of descriptive ethnography is to contrast the individual perceptions of the world given by individuals and ethnic groups with each other. By giving a rationale to their specific research, ethnographers define their motivation, their background, as well as the conception of dis/abled otherness or The dis/abled Other to their audience. They combine emic (inside), etic (outside) and mediatory (mediating) stances in ethnography.

Ethnography in disability studies is helpful to “explore the lived experience of disability in a world dominated by non-disabled people” (Online: Disabilities studies 2015)³⁷. Here ethnography on disability follows a mediatory impulse. It allows cross-handicap perspectives (e.g. from blindness to dwarfism etc.), as well as from the abled carers of one caring situation to another (e.g. from Alzheimer to paralysis etc.). This comparative effect of ethnography on disability, as noted in the citation above is directed at bridging the gap between the disabled and the abled.

3.1 Perceptions of Ethnography towards The dis/abled Other

I want to emphasize one focus of ethnography on The Others by giving attention to the bodily limitations of people. Knowing that such an approach would be far too simplistic, ethnography describes The Other in context, that is, in the realm of the disabled and the abled. On the other hand, this context also limits the objectivity of ethnography.

During my research I learned that only by disclosing a researcher’s subjectivity can objectivity be claimed. Going one step further, an ethnographic intersubjective approach addresses otherness well. The idea of intersubjectivism in ethnography, as mentioned by Pels (2014:229), leads to “shared time” which is “intersubjective time” or history. In his opinion this is basic to the founding of ethnographic objectivity. Nonetheless the “object” of research represents itself best through its own voice. The auto-ethnography on *Venus on Wheels: The Life History of a Congenital Amputee* (Frank 1981) reflects that well. Researcher and object are the same person. A focus on otherness through social indication becomes obvious. In this example, ethnography reflects the self-perception of a disabled person in her own world *and* the world of the abled, two *Lebenswelten* that come together. In contrast, in Swinton’s analysis

³⁷ Disabilities studies 2015. Disabilities Studies. Medical Anthropology Wiki. University of South Florida. Online: URL: <http://medanth.wikispaces.com/disabilities+studies> [accessed 2017-05-12].

of Vanier's L'Arche communities, the focus is on the world of the disabled that live together with the abled to learn from each other (Swinton 2008:11-12). Thus, an ethnographer takes a position in the ethnography and aims to present the difference but also the parallelism of both worlds (Cliqué 2001:7, 17, 27).

3.2 Areas of Life – Aesthetics, Struggles and Hopes

In ethnography a researcher focuses on the whole of an ethnographic encounter. While dealing with the concept of dis/abled otherness, difference is most important. What makes up difference is best defined in the dependency from others (care, daily help, social law and welfare), in the otherness constituted by disability (e.g. dwarfism, congenital amputee, paralysis etc.) and/or in the question of self-esteem within the individual's state of being. The latter is particularly important in view of whether ethnography is meant to develop new approaches or to exemplify a given situation. The range of self-acceptance goes from full to little: the first, often and logically by people born with impairments, and the latter by those entering otherness during their lifetime, thus facing a new perspective on life. Both attitudes are important in ethnography on disability and sometimes overlap regarding specific life-situations. Important areas of life are managing disability financially, finding a spouse, or earning respect through life efforts.

As obvious in the medical model, the basic assumption of abled towards disability is something that disturbs, must be removed, resolved or put aside by ignoring or covering it (Tataryn & Truchan-Tataryn 2013:10-11). I assume that the basic orientation of conscience, be it a shame or guilt characteristic, leads the disabled to take over that attitude. Thus, the collective subconsciousness leads to an overall attitude of pity and sorrow that constitutes a state of superiority by the abled towards the disabled applicants they represent. This is most obvious in a social welfare system as in Europe where the petitioner seldom has rights but is urged towards a dependency by a clerk. Often the secondary need for medical aid takes so much time and effort that it becomes a main task. Yet, the only thing won is taking part in public daily life. The ethnographies mentioned above seldom deal with these questions, but more with the tension of the encounter between abled and disabled in specific situations (e.g. shopping, church, visit to doctor). The authority and power flow that goes with these encounters in North-American and European Western countries is uni-directional from the abled to the disabled. Even if the disabled are in a privileged position (e.g. wealth, legal knowledge, being a clerk or lawyer) the dependency on the "system" (here official social welfare) is enormous.

4. Summary, implications

In this article I address the question of ethnography in relation to disability studies. I explained the relationship of anthropology and disability studies by looking back at the development of disability studies in history. Ethnographies of the 1970s to the 1980s are based on emic, etic and mediatory data and present the concerns, challenges and possibilities of bridging the gap between people with disabilities and the abled. I demonstrated an awareness of this gap in the perception of otherness regarding dis/abled. The concept of The Other or otherness as a stigma of the disabled by the abled is historically deeply rooted in many societies. However, it also mirrors similar perceptions of the disabled on the abled, reflecting experiences of exclusion, mistrust and discrimination. Descriptive ethnography focusses on this phenomenon of otherness by first describing it, then by comparing its outcomes in different societies with each other and lastly through raising awareness. This consciousness aims to bridge the gap between the spheres of life (*Lebenswelten*) of the disabled and that of the abled. Either way, whether disabled write ethnographies for the abled or vice versa, otherness will always be a reciprocal social mark. Thus, as I wanted to indicate, one aim of ethnography is to become aware of the conjoint linking of social elements and the factors and prejudices that hinder communication. Due to the nature of ethnography, objectivity is not to claim; instead an intersubjective approach and a mediatory task in ethnography bridge the gap.

The content, history and outcome of the three recently developed models of disability studies, namely the *medical*, the *social* and the *cultural* model, consider dis/abled otherness as a social mark. Those marked as outside of normalcy and “in need” of being restored (medical model), those that are under care or define themselves disabled by the reflecting society (social model), or those that are regarded as dependent, discriminated against or not worth inclusion (cultural model). A general focus on disability was based on a society’s perception of the body (positive awareness) and its malfunction (negative sense), the functional limitations of society, and the different perceptions of disability by society, spanning from rejection to admiration. The concepts of the other or otherness are on the one hand helpful to define social boundaries, on the other hand these boundaries, as is the case for people with disabilities, are responsible for the inclusion of social groups.

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