

DEAF HUMAN RIGHTS ACTIVISM IN PRACTICE

The Tension between Disability and Cultural Approaches to Deafness

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Acronyms

CoE	Council of Europe
CAT	Convention Against Torture
CEDAW	Convention to Eliminate All Forms of Discrimination Against Women
CERD	Convention on the Elimination of All Forms of Racial Discrimination
CI	Cochlear Implant
CODA	Child Of Deaf Adults
CPMW	Convention on the Protection of the Rights of All Migrant Workers and Members of Their Families
CRC	Convention on the Rights of the Child
CRPD	Convention on the Rights of Persons with Disabilities
EUD	European Union of the Deaf
ICCPR	International Covenant on Civil and Political Rights
ICESCR	International Covenant on Economic, Social and Cultural Rights
UN	United Nations
UN ESCO	United Nations Educational, Scientific and Cultural Organisation
WFD	World Federation of the Deaf
WHO	World Health Organisation

Abstract

Deaf people are commonly considered as people with a disability, but many rather consider themselves as belonging to a linguistic and cultural minority. These distinct constructions entail different human rights issues and argumentation in people's daily lives. This thesis examines deaf human rights activism in practice and analyses the tension between the two concepts of disability and culture. The interdisciplinary approach, with an anthropological focus, contributes to an understanding of the practice of localising international discussions. It will help to grasp the meaning of "deaf culture" and important developments in the disability rights movement. The presented cases of 'Cochlear Implants' and 'Deaf Education' – with empirical material from Austria – represent currently important issues for deaf human rights activism in Europe. The examination of their context and use of argumentation will help to analyse the applicability of the disability and culture concepts in practice. It further shows the potentials and limits of both approaches for deaf human rights activism. The thesis aims to contribute to a better understanding of the needs and expectations in the practice of deaf human rights activism, in order to ensure that the various experiences and needs of deaf people are taken into consideration.

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Preface

In the course of writing this thesis, I was repeatedly asked why I chose to write on the topic of human rights for deaf people. It is quite an easy answer; I have a deaf brother and thanks to him I got to know many deaf people in Austria. I have always been impressed by their strong sense of community and the beauty of sign language. In my eyes, the label of disability just did not seem to fit to the experiences I had in my brother's company. So even before I started my research for this thesis, I have been observing and reflecting a lot on society's perception of deaf people and relevant human rights issues. As a social anthropologist I have been curious to find out what the idea of "deaf culture" actually means in everyday life; including the implications of people's self-identification and networks for the practice of human rights activism.

The argument 'nothing about us without us' continuously arises in debates on the topic of disability and deaf rights. There is no doubt that this statement should be respected concerning decisions and policies that affect the lives and human rights of deaf people. Their opinions and experiences are definitely essential in order to find the most adequate way to act. Therefore, I am very thankful to my brother and his wife, who are both very active in the Austrian deaf community. They patiently answered to my questions and gave me the continuous possibility to talk to insiders, while providing very helpful input for the work on this topic. I believe this has been very beneficial for the value of this thesis, because as a hearing person I am an outsider per definition and it will not be possible for me to completely understand what it means to be deaf. But I believe I can use my personal experiences and my education to try to present relevant issues and contribute to awareness raising for deaf human rights.

1. Introduction

People with disabilities are often referred to as the world's largest minority. According to data of the World Health Organisation (WHO), global numbers for disability are increasing because of an ageing world population and the fast spread of chronic diseases, as well as better methodologies to measure disability. Nowadays, disability is more and more perceived as part of the human condition; it is to be expected that at some point in life, almost everyone will be temporarily or permanently impaired. Estimates on the amount of people currently living with disabilities vary; according to the WHO, around 15 percent of the world population were affected in 2010.¹

I want to put the focus of this thesis on the rights of certain people who are commonly regarded as part of the world's biggest minority of people with disabilities: deaf people. Yet, when looking a little closer at their self-image and the concept of deaf culture, it becomes clear that deaf people rather refer to themselves as a cultural and/or linguistic minority than as being disabled.

1.1 Research Question

The tension and disparity of the two perspectives of disability and cultural minority lead to my research question: *How does the tension between disability and cultural approaches to deafness play out in relation to human rights activism and the concomitant arguments regarding human rights issues?*

Rights of deaf people were considered in the drafting process and included in the United Nations Convention on the Rights of Persons with Disabilities (CRPD), but this still does not necessarily imply adequacy of the label for deaf people's self-identification. There have been extensive discussions on the so called medical and social model of

¹ WHO, 2011, p. 7.

disability, which are a good starting point for a closer look at the argumentation used in deaf human rights activism. And, I believe, in order to cover all relevant human rights aspects for deaf people, it is highly important to go beyond the medical perception of deaf people as people with impairments and instead, include social and cultural factors. These are pertinent issues when speaking of barriers in daily life, and also when speaking of human rights claims.

Anthropological research has highlighted social relations and the issue of deaf culture across borders. I want to elaborate on the scope of this idea of deaf culture, and not only analyse its importance when looking at human rights for deaf people, but also see what kind of advantages or disadvantages it entails in the practice of deaf human rights activism. Understanding the interplay between deaf culture and deaf human rights activism can be beneficial for future negotiations and developments in that area. It will help to ensure that all relevant human rights issues of deaf people are considered, as some of them might not come up when only applying a perspective of disability rights.

1.2 Methodology and Thesis Structure

In order to answer my research question I will first draw on the two involved concepts of disability and culture and review relevant literature on both. This will not only include anthropological contributions on the topic, but also bring in other pertinent perspectives and introduce the matching human rights documents, such as the UN Convention on the Rights of Persons with Disabilities and the UN Declaration on the Rights of Persons Belonging to National or Ethnic, Religious and Linguistic Minorities.

The method used for answering the research question is a case method. I will use the cases of ‘Cochlear Implants’ (CI) and ‘Deaf Education’ to analyse the applicability of the disability and culture concepts in practice. Both cases represent an important issue for deaf human rights activism. People all over Europe and America are concerned with these matters; in Africa CIs are currently still too expensive to be a big issue, but deaf education definitely is. The two chapters will each start with an empirical example from

Austria, for which I will use material collected from media reports and newspaper articles as well as reports and statements by deaf associations. More than 400,000 people in Austria have a hearing impairment, yet not all of them consider themselves as belonging to a deaf culture and community; therefore the number of deaf people in Austria is much lower and lies between 8,000 and 10,000.² This already reveals the tension between the two analytical concepts of disability and culture. It is exactly this tension, which will be presented in a broader and more general context following the empirical examples in the respective chapter.

This will show the meaning and limits of deaf culture when talking about human rights issues; not all hearing impaired persons worldwide are included in the concept of deaf people. Nevertheless, I believe, the analysis of the use of common experiences and culture to empower the transnational minority of deaf people can contribute to a better understanding of the needs and expectations in the practice of deaf human rights activism going beyond the national level.

1.3 Background

There are, for several reasons, no exact numbers of deaf people in the world, and, as we will see in this thesis, being deaf and being part of a ‘Deaf community’ or ‘Deaf culture’ is not the same. The term ‘deaf’, with a lowercase ‘d’, is often used to refer to those people for whom deafness is primarily an audiological experience. Being deaf signifies a medical and auditory condition. For the most part, these people lost their hearing completely or partially in early or late life, and prefer no contact with signing Deaf communities. Instead, they put their efforts towards staying a member of the majority (hearing) society in which they were socialised. ‘Deaf’, with an uppercase ‘d’, is an emic term and refers to people who were born deaf or deafened in early (sometimes late) childhood. It signifies a belonging to a culture based on shared language, identity, and history. Sign languages, communities and cultures of Deaf people represent the

² Krausneker & Schalber, 2007, p. 80.

principal experiences and allegiance of a Deaf person.³ However, since there are not only two different kinds of hearing impaired people (deaf or Deaf) – their knowledge and use of sign language differ as well as the amount of social interaction with other hearing impaired people – and I do not want to make it more confusing than it needs to be, I will only use the term deaf with a lowercase ‘d’.⁴ I do not want to diminish the work of people who established the ‘Deaf’ concept; on the contrary, I will refer to a lot of their thoughts and opinions. Being ‘Deaf’ implies a conscious process of claiming an identity. With my use of the term ‘deaf’ I mostly refer to people who have been hard of hearing or not able to hear for the most part of their lives. I do not want to exclude the interests of people who might not have the means to take part in elitist debates on what it means to be ‘Deaf’, but who still might fulfil several of the necessary criteria for a cultural understanding of being deaf. Therefore, my use of ‘deaf’ combines the meaning of the audiological condition with cultural and linguistic aspects and I want to stress the heterogeneity of ‘deaf people’. If I just refer to the audiological condition without implying any cultural characteristics, I will not use the term ‘deaf’ - but ‘hard of hearing’ or ‘hearing impaired’.

More than 360 million people have disabling hearing loss, according to global estimates by the WHO from February 2013.⁵ The World Federation of the Deaf (WFD) states that it is representing approximately 72 million deaf people worldwide. This already reveals that it is quite unlikely that all deaf and hearing impaired people participate in their national organisations or that they have been registered by them. Therefore, it is a particular challenge for the organisation to represent all of these people’s needs and campaign for their rights. The claimed existence of deaf culture, based on sign language, deaf identity and history, supports a presumption of transnational networks of deaf communities or at least a certain foundation to establish such networks, incorporating all deaf persons. A feeling of solidarity can be recognised in the theme of

³ Ladd, 2003, p. xvii; Burch & Kafer, 2010, p. xxi.

⁴ Exceptions are quotes of authors who are differentiating between ‘deaf’ and ‘Deaf’.

⁵ UN News Centre, More people than ever have hearing loss that can be improved or treated, UN reports, 27 February 2013, at: http://www.un.org/apps/news/story.asp?NewsID=44245&Cr=health&Cr1=#.UWVljjeD4_w (consulted on 10 April 2013).

the Second International Conference of the World Federation of the Deaf, taking place in October 2013 in Sydney, Australia; ‘Equality for Deaf People’. The aim is to ‘to promote equality for deaf people, amongst deaf people and promoted by deaf people.’⁶ Nevertheless, it has to be considered that needs and human rights claims of a deaf person in Africa most likely differ from those of a deaf person in Europe. Being deaf does not constitute a person’s whole identity. Factors like sex, age, and economic standing can create different situations for each individual. Both deaf and disability studies have been criticised by academic scholars and by activists with a perspective based on feminist, queer, or critical race studies. They are blamed for not considering the diversity within deaf people and disabled people. It is not a respectively homogenous group, rather very heterogeneous groups of individuals with a wide variety of experiences, identities, and practices; ‘deaf and disability are always already inflected by other categories of difference in ways that differ by cultural location and historical context.’⁷

Therefore, however promising it sounds, I believe, using the concept of deaf culture in activism for deaf human rights causes, next to specific advantages, exclusion on several levels. Not necessarily all people with hearing impairment are participating in these networks and the wide scope of deaf people will not always be fully considered by institutions and organisations that are campaigning for deaf human rights. Accessibility, both institutionally and linguistically, to deaf culture and its networks as well as organisations for deaf people depend on various factors.

First of all, institutional accessibility for deaf people is depending on the general accessibility of institutions in one country for any of its citizens, but in addition, there are some other barriers. Like the disability rights movement’s slogan ‘nothing about us without us’ reveals already, it is important to have your needs be represented by someone who is in the same position or can at least relate to it. Then the possibilities to find an adequate contact might be difficult depending on the geographical region,

⁶ WFD, Theme – Equality for Deaf People, at: <http://www.wfdsydney2013.com/theme.php> (consulted on 8 April 2013).

⁷ Burch and Kafer, 2010, p. xviii.

because '[w]hile organizations *for* disabled people, charity organizations, have a long history in North America and Europe and are fairly well established in countries of the South, organizations controlled *by* disabled people themselves are relatively new in developing countries.'⁸ Even if every country worldwide has some sort of disability institutions, their accessibility for people who need them can vary tremendously. When thinking about activism for deaf rights, it should be considered that not all countries have programs and institutions specifically for deaf people, and, if they do, a deaf person living in a remote area does not necessarily know any other deaf person, let alone know about these institutions and organisations.⁹

Another point to consider is that activists are a minority of the people concerned by the same issue; it is mostly the elites who are taking part in activities and have access to the deaf culture and sign languages. Accessibility is also influenced through language. Even though an international sign language exists, every country still has its own sign language and dialects exist within these. Deaf people who do not know sign language will face difficulties to access available information. This becomes clear with one look at the website of the European Union of the Deaf (EUD) for example, where a lot of the information can only be found in videos of people signing. It is an absolute requirement to know sign language in order to have access to this information.

As disability can be considered as a social construct, anthropological research is of special value. To reflect and understand a phenomenon, anthropology considers circumstances – like time, place, and other conditions – and makes comparisons possible. Ethnographies are of high relevance to disability studies; they can inspire and challenge each other. This becomes especially interesting in the field of human rights and disability, because anthropology does not simply accept the relevance of disability policy, declarations of rights, universal definitions, or identity politics for people's experience without putting it into question. Analysis examines the influence of relations with institutions, organisations and media on a person's situation and comprehension

⁸ Ingstad & Whyte, 1995, p. 24 (emphasis in original).

⁹ Ibidem, pp. 15 -16.

thereof; also processes of change are of interest. Disability is an important political issue. With an increase in life expectancy and the advancement of technologies that make the survival of people with impairments possible, the numbers of disabled people worldwide are increasing strongly.¹⁰

For a long time, a big concern within medical sociology regarding impairments was the process of their interpretation, negotiation, and labelling. Since the 1960s, disability studies have been shaped by several analytical issues and included research on the social production of reality; disability studies arose with a central focus on recognition, personal experiences, and the social and cultural processes of disablement.¹¹ In the social process of interaction, individuals are both subjects and objects in interaction with others. A discourse analytical approach to the issue of disability shows how important it is to look at the reasons and actors behind processes of construction and representation. Discourses utilise words, institutions, and practices to construct their object in a certain way.¹² The cultural context of a person with impairment is partaking in constructing the actual experience of disabilities. '[C]ultures structure experience; they consist of a set of meanings that interpret the world in a particular way.' The consequent risk is that cultural constructions are considered 'as a given pattern of ideas and practices that are consistent and satisfactory for those who use them – as if culture always provides answers to the questions people have.'¹³ Anthropological research can help to view these cultural constructions from another perspective and maybe in a longer term lead to a change, until they are no longer considered as a given and satisfactory understanding of disability experiences. Susan Whyte and Benedicte Ingstad look at the differences between the discursive practice of governments and disability organisations and the subjective experiences of individuals with impairments. The two anthropologists frame impairment as a cultural and social issue, rather than a

¹⁰ Ingstad & Whyte, 2007, pp. 1-6.

¹¹ Whyte, 2009, p. 8.

¹² Ingstad & Whyte, 1995, p. 19.

¹³ Whyte, 1995 (a), p. 240.

medical or technical one. It is more about the cultural understanding of disability than about the analyses of functional implications of impairments.¹⁴

When looking into deaf human rights activism it becomes interesting to find out about the reasons for claiming a deaf identity rather than a disabled one and what it actually means in practice to do so – considering that historical experiences of oppression are similar on both sides.¹⁵ This investigation will try to respect both identity concepts and their specificities, thus challenging the notion of homogeneity. Especially when one starts exploring the concept of deaf culture, it seems inadequate to speak of deaf people as disabled, but, for example, the CRPD is a commonly used instrument in deaf human rights activism. As the fight for rights is based on an identity that distinguishes from the majority, it becomes relevant how that identity is formulated and if there are advantages for deaf people to fight for their rights as a cultural/linguistic minority instead of fighting for their rights as disabled persons. Identity is a very important factor in this context, as it is a basis for the formulation of law and legal action as well as activism and how people use the conventions. Many factors contribute to the formation of a person's identity; the next chapter will introduce the first analytical concept of this thesis that is connected to this process: the concept of disability.

2. Disability Rights

In order to talk about deaf human rights, it is necessary to cover the issue of disability rights as well. This might seem contrary to 'deaf advocates and scholars [who] have claimed "deaf" as an empowered personal identity by rejecting the pathologization of hearing loss'¹⁶, and also contrary to deaf communities increasingly rejecting 'disability' as an adequate category to describe and understand deafness. Instead of being disabled, deaf persons identify as members of a linguistic and/or cultural minority, which would

¹⁴ Whyte, 1995 (b), p. 285.

¹⁵ Burch & Kafer, 2010, p. xiii.

¹⁶ Ibidem, p. xvi.

entail that there is no overlapping between deaf and disability.¹⁷ Still, when looking at deaf human rights activism in practice, in the work of the WFD for example, disability rights as they are anchored in the CPRD are prevailing in the argumentation for claimed rights. For this reason, disability rights are one important side of deaf human rights activism, which might contribute to a better understanding of its practice and subsequently lead to its improvement.

In the past, European and American academics and activists had a common perception of theoretical frameworks for understanding deaf and disability identity and community; therefore it does not seem too farfetched to link these possibly separate groups with each other. Both sides should be considered within the context of two models of disability; the so called ‘medical model’ has been rejected both by deaf studies and disability studies, and instead deaf and disability researchers and community members preferred a ‘social model’ of analysis.¹⁸ For several actors additional to human rights activists and advocates, such as health practitioners, policy makers and people responsible for welfare programmes, it is essential to challenge the meaning and use of the term disability. ‘While an older professional approach to disability focused on impairments and functioning of the individual body, the social model points at the way societies impede or facilitate people classified as disabled.’¹⁹ The following section will describe the changes in the understanding of disability as a medical pathology to a concept that includes the social context which makes impairment into a handicap.

2.1 Medical Model of Disability

For a long time in modern history, the medical model of disability has been a very powerful influence on the conceptualisation of disability.²⁰ It thus also defined the policy responses and public perceptions of a necessity of treatment. In the past,

¹⁷ Ibidem, pp. xvi-xvii.

¹⁸ Ibidem, p. xviii.

¹⁹ Whyte, 2004, p. 169.

²⁰ Oliver, 1980 as quoted in Kayess & French, 2008.

disability policy was either ‘a charitable response to perceived miseries’ or ‘an attempt to cater to the economic doctrine of maximizing social output.’²¹

Under the medical model, disabled people are defined by their illness or medical condition. It is understood that the impairment is the main reason of ailments. Disability is seen as a ‘deficiency or deviation from the norm, located in the individual, and carries an action implication to treat or change the person so that they can conform to existing social processes and structures.’²² The aim, therefore, is to provide cure, treatment, care and protection to change the person and achieve assimilation to the social norm. The impairment of a person’s body or mind has to be repaired by medical interventions. The actual intervention is expected to take place at the level of the individual and family, and not at the level of the state and society. Nowadays, it is argued that the medical model leads to a disempowerment of disabled people; through medical diagnoses access to social benefits, housing, education, leisure and employment are controlled and regulated. The main idea that the impairment is the principal cause of limitations justifies exclusion of disabled people from society. It somehow frees society of its own responsibility in disabling people with disabilities. The disabled person is seen as the problem, and not society. This model does not consider any social context of the person, neither in its understanding of disability, nor in its attempts of treatment. Treatment is often provided in service systems and establishments away from the general community. This isolation does not only apply to the health domain, but often also to other or even all areas of a person’s life; like special education or institutional residential services. It is essential though to recognise the role of the social environment in its function of disabling persons with impairments.²³ Leaving this factor out and only using the medical model would lead to a quite different understanding of disability rights than what is actually needed in practice. A human rights approach to disability requires a different view of the notion of disability than the one that was usually used in the medical community. Disability advocates were not satisfied with the medical model

²¹ Bickenbach, 2001, p. 567.

²² Kayess & French, 2008, p. 6.

²³ Kayess & French, 2008, p. 6; Burch & Kafer, 2010, p. xvii.

and promoted a perspective on disability law and policy based in human rights, instead of ‘a matter of charity, professional need, compensation, or economic necessity.’²⁴

Applying the medical model of disability on deaf people reveals its deficiency in order to use it for human rights activism. It would mean that the inability to hear or limited hearing is the cause of problems in these persons’ lives. The first solution therefore would be to try to restore the person’s hearing as best as possible. It is true that various degrees of hearing loss, measurable with audiometric methods, allow a medical classification of a person’s impairment, but this does not yet reveal the person’s cultural affiliation and usage of sign language. Therefore, it is necessary to have a wider understanding of disability that also includes other factors than just the medical conditions of a person.

2.2 Social Model of Disability

The necessity of considering the social environment of a person stimulated the disability rights movement in the UK in the mid-1960s to conceptualise the social model of disability. Contrary to the medical model, it ‘locates the experience of disability in the social environment, rather than impairment, and carries with it the implication of action to dismantle the social and physical barriers to the participation and inclusion of persons with disability.’²⁵ The main argument of this approach is that limitations result from disability and not from the impairment itself. In this context, disability is understood as a result of social and cultural conditions surrounding the person; it is seen as a form of social oppression. Barriers existing in education, access to information and communication, transportation, housing, work places, health and social services, and more, prevent the person from being part of society like any other person without impairment. Thus, the pursued aim under this model is not anymore focused mainly on treatment, care and protection, but rather striving for an acceptance of impairment as a positive side of human diversity. The problem is no longer the disabled person itself,

²⁴ Bickenbach, 2001, p. 567.

²⁵ Kayess & French, 2008, p. 6.

but rather the social norms that lead to an excluding practice. The social model of disability has become a dominant frame for disability studies and disability rights advocacy, and it had a very strong influence in the development of the CRPD. It was realised that a human rights approach to disability requires a differently conceptualised understanding of disability than the one that was usually used in the medical community.²⁶

From now on, disability is considered as a consequence of a person's impairment in combination with the social and physical environment in the person's life. Due to being disabled, a person has limited possibilities in the activities he/she can perform. Whether an activity can be carried out by a person is influenced by environmental conditions, physical or social, which can restrict or hinder performances, or it can also be influenced by resources that make performances easier. No longer is disability seen as 'a feature of an individual's body or mind', but instead as a 'socially constructed complex of relationships, some intrinsic to the individual and some part of the physical and social world.'²⁷

The social model is essential when considering a human rights approach to the situation of persons with disabilities. Social attitudes, behaviours, and policies are often the responsible factors creating barriers to full participation of disabled persons. Therefore, the focus of arguments in human rights activism is aiming at equal treatment and taking into consideration that 'social institutions and attitudes are responsible for creating disabling barriers that limit a person's participation in life activities.'²⁸ Interesting for this thesis is now to ask, what the social model of disability means for deaf people, and how it fits with the concept of deaf culture. The inability to hear constitutes the medical fact, the impairment, of a deaf person. This state alone does not yet give information on the rights that are striven for. Depending on which approach is taken, the argumentation in deaf rights activism will differ. With the medical model of disability in mind, it might be obvious to call for hearing aids or even cochlear implants to compensate this

²⁶ Kayess & French, 2008, p. 6; Bickenbach, 2001, p. 567.

²⁷ Bickenbach, 2001, p. 567.

²⁸ Ibidem.

impairment and enable deaf persons to hear. The social model of disability would lead to measures not trying to change the deaf person, but try to remove barriers in society.

An emic view on deaf people, moving away from a medical position and building on a socially constructed understanding of disability, is supported by the deaf married couple Carol Padden and Tom Humphries²⁹. They suggest to look at deaf people from another perspective, namely as humans, who are not primarily missing something (their ability to hear), but who are living under different prerequisites than other humans. Deaf people have their own ways of living and behaving, customised to their circumstances of life. This includes their language, their point of views, use of symbols and their interpretation of experiences. Consequently, deaf people are not missing anything. Just like hearing people would not characterise themselves primarily with the abilities that they do not have.³⁰ The concept of deaf culture elaborates this idea further and will be mentioned in more detail later in this thesis.

The paradigm shift from a medical to a political and social focus is important for progress within disability and deaf studies, but also for progress in international efforts to ensure human rights for all people with disabilities. As we will see in the following paragraphs, the CRPD has managed to move forward from the medical model of disability and incorporates an understanding of a social model into the document and the expressed rights. It recognises in its preamble ‘that disability is an evolving concept and that disability results from the interaction between persons with impairments and attitudinal and environmental barriers that hinders their full and effective participation in society on an equal basis with others.’³¹

A culturally deaf view is not totally in line with the social model of disability, but due to the lack of a similarly powerful movement deaf communities have been involved in the social model movement. As they partially benefited from this connection, it was difficult to express reservations about the movement, but I want to mention here that

²⁹ Padden & Humphries, 1988.

³⁰ Ibidem.

³¹ A/RES/61/106 (CRPD), 13 December 2006, Preamble(e).

[m]any are uncomfortable with their inclusion in the disability social model because, however it might try to construct itself to assimilate them, the criterion used for including Deaf communities in their ranks is that of physical deafness – in other words, the medical concept. Thus social-model legislation is suitable for needs arising out of *individual hearing impairment*, such as flashing light doorbells, text telephones and TV subtitles, and applies to Deaf and deafened people alike – these are not specific to Deaf communities, nor does it address their own deeper needs.³²

I believe that support in this form is adapted to the social model in a very good way, but it is true that it is nevertheless based on an understanding of disability, which does not adequately fulfil the needs of a linguistic and cultural minority. Desirable measures for deaf people would mainly include the promotion and support of the use of sign language. Nevertheless, will the focus of the next section be the CRPD, which provides a valuable tool for the disability rights movement and is therefore of interest for hard of hearing people.

2.3 Disability Rights and the CRPD

Disability rights and the CRPD are a part of a wide range of internationally proclaimed and protected human rights. The beginning of the internationalisation of human rights is dated with 1945, the end of the Second World War and the establishment of the United Nations Organisation. Before, several groups of people were protected by doctrines and institutions under Classic International Law, but there was no global protection of rights of human beings per se. The Universal Declaration of Human Rights was passed in 1948, but as a resolution of the UN General Assembly it is not legally binding and only a recommendation for member states. Therefore it was essential to pass human rights instruments with a legal character that makes them binding for States which ratified them. In December 1966, the International Covenant on Civil and Political Rights (ICCPR) and the International Covenant on Economic, Social and Cultural Rights (ICESCR) were passed by the UN General Assembly, and they came into force in 1976. Together with the UDHR they form the so called International Bill of Human Rights.³³

³² Ladd, 2003, p. 15.

³³ Gómez, 2009, pp. 22 - 25, 37 - 38.

The CRPD is one human rights instrument that aims to reframe the needs and concerns of persons with disability in terms of human rights. The institutional history of disability rights starts before this most recent document which builds its implicit rights on a social model of disability. Before 1970 and the paradigm shift within disability studies, the UN was handling disability issues not from a rights based approach³⁴, but from a perspective based on social welfare. Its work focused on prevention and rehabilitation and just scarcely recognised barriers formed by society and institutions.³⁵ In 1971, the first international statement of disability human rights, the Declaration on the Rights of Mental Retarded Persons, was adopted.³⁶ As the name already reveals, the document did not include all people with disabilities, why it was followed by the more inclusive Declaration on the Rights of Disabled Persons in 1975.³⁷ The 1975 Declaration proclaims equal civil and political rights for persons with disabilities and, in order to improve social integration, establishes standards for equal treatment and access to services.³⁸ In the 1980s, the UN set a stronger focus on the issue of human rights for people with disabilities. 1981 was sponsored to be a Year of the Disabled Persons, and a Decade of Disabled Persons from 1983 to 1992 followed. Campaigns and negotiations aimed at expanding protection for people with disabilities worldwide and international disability rights advocates called for more participation in society by people with disabilities.³⁹ These efforts led to the adoption of the Standard Rules on the Equalization of Opportunities for Persons with Disabilities⁴⁰ by the UN General Assembly. Even though they are lacking a legal enforcement mechanism, the Standard Rules still offer international standards for programs, laws, and policy on disability.⁴¹ Another document worth mentioning in the development of disability rights is the Vienna Declaration and

³⁴ ‘The rights approach is the opposite of the medical approach to disability, the professional approach, the basic needs approach, the service approach, the charity approach, and so on. [...] Across the UN system, the human rights and development agenda characterises the human rights approach as a strategy grounded in human rights and the political and administrative processes required for implementing human rights’ (Bickenbach, 2009, p. 1114).

³⁵ United Nations Secretariat, 1997.

³⁶ U.N. Doc. A/8429, 1971.

³⁷ U.N. Doc.A/10034, 1975.

³⁸ Bickenbach, 2001, p. 573.

³⁹ Mori, 2010, p. 235; Braddock & Parish, 2001, p. 50.

⁴⁰ UNGA, A/RES/48/96, 4 March 1994.

⁴¹ Mori, 2010, p. 235; Braddock & Parish, 2001, p. 50.

Programme of Action, which was enacted in 1993.⁴² Even though it is not specifically on disability rights, it pushed the social model of disability by stressing equal opportunities for people with disabilities by eliminating socially constituted barriers.⁴³

On 13 December 2006, the United Nations General Assembly adopted the Convention on the Rights of Persons with Disabilities (CRPD) and an Optional Protocol, regulating enforcement mechanisms.⁴⁴ The treaty reached the highest number of signatures any human rights treaty ever did on its opening ceremony. On 30 March 2007, 81 states and the EU signed the CRPD and 44 states signed the Optional Protocol.⁴⁵ In April 2013, the Convention was signed by 154 countries (and the EU), ratified by 130; and the Optional Protocol had 91 signatories, and 76 ratifications.⁴⁶ The numbers of ratifications are high, still when looking back to the history of human rights, one might question the necessity of adding another human rights treaty to the already existing others like the International Bill of Human Rights. The Final Document of the First International Conference on Human Rights in Teheran in 1968 recognised the indivisibility and interdependence of the often called first (the civil and political rights) and second (economic, social and cultural rights) generation of human rights.⁴⁷ Also the Final Document of the Second World Conference on Human Rights in Vienna in 1993 acknowledges the indivisibility, interdependence and universality of all human rights.⁴⁸ Based on these declarations, human rights for people with disabilities should be covered as well.

Applying a human rights approach to disability rights implies a universalism of rights, meaning that everyone is equally entitled to human rights. Criteria, like race, religion,

⁴² Vienna Declaration and Programme of Action, World Conference on Human Rights, Vienna, from 14 to 25 June 1993, A/CONF.157/23, 12 July 1993.

⁴³ Stein, 2007, p. 90.

⁴⁴ The CRPD and the CRPD Optional Protocol were adopted during the 61st Session of the GA; see GA Res. A/61/106, 13 December 2006.

⁴⁵ Kayess & French, 2008, p. 2.

⁴⁶ UN enable, <http://www.un.org/disabilities/> (consulted on 30 April 2013).

⁴⁷ Proclamation of Teheran, Final Act of the International Conference on Human Rights, Teheran, from 22 April to 13 May 1968, A/CONF. 32/41 at 3, 1968.

⁴⁸ Vienna Declaration and Programme of Action, World Conference on Human Rights, Vienna, from 14 to 25 June 1993, A/CONF.157/23, 12 July 1993.

language, culture, geographical location, disability, and so on should not influence this entitlement, because the only criterion needed to be a beneficiary of human rights is to be human.⁴⁹ This statement leads me to continuously debated issues in anthropological studies; these are the universality of human rights and the universality of disability. These are sensitive issues and need to be mentioned here, because ‘[a]nthropology’s prolonged love affair with local cultures has meant that at various junctures, anthropologists have positioned themselves in critical opposition to universal values and transnational processes such as “human rights”’.⁵⁰

Since the drafting process of the UDHR and after its adoption by the UN General Assembly on 10 December 1948, anthropologists have been involved in discussions on the formulation and meaning of these rights, which increasingly contributed to a broadening of the international discourse on human rights. However, when the American Anthropological Association (AAA) submitted their ‘Statement on Human Rights’ to the Commission on Human Rights of the UN in 1947, they primarily criticised the notion of universal human rights; cultural relativism did not match the set of standards applied to all of humanity. The AAA’s statement was followed by long discussions on universalism and cultural relativism; one of the arguments being that demanding respect for cultural differences bears the risk that these differences might be used for a legitimization of serious human rights violations.⁵¹

Even though the world population is still very heterogeneous and millions of people barely have any rights at all, let alone know about the International Bill of Rights, anthropological studies brought forth clear arguments for the universality of human rights. Since 1948, numerous conventions, treaties, charters and declarations have been issued to achieve common standards in human rights practice. In this process the question of universality came up concerning ‘whether a universal body of rights is conceptually possible and philosophically justifiable’, and ‘whether such a standard can

⁴⁹ Bickenbach, 2009, p. 1112.

⁵⁰ Wilson, 1997, p. 1.

⁵¹ Messer, 1993.

be globally implemented.⁵² There are various forms of universality of human rights and also various ways to reach it. For a long time, the discussion concentrated on the views of universalism and particularism. As Hastrup acknowledges, these doctrines might be mutually exclusive, but when dealing with practice it seems adequate to ‘agree that beyond the manifest differences there might actually be something shared by all humans – equal worth, for instance.’⁵³ Despite problems of practical implementation of international standards, former UN High Commissioner of Human Rights, Mary Robinson, declared that the UDHR

[...] has exerted a moral, political and legal influence throughout the world, far beyond the aspiration of its drafters. It has been the primary source of inspiration of all post-war international legislation in the field of human rights ... Its detailed provisions have served as a model for many domestic constitutions and laws, regulations and policies that protect human rights ... Many of the provisions of the Declaration have become part of customary international law, which is binding on all states whether or not they are signatories to one or more multilateral conventions concerning human rights. Thus what started its existence as a solemn but non-binding proclamation of rights and freedoms has, at least in some respects, if not all, acquired through state practice the status of universal law.⁵⁴

Anthropologists can contribute to find the best ways of practical implementation. One example of this is Sally Engle Merry’s research on how transnational ideas become meaningful in local settings.⁵⁵ It is necessary to understand both transnational human rights and local cultural practices. Calling them translators, she describes actors like community leaders, NGO participants, and social movement activists as intermediaries who help translating ideas from the global arena down and from local arenas up. Even though Merry looks at the example of human rights approaches to violence against women, I believe her approach can also be used for the purpose of my work. She ‘explore[s] the practice of human rights, focusing on where and how human rights concepts and institutions are produced, how they circulate, and how they shape everyday lives and actions.’⁵⁶ Aware that human rights ideas and practices are

⁵² Hastrup, 2001, p. 1.

⁵³ *Ibidem*, p. 2.

⁵⁴ Robinson, 1998; as quoted by Hastrup, 2001, p. 3.

⁵⁵ Merry, 2006.

⁵⁶ *Ibidem*, p. 39.

developed in one locality, it becomes interesting how they then are adopted or imposed on an international level. Instead of dealing with the universalism–relativism debate, the focus lies on the social processes of human rights implementation and resistance. She is not questioning if human rights are a good idea, but explores what difference they actually make in local practices.⁵⁷ The cases of ‘Cochlear Implants’ and ‘Deaf Education’ and human rights activism concerned with these issues fit to the anthropological practice of localising discussions; therefore I will use Merry’s approach for my analysis in the case studies.

Applying this approach to deaf human rights activism becomes interesting when looking at the arguments used in talks about currently relevant human rights issues. The international human rights ideas for people with disabilities are applied on a ‘local’ level for deaf people, who rather identify as a linguistic and cultural minority. In ethnographies on the practice of human rights – just like Merry uses ‘empirical examples of the appropriation of women’s human rights to analyze the process by which human rights are remade in the vernacular’⁵⁸ – it becomes clear how ideas from transnational sources (such as the CRPD) are adapted to local meanings. It is the role of the ‘translators’ to ‘reframe local grievances up by portraying them as human rights violations. They translate transnational ideas and practices down as ways of grappling with particular local problems.’⁵⁹ It is important to find the right arguments and ways to represent and fight for human rights for a group of people. For human rights to be accepted they must fit to the local context and in order to be part of the international human rights system, they must stress ideas intended by the legal documents that constitute human rights law.⁶⁰

This process of translation will be informative for finding out about the implications of the different approaches to deafness and people’s self-identification for human rights activism in practice. The self-image might not fit the global understanding of disability,

⁵⁷ Merry, 2006.

⁵⁸ *Ibidem*, p. 29.

⁵⁹ *Ibidem*, p. 42.

⁶⁰ *Ibidem* p. 49.

but the CRPD's existence provides an international human rights document that can be used to advocate deaf interests.

Another controversial notion of universality relevant for the field of human rights and discussed in anthropological debates is the universality of the concept of disability. There is a wide variety of life situations of people with disabilities worldwide and within these situations, the understanding of disability and the related human rights claims differ.

The agenda of activists from the more developed countries may not similarly touch upon the core problems for persons with a disability in the less developed countries. Thus for a poor hearing-impaired woman in a village in the Kalahari it is presently of little interest whether she is called "deaf," "disabled," or a "person with a disability". (She does not have the equivalent words in her language anyway.) Her agenda would more realistically be summarized as access to food and firewood, and care from her children tomorrow.⁶¹

Ingstad is very explicit about the problem of context of disability and human rights. She takes the UN Standard Rules and questions the relevance of its universal vision for families with a disability in Botswana's Kweneng District. The UN Standard Rules were developed in cities in the North and adopted in the UN General Assembly. Lawmakers and organisations in other countries refer to them (or not) for their cause and advocacy. Ingstad shows that there is a lacking connection between disabled families in the Kweneng District and programs invoking the UN rules. Assumptions made in the context where the rules were developed do not necessarily make sense in another context.⁶² It is important to understand the issue of human rights for persons with a disability in a local context, and especially in the context of poverty. Some needs can be universal, but others are depending on the respective locality and culture. Activist groups are often from so-called developed countries and supported by elite activists in developing countries; human rights approaches thus not always fit those who are severely multi-handicapped or poor rural people with disabilities in developing countries.⁶³ Therefore, even if there are commonalities in the experiences of deaf people

⁶¹ Ingstad, 2007, p. 254.

⁶² Ingstad & Whyte, 2007, pp. 10-11.

⁶³ Ingstad, 2007, pp. 238-239.

worldwide, the criterion of deafness does not make them to a global homogeneous group with the same human rights issues.

Ingstad questions the universality of human rights and their applicability. Questioning if there are universal and cross-culturally valid issues, it might be necessary to first consider the situation of persons with a disability in terms of their context. Yet seeing disability in context does not mean to look at one particular isolated cultural setting. The context has to include ideas about rights for persons with a disability and also the possibilities, constraints, and beliefs inflicted by the local physical, social, economic, and cultural frame.⁶⁴ Whyte and Ingstad argue that the potential of human-rights declarations and policies should be measured in the context of local worlds, because this is the arena where people are trying to make things work, and where the actual effectiveness can be observed.⁶⁵

Again, anthropological work is useful for the practice of human rights approaches and activism. It can help planners and activists to avoid the risks of relativist and universalist perspectives. On the one hand, studies can support universal rights with studies documenting their implementation and the extent of their success or failure. On the other hand, it can improve the understanding of disability as it is perceived and experienced by the people with a disability themselves. Ingstad takes the position to ‘accept the need for universal principles as guidelines for governments in the work to improve the living conditions of citizens with a disability. But at the same time [...] stress the need to consider these ideals (standard rules), to assess and question their applicability, and also their (possible) unintended consequences, in various cultural settings.’⁶⁶

In order to invoke human rights protections before the CRPD came into being, disabled persons had to ‘either fall under a universal provision or possess a separately protected

⁶⁴ Ibidem, pp. 239, 250.

⁶⁵ Whyte & Ingstad, 2007, pp. 24-25.

⁶⁶ Ingstad, 2007, p. 253.

characteristic in addition to his or her disability.’⁶⁷ Then they could get protection under the universal scope of ICCPR, ICESCR, and CAT, or if fulfilling the necessary criteria, they could get protection under CERD, CRC, CEDAW, CPMW. One of the main reasons supporting the necessity of a human rights treaty specifically for people with disabilities is that even though people with disabilities were theoretically covered by already existing central UN treaties, these treaties were hardly applied in practice.⁶⁸ The CRPD, as an internationally binding legal instrument, contributes to the possibilities of disability activism and disability politics, because from now on, state responsibility can be addressed as a legal issue and goes beyond claims in political rhetoric.⁶⁹

The CRPD contributes immensely to human rights work to secure the freedom and dignity of people with disabilities. It acknowledges the role of societal barriers as a bigger obstacle to the full enjoyment of human rights for people with disabilities than the physical impairment itself. Also deaf people face these barriers; major issues are ‘lack of recognition, acceptance and use of sign language in all areas of life, and lack of respect for Deaf people’s cultural and linguistic identity.’⁷⁰ Deaf people may prefer to be seen as a linguistic and cultural minority instead of belonging to the minority of people with disabilities, but nevertheless, human rights protection provided by the CRPD is also designed to meet essential interests of deaf people; the Convention expands international human rights legislation and sets a framework for deaf people’s rights. Sign language, a crucial aspect of deaf culture, is referred to in several articles of the Convention. These include the definitions in Article 2, Article 9 on accessibility, Article 21 on freedom of expression and opinion, and access to information, Article 24 on education, and Article 30 on participation in cultural life, recreation, leisure and sport. Article 30 paragraph 4 is especially interesting, because it links the disability concept to the cultural concept, explicitly mentioning deaf culture; ‘Persons with disabilities shall be entitled, on an equal basis with others, to recognition and support of their specific cultural and linguistic identity, including sign languages and deaf

⁶⁷ Stein, 2007, p. 80.

⁶⁸ Stein, 2007, p. 79.

⁶⁹ Bickenbach 2009, p. 1111; referring to Irish lawyer and disability advocate Gerald Quinn.

⁷⁰ Hualand & Allen, 2009, p. 8.

culture.⁷¹ Even though the Convention emphasises the essentiality of sign language, looking at the daily proceedings of the UN shows that difficulties remain in transforming rights included in the CRPD into actual practice.

Historically, the UN was not very coherent in its practices and its principles. For deaf people it is crucial to have access to information and discussions through sign language. Therefore, it is mainly the availability of interpreter services that is deciding about the fulfilment of the principles of social justice, collaboration and inclusion for deaf people. Sign language interpreters are usually not offered at the national level in numerous countries, but also, for example, at the UN headquarters in New York City. Deaf people do not have full communication access; the official languages of the UN are only spoken and not signed languages. Deaf people's access is limited depending on their knowledge of written forms of official languages, but beyond this there is no meaningful engagement possible. Even if the WFD officially participates at UN meetings, deaf persons must organise their interpreters themselves. This leads to financial and logistical expenditures, and their coverage by the UN is often difficult and does not meet the full amount.⁷² Although, the CRPD was drafted at the UN, it is not even possible for this very institution to fully meet the proclaimed rights. Access is not yet properly regulated at the Department of General Assembly Affairs and Conference Services; this situation continues the disablement of deaf signers and depicts how central features of disability activism have not yet been fully granted to deaf people despite a Convention on the Rights of People with Disabilities.⁷³

On a theoretical level it seems like human rights for deaf people are well covered by the CRPD, also taking into consideration the importance of sign language and recognising it as a language, yet the problem remains in the implementation and advocacy work will have to continue. Another question is, if all human rights issues are really covered by this disability convention. Next to enabling access to public facilities, information, communication and other services through the use and support of sign language, other

⁷¹ A/RES/61/106 (CRPD), 13 December 2006, art 30 para 4.

⁷² Mori, 2010, p. 235-237.

⁷³ Ibidem, p. 242.

challenges can arise. As we will see in the chapter on deaf culture, members of this culture had to face several threats in the past. If deaf people are considered as a cultural minority, human rights protection might include other aspects than language. This will be explained in more detail later in the two cases of ‘Cochlear Implants’ and ‘Deaf Education’. Before focusing on these issues and empirical examples, the next chapter will present shortly an approach to human rights for deaf people based on rights for cultural and linguistic minorities. This is relevant for deaf human rights, because compared to priorities of the disabilities rights movements, the focus of deaf people lies elsewhere. It does not emphasise the need for better medical care, rehabilitation services, and personal assistance services but instead deaf people campaign for acceptance of their language and an improvement of the quality and quantity of sign language interpreters.⁷⁴

3. Cultural Rights

In this section, I will start with an introduction of a few human rights documents covering linguistic minorities. To put deaf people into this context, I will then have a closer look at different academic contributions to the concept of “deaf culture”⁷⁵. Like always in anthropological discussions, one thing becomes clear quite quickly, (deaf) culture is not easy to define. This, I believe, is a good thing. There is a risk to bear in mind, if you explicitly define what constitutes deaf culture, some people could be left out. Like any other culture, deaf culture should be perceived as a fluid process. This understanding leaves possibilities for change and development open, and makes it more feasible to avoid discrimination.

⁷⁴ Lane, 2005, p. 305.

⁷⁵ The use of quotation marks should point out the fluidity and changeability of the concept of deaf culture, but are for reasons of legibility not used in the remaining parts of the thesis.

3.1 Rights as a Cultural and Linguistic Minority

There are quite numerous academic contributions on the issue of deaf culture and experiences of deaf people, but only a few of them consider this question of identity in relation to claimable rights and general human rights issues for deaf people. Quite often, the assumption is that deaf people fall under the category of people with disability and therefore the CRPD applies, but Harlan Lane has a different approach and even considers the labelling of deaf persons as people with a disability as a certain threat to the 'Deaf-World'. He is only talking about deaf people in the United States of America, but maybe the cultural perspective has not gotten enough attention and can be applied on a wider scale. At least it is an opinion that should be mentioned in relation to activism for deaf human rights; as he is arguing about the harming effects of the disability approach. With a closer look at the deaf community in the US, Lane argues for its constitution as an ethnic minority, and mentions four reasons why it is not suitable to define deaf people as a disability group;

Deaf people themselves do not believe they have a disability; the disability construction brings with it needless medical and surgical risks for the Deaf child; it also endangers the future of the Deaf-World; finally, the disability construction brings bad solutions to real problems because it is predicated on a misunderstanding.⁷⁶

Lane argues that people belonging to the 'Deaf-World' qualify as an ethnic group, which has different needs and would therefore claim other rights from a group considering itself as people with disabilities. Several criteria are identified to be necessary for a group to characterize as an ethnic group; collective name, customs, feeling of community, social structure, norms for behaviour, language, values art forms, knowledge, history, and kinship. Many of these criteria will be covered in this thesis' chapter on deaf culture. A desirable outcome of defining deaf persons as an ethnic group would be that people behave appropriately with deaf people; meaning that they make an effort to learn sign language, study deaf history and defend deaf heritage.⁷⁷ Then it would make sense to ascribe the same rights and protections like other ethnic groups under international human rights documents and treaties, which would include

⁷⁶ Lane, 2005, p. 291.

⁷⁷ Ibidem. 291- 295.

the UN Declaration of the Rights of Persons Belonging to National or Ethnic, Religious and Linguistic Minorities.⁷⁸ It would be apparent to speak of a linguistic minority when referring to deaf people, since the main difference to the hearing population is the language.

The Declaration was adopted by the General Assembly in 1992. It includes a list of rights to which persons belonging to minorities are entitled, including the right to enjoy their own culture and to use their own language. This is also covered by Article 27 of the legally binding ICCPR; ‘In those States in which ethnic, religious or linguistic minorities exist, persons belonging to such minorities shall not be denied the right, in community with the other members of their group, to enjoy their own culture, to profess and practise their own religion, or to use their own language.’⁷⁹ The “General Comment No. 23: The rights of minorities” further states that ‘[a]lthough the rights protected under article 27 are individual rights, they depend in turn on the ability of the minority group to maintain its culture, language or religion. Accordingly, positive measures by States may also be necessary to protect the identity of a minority and the rights of its members to enjoy and develop their culture and language.’⁸⁰

From a culturally deaf perspective these rights would fit to the interests and practical issues arising, like the importance of sign language and the perceived threat by cochlear implants. However, deaf people are not officially treated as a linguistic and cultural minority and therefore do not fall under the proclaimed minority rights. The UN document *Minority Rights: International Standards and Guidance for Implementation* shortly mentions the question whether persons with disabilities (among others) constitute minorities. As an answer it states that ‘the United Nations Minorities Declaration is devoted to national, ethnic, religious and linguistic minorities,’ but also highlights the importance of fighting multiple discrimination.⁸¹ This means the rights of

⁷⁸ UNGA, A/RES/47/135, 18 December 1992.

⁷⁹ International Covenant on Civil and Political Rights (adopted 16 December 1966, entered into force 23 March 1976) 999 UNTS 171 (ICCPR), art 27.

⁸⁰ OHCHR, ‘General Comment No. 23: The rights of minorities’, CCPR/C/21/Rev.1/Add.5, 8 April 1994.

⁸¹ UN, 2010, p.3.

deaf people, when considering them as people with disabilities, would fall under the multiple discrimination aspect. It would make anti-discrimination one additional point to consider next to the human rights situation of the religious, ethnic, national, linguistic minority that the person falls under. It would not cover the deaf culture as such. For this deaf people would have to be considered as a linguistic minority.

Maybe the Declaration on the Rights of Persons Belonging to National or Ethnic, Religious and Linguistic Minorities does not mention deaf people and sign language specifically, but on a regional level, there are other human rights documents referring to deaf people and minority rights. The Council of Europe (CoE), for example, in its Recommendation 1492 (2001) on the 'Rights of national minorities' mentions sign language and demands a protection like it is granted for regional or minority languages; 'give the various sign languages utilised in Europe a protection similar to that afforded by the European Charter for Regional or Minority Languages, possibly by means of the adoption of a recommendation to member states.'⁸² Two years later, the CoE issued another recommendation, this time specifically on the protection of sign languages in the member states.⁸³ With this recommendation the CoE expressed its recognition of sign language as 'a feature of Europe's linguistic and cultural heritage'⁸⁴ and its opinion that 'official recognition of these languages will help deaf people to become integrated into society and gain access to justice, education and employment.'⁸⁵ Without being mentioned as people with disabilities, deaf people and their language are presented as part of Europe's cultural diversity which must be promoted and protected by adequate measures. These measures include education in sign languages and training for teachers to prepare them for working with deaf and hard of hearing children.⁸⁶

After looking at human rights of deaf people from a disability and a linguistic and cultural minority perspective, I believe it is necessary to dive into the concept of deaf

⁸² Council of Europe, Parliamentary Assembly, Rights of national minorities, Recommendation 1492 (2001), 23 January 2001.

⁸³ Council of Europe, Parliamentary Assembly, Protection of sign languages in the member states of the Council of Europe, Recommendation 1598 (2003).

⁸⁴ *Ibidem*, art 3.

⁸⁵ *Ibidem*, art 5.

⁸⁶ *Ibidem*, art 10.

culture in order to understand the current human rights issues and activism dealing with them in practice.

3.2 “Deaf Culture”

The academic field of ‘Deaf Studies’ specialises on deaf people and on social aspects of their lives. A very central issue of these studies is language, and its role and use in the shaping of a cultural identity. But also other academic fields contributed to the knowledge we have about deaf culture today, especially anthropological research is helpful for the investigation of this thesis’ research question. The chapter will only consider European and North American developments. For reasons already mentioned in the section on universality of human rights and disability, including other regions would be spread too far, especially when thinking about the relevance of deaf culture in deaf human rights activism.

Historical references to hearing impairment are going back to ancient Greece and the Old Testament,⁸⁷ but the term of deaf culture itself was only developed in the 1970s. It conceptualises the lifestyle of deaf communities based on the use of sign languages. So far, research on the actual meaning of this terminology has not been very profound, making precise statements on principles and content of deaf culture, such as norms and values, difficult.⁸⁸ Even though the name for the phenomenon is quite new, the origins of contemporary deaf culture are in the eighteenth century. It was in this time, when ‘deafness’ was discovered and schools specifically for deaf children were founded across Europe.⁸⁹ These schools became the first places, where deaf people came together in bigger groups and spent time together. Since most of them did not live in areas where there were other deaf people living as well, they used to be rather isolated.

⁸⁷Barnes & Mercer, 2001, p. 526.

⁸⁸Ladd, 2003, pp. xvii-xviii.

⁸⁹Charles-Michel de l’Épée, often remembered as the “Father of the Deaf”, is one founding figure of deaf education; he developed an instructional method of signs for teaching deaf students at school. (Sacks, 1989, pp. 15-22.)

Only the possibility of regular interaction with others boosted communication in sign language and brought forward this shared and complex means of communication.⁹⁰

One example of a high amount of deaf people living in close distance and their influence on society's use of sign language can be found in Nora Groce's book *Everyone Here Speaks Sign Language: Hereditary Deafness in Martha's Vineyard*.⁹¹ She shows how a higher density⁹² of deaf people changes the use of language and forms of communication. This island off Massachusetts was special; because of hereditary deafness the number of deaf people was relatively high for more than 200 years; it is estimated that about one in every 155 people was deaf.⁹³ In some towns and neighbourhoods the incidence of deafness was even as high as one in 25 and one in four.⁹⁴ In connection to Whyte and Ingstad's book *Disability in Local and Global Worlds*⁹⁵ this example shows how the local context influences experiences of disability. The interesting point for this thesis is the islanders' adaption to deafness and their ways of social interaction. It was not known what caused the high ratio of deaf population; anyone could have a deaf child. People were not worried; the social response instead was to accept the inability to hear. Due to the subsequently more frequent interaction with deaf people, the island's hearing inhabitants were bilingual in English and the Island sign language. The barriers in communication, and therefore in the access to all areas of society, were reduced for deaf people. The use of sign language by hearing people was rather seen as something natural. Informants remember acquiring the language as a casual process; they were not actively trying to learn sign language. As a result, community members did not experience restrictions in exchanging ideas and concerns with each other due to language problems. They used an indigenous sign

⁹⁰Barnes & Mercer, 2001, pp. 526-527.

⁹¹Groce, 1985.

⁹² Another example of high numbers of deaf people present and their impact on society would be Hauland's observations on the Deaflympics in Rome in 2001. Though, it was only a short-term impact, '[t]he density of people communicating in sign language made it impossible for the hearing surroundings to ignore this visual mode of communication, and they eventually had to adapt to the Deaf ways of communicating' (Hauland, 2007, p. 38.).

⁹³ Groce, 1985, p. 3; the last hereditary deaf person in the town of Chilmark died in 1952. (foreword by Whiting, in Groce, 1985, p. vii)

⁹⁴ Ladd, 2003, p. 100.

⁹⁵ Ingstad & Whyte, 2007.

language, which was influenced by the emerging American Sign Language when deaf children from the island started to attend a deaf school in Hartford in the nineteenth century. Bilingual language use in the society of Martha's Vineyard is not the only characteristic that makes it special. It also shows how disability is defined by society around it. It seems like, because there was no communication barrier, 'the attitude of hearing people toward the deaf and their ability to communicate easily and well extended' also removed social barriers.⁹⁶

As a strong indicator of deaf people's integration in society, Groce mentions the perception of deaf people by the hearing society; they are remembered as unique individuals, 'deaf Islanders were never thought of or referred to as a group or as "the deaf".'⁹⁷ In comparison to the mainland, where deafness is regarded as a handicap, Groce suggests instead 'that a handicap is defined by the community in which it appears.'⁹⁸ This argument is also stressed by disability and deaf rights activists, referring to the social model of disability. In order to achieve progress in deaf rights, anthropological work can contribute by research on people's personal experiences of what is disabling in their world rather than focusing on a universally applicable definition. Individual's experiences are connected with the process of defining disability and the shared criteria brought into play in particular settings.⁹⁹ Therefore, successful human rights activism in practice can benefit from this information and propose actions and solutions based on practical examples.

After considering the example of Martha's Vineyard and society's way to deal with communication barriers with their deaf family members, friends, neighbours, and so on, it is an obvious argument for deaf rights activism to promote a different perception of deaf people and more openness towards the use of sign language also by hearing people. So far, the usual situation for deaf people is 'that they have to adjust themselves to the hearing, auditive ways of communicating, because they are too few to make any

⁹⁶ Groce, 1985, pp. 51-57,75.

⁹⁷ Ibidem, p. 4.

⁹⁸ Ibidem.

⁹⁹ Whyte & Ingstad, 2007, p. 11.

significant weight against the pervasiveness of sound-based communication.¹⁰⁰ Once the concept of disability and the responsibilities of people without impairment are reconsidered, the idea that a society could adjust to disabled individuals could strengthen the rights of people with disabilities. ‘The most important lesson to be learned from Martha’s Vineyard is that disabled people can be full and useful members of a community if the community makes an effort to include them.’¹⁰¹

After this introduction to the origins of deaf culture, the question what it actually means remains still unanswered. Like I mentioned before, understandings of deaf culture differ, some believe it is necessary to distinguish between people with a hearing impairment, people who have acquired or developed hearing loss and are not native users of sign language, and people with a congenital hearing impairment who grew up in sign language using environments (at home with deaf parents or at a deaf school) and who then define themselves as deaf¹⁰² (recognising a deaf culture and seeing themselves as members; they share language, cultural values, history, and social life). The deaf community is sometimes also understood to include hearing people; this is a controversial issue and normally only signifies children of deaf adults (CODA¹⁰³) who grew up with sign language and other experiences of deaf culture.¹⁰⁴

Most sources state that hearing loss by itself is not a satisfactory criterion or description of deaf culture. It must be distinguished between the medical condition of being deaf and the cultural experience of deafness, because characteristics of deaf culture and their

¹⁰⁰ Hualand, 2007, p. 38.

¹⁰¹ Groce, 1985, p. 108; Certainly, it would be even more interesting to find out how the deaf people themselves perceived that situation, but since all of them have died, this will not be possible to research. ‘Most Vineyarders remembered that those who were deaf regarded their inability to hear as a nuisance rather than an overwhelming problem, an attitude not uncommon among many deaf people (Higgins 1980). Most, when pressed on the point, believed that local people, hearing or deaf, preferred to have hearing children, but the birth of a deaf child was regarded as a minor problem than a major misfortune. This apparent lack of grave concern reflected the extent to which Vineyard society had long ago adapted to its indigenous genetic alteration’ (Groce, 1985, p. 53).

¹⁰² I chose a lower-case ‘d’, but in literature it is often written with an upper-case ‘D’ to show that the term is implying to claim an identity and belonging to a culture.

¹⁰³ ‘Hearing children born of deaf parents identify with this community and experience it as normal. But ultimately their membership is ambiguous because they can hear. They have a polarized understanding of deafness as viable and normal, and as stigma and deficit’ (Ingstad & Whyte, 1995, p. 17).

¹⁰⁴ Davis, 1995, p. 100.

members go beyond the condition of not being able to hear. It is not only about being different than the majority population - by not being able to hear -, but also about shared aspects within the group. Paul Preston conducted more than 100 interviews with adult hearing children of deaf parents to gather information for his book *Mother Father Deaf*.¹⁰⁵ He bases his view on deaf culture on four aspects of culture: a system of shared ideas and behaviours, which are distinct, which are learned, and which provide a template for personal and social interaction. Being culturally deaf has two sides; the individual must identify with the group, and the group must accept the individual as one of them. Membership and boundaries of deaf culture are a continuous topic of debate. Acceptance is based on an assessment of the individual's sense of cultural familiarity. Connected thereto is a range of life experiences associated with being deaf and regular participation in deaf social events and interaction. Furthermore, it is expected of a culturally deaf person to have common social behaviours and historical traditions with other members of this culture.¹⁰⁶

Harlan Lane, a hearing professor of psychology, has become an often controversial spokesman for the deaf community and critic of cochlear implants. In the article *Do Deaf People Have a Disability?*¹⁰⁷ he questions the concept of disability and wonders what determines whether one form of human variation is a disability. Calling someone deaf refers to a socially constructed set of meanings. Lane's article *Ethnicity, Ethics, and the Deaf-World*¹⁰⁸ contributes a thought to the debate on deaf culture's boundaries and distinguishes hard of hearing people from deaf people. As opposed to deaf people, they

had conventional schooling and became deaf after acculturation to hearing society; they communicate primarily in English or one of the spoken minority languages; they generally do not have Deaf spouses; they do not identify themselves as members of the Deaf-World or use its language, participate in its organizations, profess its values, or behave in accord with its mores; rather, they consider themselves hearing people with a disability.¹⁰⁹

¹⁰⁵ Preston, 1994.

¹⁰⁶ Ibidem, pp. 13-16.

¹⁰⁷ Lane, 2008.

¹⁰⁸ Lane, 2005.

¹⁰⁹ Ibidem, p. 291.

The book *Seeing Voices: A Journey Into the World of the Deaf* by the neurologist Oliver Sacks¹¹⁰ has become the probably best known book on the issue of deafness. He explores the history of deaf people and how they were seen and treated in the past. Also the new perception of the condition of being deaf, starting in the eighteenth century, leading up to situation of the deaf in the 1980s (with accounts on the *Deaf President Now* student protests at the Gallaudet University in March 1988) is covered; still a situation which can be characterised as one of misunderstanding and mistreatment. Sacks highlights the importance of having the possibility to acquire a language and how using sign language is equal to using speech. He even argues that sign is more natural and more communicative than speech. He claims that to be born deaf and never to acquire language or to acquire it only partially is to be cut off from higher thought, the most distinctively human trait. But Sacks also describes how only his visits to the Gallaudet University and this experiences there changed his perception of being deaf; ‘I had to see all this for myself before I could be moved from my previous “medical” view of deafness (as a “condition,” a deficit, that had to be treated) to a “cultural” view of the deaf as forming a community with a complete language and culture of its own.’¹¹¹

A cultural understanding of being deaf implies particular attitudes and social duties; being culturally deaf is about one’s personal attitude, interaction with other deaf people and the meaning of community. It includes people with a wide range of hearing and speaking abilities and is described by Preston’s interview partners as ‘coming to terms with one’s deafness, of making the transition from deaf to Deaf.’¹¹² This is a process, not a static medical condition. Ladd, himself a deaf scholar and activist, calls it *Deafhood*¹¹³; it

[...] represents the struggle by each Deaf child, Deaf family and Deaf adult to explain to themselves and each other as a community, and enacting those explanations [...], Deaf people are engaged in a daily praxis, a continuing internal and external dialogue. This dialogue not only acknowledges that existence as a Deaf person is actually a process of *becoming* and maintaining ‘Deaf’, but also

¹¹⁰ Sacks, 1989.

¹¹¹ Ibidem, p. 127.

¹¹² Preston, 1994, p. 48.

¹¹³ Ladd, 2003.

reflects different interpretations of Deafhood, of what being a Deaf person in a Deaf community might mean.¹¹⁴

An important and formative source passing on cultural values, behaviours and traditions are often times a person's parents. This is different for most deaf children. Deaf children of deaf parents are an exception and therefore constitute the symbolic, and even practical, core of deaf culture. But most deaf children have hearing parents. Their source to learn deaf culture lies outside their family. The main transmitters of deaf culture are deaf peers.¹¹⁵ On the contrary to hearing culture, where socialisation primarily takes place in the family, socialisation in deaf culture is primarily peer socialisation.¹¹⁶ Considering the question of education for deaf children, with this cultural explanation in mind, one must not only take into account the use of language, but also the need for interaction with deaf peers in order to sustain deaf culture.

It is mostly in schools, where deaf children learn their language and find out more about their distinct culture and shared identity. Even though their lives will most likely take them on different paths, deaf children tend to develop close and lasting friendships with their deaf school colleagues. Also, deaf adults continue to primarily socialise with other deaf people. Deaf culture members have a very high endogamous¹¹⁷ marriage rate and often participate in all kinds of deaf social organisations. Depending on personal interests these organisations range from sport clubs to religious groups.¹¹⁸

An anthropological study on deaf individuals and their identity processes is Breivik's book *Deaf Identities in the Making. Local lives - Transnational connections*.¹¹⁹ He based his results on fieldwork and interviews with deaf people from Norway, but is trying to apply some of his conclusions on a global scale. Describing the internationalism of Deafhood, with a reference to his own experience at the Thirteenth

¹¹⁴ Ladd, 2003, p. 3.

¹¹⁵ Padden & Humphries, 1988.

¹¹⁶ Preston, 1994, p. 7.

¹¹⁷ 'Although deaf people generally prefer the company of other deaf people regardless of citizenship or racial differences, marriages among deaf people generally maintain racial boundaries' (Preston, 1994, p.57).

¹¹⁸ Preston, 1994, p. 13.

¹¹⁹ Breivik, 2005.

World Deaf Congress, he supposes a translocal nature of deaf identities and social practice. Breivik's informants 'describe their lives in terms of barriers, oppression and exclusion, as well as their sense of belonging to a linguistic minority which gives them a cultural identity different to that of the mainstream community.'¹²⁰ Their feelings about being deaf range from proudness of their language and culture, wanting to become part of a wider deaf community, to frustration and a wish to fit in with the mainstream society.

Interesting for thoughts on deaf human rights activism are Breivik's comparisons of deaf identity politics to other minorities with a weakened tie to national politics. He is drawing connections to recognised ethnic minorities, disabled people, and LGBT people. Among LGBT communities international links and membership may exist, next to one's sexual identity, through common events, and the use of internet, media, and other forms of communication. Deaf people are involved in identity politics, opposing phonocentrism and focusing on the pride and strength of being sign language users.¹²¹ These connections and links can also be used for political and human rights advocacy.

As we saw at the beginning of this section, a high number of deaf people can influence the society around them, and also, like it happened in deaf schools, support the development of deaf culture. The establishment of schools for deaf children has not only a formative influence on deaf culture, because of the possibilities for interaction with other deaf people, but also because of the common experience of oppression in education systems.

3.3 Education

¹²⁰ Nunn, 2007, p. 65.

¹²¹ Breivik, 2005.

For many deaf children their experiences in deaf schools constitute an important factor for consolidating their identity and finding a way into deaf culture. If children did not have contact to other deaf people before, these schools offer an opportunity to transform 'experiences of alienation and isolation into one of community and culture.'¹²² Sometimes these schools continue to be a central social arena for deaf adults; friendships that started in school can set up social networks.¹²³

Starting in the 1750s, scientific interest in deaf people and their language increased strongly. At the same time, schools for deaf children were founded in Europe and North America. It was not unusual for deaf people to become teachers or headmasters in these schools. For a long time, the discussions focused on whether deaf children should be taught using signs (also known as the manual method) or using speech (also known as the oral method). The use of sign language in deaf education was widely accepted and supported, but not all people had a positive attitude towards deaf people; discourses favouring speech and denoting deafness as a deficit continued to exist as well. Yet, the most radical change in attitudes towards deaf people came with the Milan Congress in 1880. The opinion spread that the use of sign language would harm speech development; the following abolition of teaching in sign language should improve the deaf students' education and facilitate their integration into the non-disabled society. This was the beginning of many years of oppression of deaf people and by the end of the nineteenth century it was widely believed that speech is superior over sign language, despite numerous reports that the oral approach in education for deaf children failed them over and over again. Their literacy level remained low, and continued to be a reason for limited access to and participation in civil life. Oralists strongly represented the opinion that people who used sign language were less evolved than people who spoke. Consequently, the possibility to partake in an education in their first language was denied; instead deaf people were forced to adjust to the hearing world. Manual education of deaf students was replaced by oral education, a trend that was strongly opposed by deaf adults; nevertheless, it continued into the mid-twentieth century. The

¹²² Preston, 1994, p. 77.

¹²³ Ibidem.

enforcement of oral education methods often involved physical abuse of students by teachers in order to suppress the use of sign language.¹²⁴

Shortly after the nineteenth century began, ‘sign languages and deaf teachers were almost totally eradicated from the educational system.’¹²⁵ The main goal in the education of children with hearing impairments became the production and perception of speech.¹²⁶ It was only in the 1950s, when the linguist William Stokoe at the Gallaudet University¹²⁷ confirmed with his research that sign languages were *bona fide* languages, following their own grammatical rules. Still, sign language was not used for educational purposes in schools. Children would sign with each other, but continued to rely mainly on lip reading to understand the teacher and follow the lessons. From an educational perspective, it was still believed that deaf and hard of hearing students who learned to speak were the more successful ones and had the best prospects for their future.¹²⁸

Finally in the end of the twentieth century, a more differentiated perception of deafness reoccurred. This supported a reinforcement of deaf identity and the establishment of sign language as an adequate means of communication. Opinions on the “right” form of education for deaf children are still diverging today,¹²⁹ and as we will see later on, education remains a main issue in deaf human rights activism.

The following paragraphs will go into one more essential characteristic of deaf culture and explore the phenomenon of international, transnational and national deaf associations, clubs, networks and other forms of social connections - which are, because of their reach and ability to act, of great interest for human rights activism.

¹²⁴ Ladd, 2003, pp. 104-107; Baynton, 1996; Porter, 1894; Lane, 1984; Hualand & Allen, 2009, p. 28.

¹²⁵ Ladd, 2003, p. 119.

¹²⁶ Kermit, 2009, p. 147.

¹²⁷ In 1988, the 2000 students occupied the university for 10 days, demanding their first ever ‘Deaf President Now’ (Ladd, 2003, p. 32); they were successful in the end.

¹²⁸ Ladd, 2003, p. 150; Kermit, 2009, p. 147.

¹²⁹ Ladd, 2003.

3.4 Deaf Clubs and Networks

Community is a strong characteristic of deaf culture. Sharing experiences with other deaf people unites individuals on a regional level and beyond. Deaf culture, according to Breivik, is not embedded in a single nationality or territory. Instead, the community – and with it also deaf culture, society and identity – exists translocally and goes beyond national borders. It is not necessary that members of the community share their daily lives; they can live in geographically distant places.¹³⁰ Next to deaf clubs and events especially for deaf people, there are national associations of the deaf in most countries of the world, representing the interests of deaf people in their countries. There is also an internationally representing organisation, the World Federation of the Deaf (WFD), and regional organisations, like the European Union of the Deaf (EUD). These networks offer support and the opportunity to experience solidarity, while also assisting in educational and cultural developments. Their national and international events are a chance for interested individuals to meet others and exchange experiences, as well as views on the cultural situation, historical and political developments, or just personal stories and anecdotes.

The importance of deaf clubs and networks for experiences of deaf culture become clear both in Breivik's study, where the deaf club represents an entry point into deaf culture for his informant Hilde, who has been struggling her whole youth to accept her deafness¹³¹, and in Preston's study, where informants describe deaf clubs as 'microcosms of the Deaf world'.¹³² These clubs provide a space where people with a shared identity can meet regularly. Quite often, clubs are 'segregated according to age, class, race, or method of communication. [...] Although there are subgroups within the Deaf community, an underlying sense of shared identity and common destiny cuts

¹³⁰ Breivik, 2001.

¹³¹ Ibidem.

¹³² Preston, 1994, p. 77.

across these differences. The various social and political activities are united by the cornerstone of this culture: the interest in and the opportunity to communicate.¹³³

Traditional spaces for construction and maintenance of deaf communities and deaf ways of life have been deaf schools and deaf clubs. But Hilde Hauland¹³⁴ has been observing changes in deaf ways of socialising as numbers of students in deaf schools are decreasing, and more and more deaf clubs in Europe and North America are being closed down. She believes that the ‘desire to be in a place where visual communication dominates remains strong, independent of personal education history or connectedness to formal Deaf networks (like associations or clubs) at home’¹³⁵ and investigates in her study on the Deaflympics 2001 in Rome, international events as one of the ‘strong centers of gravity in the Deaf world.’¹³⁶ As an occasion to gather and socialise with deaf people from all over the world, these events are of high significance for deaf individuals. Deaf tourists are coming from many different countries to attend and are diverse in many aspects. But they come together to celebrate their sense of a common culture and form of communication, even though they are using different sign languages. The Deaflympics last only two weeks, nonetheless they strengthen the participant’s identity and friendships for a longer term. This in turn contributes to the sense of transnationality in the (imagined¹³⁷) deaf community. By celebrating their own language and culture, deaf people reaffirm their distinct identity and strengthen the boundary distinguishing them from the hearing population.¹³⁸ During the games, the otherwise rather invisible community becomes very noticeable and leads to ‘an opportunity to articulate imagined cultural differences between deaf and hearing/nonsigning people.’¹³⁹

¹³³ Ibidem, p. 88.

¹³⁴ Hauland, 2007.

¹³⁵ Ibidem, p. 42.

¹³⁶ Ibidem, p. 34.

¹³⁷ Anderson, 1983. Even though Anderson is referring to nations as ‘imagined communities’, I think his concept can also be applied here. I do not consider the Deaf community as a form of nationalism, but as a strong community, sharing the same interests without necessarily interacting on a face-to-face level.

¹³⁸ Lane, 2005, p. 294.

¹³⁹ Hauland, 2007, p. 40.

One important point to keep in mind is that people attending international events, like the Deaflympics, belong to an elite. Therefore, when talking about human rights issues, their opinions and experiences are not representative of the whole deaf world population. Rather, they represent a small part of this population, which has enough time and money to travel and to visit international events. Their socioeconomic status gives them a certain degree of mobility, which allows them to freely choose where to be. The majority of the deaf world population does not enjoy the same level of living conditions and does not have the same freedom of mobility.¹⁴⁰

It is also an elite, which is taking part in the international organisation of the World Federation of the Deaf. In 2007, Rashid, a professor at the Gallaudet University, went to a WFD Congress in Spain and she reports her surprise about the very low number of presentations on economic issues of deaf people. Most presentations were about 'higher-order needs, such as passing legislation on language rights and self-fulfillment.'¹⁴¹ In her opinion, these are not the main interests of people who are not from privileged backgrounds and are an explanation, why not many people from developing countries attend the meetings. Apparently aware of this inequality and trying to reduce disparities, WFD sponsors at least two people from each poor member country so that they can attend the conferences. Still international conferences and organisations remain inaccessible to many deaf people due to the financial costs and presented topics. A problem which can, according to Rashid, only be solved when greater inclusion and justice are achieved.¹⁴²

Nonetheless, WFD is an important international representative of deaf rights and interests. The World Federation of the Deaf is an international non-governmental organisation, was founded in 1951 and organises every four years a world congress that gives deaf people from all over the world a setting for social and political networking. By 2008, the number of Ordinary Members, which are national associations of the deaf, had reached 132. The organisation represents about 72 million deaf people worldwide,

¹⁴⁰ Ibidem, p. 43.

¹⁴¹ Rashid, 2010, p. 29.

¹⁴² Ibidem, p. 30.

of which an estimated 80 percent live in developing countries, and is recognised by the UN as their spokes-organisation. The WFD works with various UN agencies in promoting the human rights of deaf people in accordance with the principles and objectives of the UN Charter, the UDHR and recommendations of the UN and its specialised agencies. Its highest priorities are deaf people in developing countries, the right to sign language, and equal opportunity in all spheres of life, including access to education and information.¹⁴³

Another important actor, but on a regional level in Europe, is the European Union of the Deaf (EUD). The EUD is a non-profit European non-governmental organisation, was founded in 1985 and represents deaf people and national associations in all 27 EU Member States, including Iceland, Norway and Switzerland. Its tasks are to establish and maintain EU level dialogue with the EU institutions and officials; the EUD also has participatory status with the Council of Europe (CoE), is a full member of the European Disability Forum (EDF) and is a Regional Co-operating Member of the WFD. The EUD is aiming for equality in public and private life for deaf people all over Europe to ensure they can become full citizens. The organisation's primary objectives are the recognition of the right to use an indigenous sign language, empowerment through communication and information, and equality in education and employment. As a tool to achieve equality for deaf people, the Brussels Declaration on Sign Languages in the European Union was adopted in November 2010. The Declaration aims for recognition and stronger support of sign languages and their users in the EU.¹⁴⁴

Today, most countries worldwide have a national association of the deaf and most of them are affiliated to the WFD. Several associations started their work in response to the Milan Congress in 1880; for example the American National Association of the Deaf (NAD) and the British Deaf and Dumb Association (BDDA, later BDA). In the recent past, it was necessary in some countries to establish new and separate

¹⁴³ wfdeaf.org and several subpages (consulted on 25 May 2013).

¹⁴⁴ eud.eu and several subpages (consulted on 25 May 2013).

organisations run by deaf people themselves.¹⁴⁵ The Austrian Deaf Association (ÖGLB) is celebrating its 100th anniversary in 2013. It is the umbrella organisation of all deaf clubs in Austria, of which the first one, today called WITAF, was founded in 1865.

These organisations and associations are especially interesting for human rights activism in practice. They can be compared to what Sally Engle Merry calls ‘translators’; advocating for and representing the rights of deaf people, it is important for these actors to adapt ideas of the international human rights system so that they fit to local issues and vice versa.¹⁴⁶

After talking about the origins and scope of deaf culture as well as the importance of social interaction and solidarity, we are still missing a very important aspect which is the base of deaf culture and many related human rights issues. The next section will therefore cover the linguistic aspect of deaf culture – sign language.

3.5 Sign Language

Deaf people are often referred to as a linguistic minority, instead of a disability group, because a main element of deaf culture and identity is sign language, since the ‘major impact of deafness is on communication.’¹⁴⁷ The use of sign language varies among culturally deaf people, not all are equally fluent. But the knowledge of sign language and the ability to use it is substantial to take part in transnational deaf spaces. Supporting educational programmes and welfare policies assumably influences opportunities to participate in the increasingly relevant global arenas.¹⁴⁸

Deaf children, who are exposed to sign language from early on in their lives, will start to sign at least as early as hearing children begin to speak. Research even showed that the ability to sign may be reached earlier than the ability to speak. Yet, if a deaf child is

¹⁴⁵ Ladd, 2003, p. 65.

¹⁴⁶ Merry, 2006.

¹⁴⁷ Baynton, 2000, p. 391.

¹⁴⁸ Hauland, 2007, p. 46.

only given oral speech instruction and is not exposed to sign language, the child often has a functional vocabulary of only several dozen words by the age of five.¹⁴⁹ However, a person's options are limited if one has no access to the language of the majority community. Learning to speak and lip-reading is a sensitive issue in debates about deaf education and language use. Historical experiences of 'attitudes of repression toward and even annihilation of sign language' in oralist¹⁵⁰ education systems contributed strongly to cultural deaf solidarity and continue to be remembered today.¹⁵¹ Another educational model than the oralist model, is a bilingual¹⁵² one, which has been mainly adopted in Scandinavian countries. If a person knows one sign language, international sign communication is quite easy to attain; the knowledge of a sign language increases the possibilities for transnational activities for deaf people. Oralism on the other hand, carries the risk of tying deaf people to one nation or one language.¹⁵³

In any way, it is crucial to provide interpreting services to ensure the best opportunities for participation and equality of deaf people. This would mean to recognise a linguistic model of being deaf. The 2010 Brussels Declaration, aiming for implementation of sign language legislation, calls for provision of sign language interpreting services. Also at the level of the UN, sign language interpretation is an issue. Because it is a problem in practice, 'there are very few qualified sign language interpreters in most developing countries, and only a small portion of them can interpret their sign language into

¹⁴⁹ Prinz & Prinz, 1979, 1980.

¹⁵⁰ Oralist/Oralism: 'Oralism can be defined as the educational system imposed on Deaf communities worldwide during the last 120 years which removed Deaf educators, Deaf communities and their sign languages from the Deaf education system. By replacing it with an exclusively Hearing-led system promoting the use of speech, lipreading and hearing aids only, and advocating no fraternisation between Deaf children and Deaf adults, they hoped to remove the "need for" Deaf communities to exist at all' (Ladd, 2003, p. xviii).

¹⁵¹ Preston, 1994, pp. 139-140, 220.

¹⁵² 'Bi-Bi' education: 'This term was coined to describe the bilingual bicultural approach to Deaf education developed in the 1980s. This philosophy accepted many of the Deaf communities' arguments about their linguistic minority status and some of their cultural arguments, and placed its emphasis on teaching the children in their perceived first language of signs, and from that base moving to the national written language. [...] The limited number of Deaf teachers and headteachers, the limited signing skills (and Bi-Bi training) of hearing teachers, and the very limited understanding of Deaf culture, all indicate that the Bi-Bi approach is still far from a truly Deaf-centred educational praxis (Ladd, 2003, p. xix).'

¹⁵³ Haualand, 2007, p. 47.

English or any of the other official spoken languages of the UN,¹⁵⁴ it exemplifies the importance of the need for more support to reach more equality and better access for deaf people.

Therefore, a main issue in deaf human rights activism, for example in the work of the WFD, is the recognition and support of sign language. This will also become clear in the two empirical examples of Austria, where sign language has been recognised by federal constitutional law in 2005; ‘The Austrian sign language is recognized as independent language. Details are regulated by the laws.’¹⁵⁵ The wording ‘independent language’ recognises sign language as a full-fledged language. The second sentence of the BVG article 8 paragraph 3 clarifies that this regulation is not directly applicable, but has to be concretised and adapted by the legislator.¹⁵⁶ Thus, legal recognition of sign language is only a first step and needs further actions to follow up and improve the actual situation of deaf people, supporting their culture and language. The gap between law and practice in everyday life becomes more evident in the following two empirical examples from Austria.

4. The Case of Cochlear Implants

4.1 The Rights of a Mother and Child in Austria

In November 2012, an incident occurred in the ENT department of a Viennese hospital that led to furore in the Austrian Deaf community. K., a deaf mother of a two months old deaf child, was pressured in order to consent to a surgical implantation of a cochlear implant (CI) for her child. When she came to the hospital to pick up the results of her child’s hearing test, a senior physician had already involved a social worker in the case.

¹⁵⁴ Mori, 2010, p. 240.

¹⁵⁵ ‘Die Österreichische Gebärdensprache ist als eigenständige Sprache anerkannt. Das Nähere bestimmen die Gesetze.’ Bundes-Verfassungsgesetz (BVG) 2005 art 8 para (3).

¹⁵⁶ Bizeps Info, Bundesverfassungsgesetz, <http://www.bizeps.or.at/gleichstellung/rechte/bvg.php> (consulted on 28 May 2013).

The social worker had been tasked to investigate whether the mother was planning to agree to the implant. But K. stated that she knows sufficiently about the surgical method and that she did not want it for her child. The social worker then explicitly announced that she will inform the youth welfare service, which in that case would have to get involved. K. went for consultation at ÖGLB and, on their advice, filed for an arbitration process according to the Viennese anti-discrimination law. The process on 25 January 2013 reached an agreement between K. and the senior physician of the hospital. The hospital had to make a written statement, accepting K.'s decision and refusing to involve the youth welfare service.

This has not been a single incident. Something similar happened in Salzburg, Austria, in 2009. Hospital staff was trying to convince parents to decide for a CI for their child and as the parents refused, the hospital threatened to involve the youth welfare service in their case. The union of deaf associations in Salzburg had a meeting with the responsible personnel of the hospital to discuss the case, but the hospital denied ever threatening to involve the youth welfare service.

In its arguments the ÖGLB takes a strong stand against one-sided consultation by ENT departments and refers to the CRPD, which was ratified by Austria¹⁵⁷ and is of high importance in these kinds of cases. Two Articles of the CRPD are especially emphasised in the statement by the ÖGLB; Article 3 (d); 'Respect for difference and acceptance of persons with disabilities as part of human diversity and humanity'; and the second part of Article 23 (2); 'States Parties shall ensure the rights and responsibilities of persons with disabilities, with regard to guardianship, wardship, trusteeship, adoption of children or similar institutions, where these concepts exist in national legislation; *in all cases the best interests of the child shall be paramount. States Parties shall render appropriate assistance to persons with disabilities in the performance of their child-rearing responsibilities.*'¹⁵⁸

¹⁵⁷ BGBl. III 155/2008.

¹⁵⁸ My emphasis.

Next to referring to the right of bodily integrity and self-determined family planning, ÖGLB regards the threat to involve the youth welfare services as a violation of the right to autonomy and demands full recognition of deaf and hard of hearing people's rights to linguistic and cultural self-determination. In practice this would entail a neutral and comprehensive consultation at ENT departments, including the medical opinion of the doctors and the sociocultural perspective of deaf people. The consultation should include information on the acquisition of language, and while doing so, not only focus on speech, but also on the use of sign language. The Austrian national association of the deaf claims a right for deaf people to live and pass on their own culture, a right to be deaf and to have deaf children.¹⁵⁹

In cases of CI consultations and decisions, it is important that parents know about opportunities and risks brought through this surgical method and that they are in a position to make an autonomous choice, which then has to be respected without constraints. Many will bring forth the argument of the child's well-being, but a deaf perspective demands from society to accept that the physical, mental and spiritual well-being of a deaf child can be guaranteed both with and without a CI.¹⁶⁰

4.2 Disability Perspective

In questions on the quality of a life with impairments the field of bioethics often brings strong arguments. Bioethical studies deal with 'fundamental questions of health and illness, life and death, the relationship of medicine to nature, what constitutes a life of quality, and whether there are ever life situations that appear worse than not being alive.'¹⁶¹ Classical bioethicists used to regard life with disability from within the medical or biomedical model, which has been criticised by disability community critics, as well as the implicit assumption that a functional impairment leads to an unacceptable and unsatisfying life.¹⁶² In cases where they cannot make their own will be known, it is

¹⁵⁹ ÖGLB, 2013.

¹⁶⁰ Ibidem.

¹⁶¹ Asch, 2001, p. 298.

¹⁶² Ibidem, p. 299.

usually the person's family who is expected to decide on behalf of the person with impairment. Yet, disability rights activists do not trust the good faith behind these decisions and try to involve disabled people as much as possible or otherwise seek support from governments and courts to protect the interests of vulnerable individuals. Aiming for an advance in dignity of people with disabilities it is the goal to facilitate 'their participation in life-and-death decisions and to circumscribe families making decisions on behalf of those who have less than full legal authority to make their own decisions.'¹⁶³ For obvious reasons, severest clashes between the interests of disability rights and bioethics are in life-and-death situations. But the clash between medical and social models of disability also exists in other bioethical discussions, such as talks about efforts to cure disability, like it is tried to be done with the CI.

This technological invention has been an issue in bioethical discussions on disability for some time now and has found both supporters and critics in the field and beyond. Supporters take a perspective based on the medical model of disability and see the implants' possibility of eliminating deafness in the future, and with it the problems that come along the medical condition.¹⁶⁴ Arguments of the supporting side claim the 'child's right to an open future', with a focus on the protection of autonomy, meaning that the child's options for the future can only remain open if the parents opt for an effort to cure deafness. Deafness is seen from a medical point of view, therefore it constitutes an individual deficit and it is a pathological state of not being able to hear. As one of the main reasons for hearing loss is illness, they argue that '[a]ttempting to cure or ease the individual's condition by means of the latest technology would normally be thought of as ethically non-controversial, routine, perhaps even sought after and deemed praiseworthy.'¹⁶⁵

Disability lawyer Tucker, who was deaf since infancy but received a CI late in her life, suggests that if children or adults can gain some hearing from the implants, they are morally obliged to have them. This implies that if parents have the best interests for

¹⁶³ Ibidem, p. 311.

¹⁶⁴ Kermit, 2009, p. 137.

¹⁶⁵ Ibidem, p. 138.

their child, there should be only one possible decision for them to make. She even proposes that in cases where people refuse the implant, they should lose access to interpreter services.¹⁶⁶ And Davis, a hearing bioethicist, objects to the cultural view of disability; ‘One of the defining differences between culture and disability is the option that human adults have to choose the extent to which they identify with and participate in their culture.’¹⁶⁷ She rejects the assumption that cultural membership is formed by physical characteristics and states that ‘Deaf children who are fitted with perfect cochlear implants will not be treated by others as deaf,’¹⁶⁸ furthermore she argues that a child’s lack of hearing places certain limits on the assumed open future that parents should want for their children.¹⁶⁹ To me, this seems a little too optimistic about the impact of the CI, as it will still be very important for a child with CI to actively learn speech and the ability to hear is limited to certain frequencies.

4.3 Cultural Perspective

From a cultural perspective on deaf communities, the growing number of implantations of this electro-magnetic device since the 1980s has often been represented as a threat to deaf culture. The CI intends a direct stimulation of the auditory nerve; yet in doing so, any residual hearing is destroyed. Medical sources claim that significant benefits in speech, lip reading and hearing skills take place nevertheless. Some members of deaf communities on the other hand regard these surgeries more critically and call them ‘unethical experiments on non-consenting Deaf children, whose parents have been either misled by distorted information or subjected to forms of emotional blackmail’¹⁷⁰; regarding the latest case in Vienna this statement actually partially refers to incidents still happening today.

¹⁶⁶ Tucker, 1998.

¹⁶⁷ Davis, 1997 (a), pp. 253-254.

¹⁶⁸ Ibidem, p. 255.

¹⁶⁹ Davis, 1997 (b).

¹⁷⁰ Ladd, 2003, p. xx.

Critics and opponents of the CI who reject this technological piece, argue that deaf people are primarily members of a linguistic minority and not disabled people in need of 'repair'. Critics go as far as reproaching surgeons conducting CI surgeries of attempting to commit ethnocide and of trying to exterminate deaf culture completely.¹⁷¹ Deaf associations stress the importance of an adequate representation of deaf people, which subsequently determines the outcome of society's (ethical) judgment. When children born deaf are not regarded as members of a cultural and linguistic minority, it is more likely that society is willing 'to conduct surgery of unproven benefit and unassessed risk, ignoring the harm that is done to the child's ethnic group.'¹⁷² It is argued that a child's cultural belonging and identity is changed by means of technology. Understanding deaf people as a linguistic and cultural minority instead of seeing them as being disabled would make it unethical to use CIs in order to eliminate deafness, because the understanding of deafness as a disability is based on 'social (mis)perceptions' and not on the daily lives and realities of deaf people.¹⁷³

Current concerns and fears of the deaf community due to medical innovations and interventions might be better understood when looking back in history, when there have been serious threats from eugenics and its attempts to improve the population's genetic composition. In the USA in the end of the nineteenth century, the emergence of Social Darwinism led to the incorporation 'of the concept of the survival of the fittest to the social and political structure', which caused suppression of many minorities.¹⁷⁴ Alexander Graham Bell was one of the leading figures of the eugenics movement, which emerged from the Social Darwinism discourses. The deaf movement in the USA, based on the use of sign language, experienced some serious opposition by well-known persons like Bell, who even explicitly rejected marriage among deaf people. His research established (unscientific) links between deaf schools and consequent deaf marriages with increasing numbers of deaf children. He used these findings to promote oralism in a very similar way to eugenic campaigns and argued that 'the production of a

¹⁷¹ Kermit, 2009, p. 137.

¹⁷² Lane, 2005, p. 305.

¹⁷³ Kermit, 2009, p. 139.

¹⁷⁴ Ladd, 2003, p. 117.

defective race of human beings would be a great calamity to this world.’¹⁷⁵ Several factors, including Bell’s resources, his connections and his ideological credibility, led to success of oralism in the USA and other parts of the world.¹⁷⁶ In the beginning of the twentieth century, education systems for deaf children did no longer include sign languages and deaf teachers, and in several US states there was legislation to sterilise deaf people or prevent intermarriage.¹⁷⁷

Also the life on Martha’s Vineyard experienced some changes with the beginning of the twentieth century. There was an increase in movement of people and the development of mass communication brought along societal changes. With these changes the attitude toward deafness shifted; people coming from outside the island regarded deafness as a stigma, as a reason to be ashamed. At the turn from the nineteenth into the twentieth century, the phenomenon of deafness on the island was mentioned on several occasions in the press by ‘eugenicists as an example of the evils of inbreeding.’¹⁷⁸

This experience of threats from the hearing world for the preservation of deaf culture is also addressed in the ARTE documentary *Gehörlosigkeit – eine Behinderung*.¹⁷⁹ One interview partner, wearing a t-shirt with the slogan ‘proud to be deaf’, is very critical of the increase in implanted CIs. This motivated him to produce a film called *The Last Deaf*.¹⁸⁰ The main plot idea of this science-fiction movie is based on the fear of consequences due to the decreasing number of deaf persons. The principal actor finds himself in a world, where all deaf persons wear CIs and originally important places of deaf culture, like the deaf club, are abandoned and closed down. A possibly exaggerate outlook into the future, but definitely not an unknown fear in deaf communities. Also the film *The End* deals with treatment of deafness through technological devices and the decline of deaf culture.¹⁸¹ In the format of a documentary, yet a fictional story, four deaf

¹⁷⁵ Bell, 1883, as quoted in Ladd, 2003, p. 118.

¹⁷⁶ Ladd, 2003, p. 119.

¹⁷⁷ Mirzoeff, 1995.

¹⁷⁸ Groce, 1985, p. 94.

¹⁷⁹ ARTE, 2011 (“Deafness – a disability”).

¹⁸⁰ Mertz, 2001.

¹⁸¹ Tracy, 2011.

people are filmed from childhood into adulthood. This is presented in the context of a changing world where technology and science provide a cure for all sensory impairments. The film tries to show what life will be like for deaf people in the future and addresses the possible disappearance of deaf culture as well.

As only about ten percent of deaf children are born to deaf parents, cultural heritage and language has to be learned anew by each generation. This means the process of enculturation for the majority is always vulnerable to ideological interventions from external powers. Ladd believes that the majority population – or interventions like oralism, CI and genetic manipulation – tries to convince hearing parents of the remaining 90 percent of deaf children that “normality” can be achieved ‘by denying the realities of deafness and keeping their children away from Deaf communities lest they be “contaminated” by them.’¹⁸² Thus from a cultural perspective CI can be considered as a threat to the future preservation of deaf culture. Contrary to the medical perspective, it is not seen as a means to improve a deaf person’s life.

4.4 The Parents and Their Child

Perhaps the biggest issue concerning deaf children is who is responsible and able to decide what is best for them. Parents, in most cases hearing themselves, will most likely think of life-long language and communication problems as well as risks of isolation. Yet, I would say, the most important considerations should be about the appropriate reactions and actions of a deaf child’s environment, which have a strong formative character influencing the identity and self-confidence. These reactions will differ depending on the parents’ own hearing conditions and life experiences. The situation of deaf children of deaf parents is described by Nora Groce as rather advantageous compared to the situation of deaf children of hearing parents;

The deaf parents’ acceptance of the child’s deafness, the ability to communicate through sign language, the availability of role models, the support of the surrounding deaf community, and the knowledge of how to manage day-to-day problems are all cited as factors in this advantage. Particularly important is the

¹⁸² Ladd, 2003, p. 35.

head start these deaf children receive in the first few years of life. Those early years are often a difficult time for deaf children of hearing parents, as their mothers and fathers come to grips with their child's disability, struggle to master sign language, and find their way through a complicated special education system.¹⁸³

Deaf children of hearing parents' experiences can (but do not necessarily have to) be different. Hilde, one informant in Breivik's study on deaf identities recounts her experience of being deaf and her problems of appreciating her own deafness as a child. Breivik blames the 'phonocentric cultural regime' for her negative perspective on deafness and the subsequent negative impact on her self-confidence.¹⁸⁴ Even though she struggled with her own deafness for a long time, Hilde was against the use of CI; she considered it as a lie that would never fulfil the promised effects and furthermore as an attack upon deafness and sign language. She no longer opposes this method, as 'there have always been different groups of deaf persons' and 'she understands the hearing parents' dilemmas and the deaf child's needs.'¹⁸⁵ Also, she does not want to strengthen a movement of "Deaf extremism", which strongly opposes the use of CI. She worries that these attitudes will sharpen the boundaries between 'the deaf and the hearing worlds,' making it even more difficult for mixed families. In Hilde's life the perception of deafness as a malfunction played a major role in her youth, she experienced herself as 'tragically different' from others and her childhood was filled with frustration and confusion. The fact that her parents did not know sufficiently about deafness and did not have appropriate skills to communicate with her, contributed to her experienced difficulties. Sign language made a big difference for Hilde; she finally acquired a sense of pride for being deaf and was happy to be able to communicate freely.¹⁸⁶

Hearing parents might consider CIs as a means to positively affect the quality of their personal relations to their child; almost as a way to bring their child closer to the 'hearing world'. Preston describes in his book *Mother Father Deaf* the relationship of

¹⁸³ Groce, 1985, p. 75.

¹⁸⁴ Breivik, 2001.

¹⁸⁵ Ibidem, p. 2.

¹⁸⁶ Ibidem.

deaf persons to their hearing parents.¹⁸⁷ His informants tell of an ‘often inseparable rift between the world of the Deaf and the world of the Hearing.’¹⁸⁸ This gap could be a reason for hearing parents to try to make their child hearing. Communication and understanding of each other’s situation could be easier, but I think it is not the only “solution” and it should be weighed against other ways to improve the relationship between hearing parents and deaf children.

Opposing voices to the use of CIs regard it as unnecessary for a deaf child to get the implants. A sociological understanding of minorities by Goffman is comparable to the composition of deaf communities; they have a common history and culture and they are in a comparatively disadvantaged position in society.¹⁸⁹ If one accepts the use of sign language as a natural language, including its capabilities in scope and quality of communication like any spoken language, it would imply that one would also accept the identity of deaf people as members of a linguistic minority. Consequently, it would be most important for deaf children to learn sign language and not to get a surgery.¹⁹⁰ Most people take their language for granted; they ‘don’t have to reflect on the fact that they can usually speak their minds, freely, and without encumbrance.’¹⁹¹ Thomas H. Eriksen recognises this importance of a person’s language and its significance for a person’s identity and concludes that ‘those aspects of personal identity which are expressed through one’s language, can be extremely important to the wellbeing of individuals. Linguistic rights should be seen as elementary human rights.’¹⁹²

In the context of this thesis, I do not have the means and time to look extensively into medical research on this topic to see which changes in understanding and speech production really exist, but there would be differences for each individual. After looking into the cultural perspective on deafness and the topic of CI, I believe that sign language and the experience of community would still be a very significant part of the person’s

¹⁸⁷ Preston, 1994, pp. 61-76.

¹⁸⁸ Ibidem, p. 62.

¹⁸⁹ Goffman 1963, p. 145.

¹⁹⁰ Kermit, 2009, p. 138.

¹⁹¹ Ibidem, p. 143.

¹⁹² Eriksen, 1991, p. 42.

life. Opting for a CI is not an obvious solution that makes a deaf person to a hearing person, because

[p]revious research on children with cochlear implants, together with the historical knowledge we have about the experiences of deaf and hard-of-hearing children, suggests that some of these children never get to realise their full lingual potential [...].¹⁹³

Parents can spend time to learn sign language, but also focus on teaching their children speech and lip reading. Most importantly though is it that they do not deprive deaf children of a deaf community and the experience of deaf solidarity. As we saw in the part on deaf culture, this experience can give a lot of strength and support to face problems in daily life in a ‘hearing-world’.

I agree, it should be acted in the best interest of the child and to find out about the specific meaning of this interest a legal analysis of decisions on that matter would be suitable and interesting. But also the anthropological perspective is contributing to the discussion, because this ‘best interest of the child’ has to be seen in context. In public debates both sides should be represented, so that people who face the decision whether to choose a CI or not, can make this decision based on balanced information and not because they were influenced by some bigger interests. Parents have to know that their child will not be completely hearing; their expectations and treatment toward the child must take this into account. It still might be beneficial for the child to learn sign language and spend time in a deaf environment to exchange experiences with ‘non-hearing’ people.

4.5 The Tension between Culture and Disability

To go back to the question of whether arguments of disability or linguistic character adequately support the interests of deaf people, I want to refer to Lane, who describes several positive aspects of understanding deaf people as a linguistic minority (or, as Lane calls it, ethnic group); ‘The variety of humankind and cultures enriches all cultures

¹⁹³ Kermit, 2009, p. 146.

and contributes to the biological, social, and psychological well-being of humankind.¹⁹⁴ Therefore, states should care for their linguistic minorities and ensure that there are adequate opportunities to learn the minority language. The Declaration on the Rights of Persons Belonging to National or Ethnic, Religious and Linguistic Minorities is an affirmation of the right to enjoy minority culture and language and entails that '[p]rograms that substantially diminish minority cultures are engaged in ethnocide and may constitute crimes against humanity.'¹⁹⁵

The arguments of the deaf community reveal their claims to a deaf identity and their understanding thereof. Deaf community members say that sign language is a distinct language that brings along a way of thinking and of situating oneself; they therefore conclude that deaf people can have a culture.¹⁹⁶ Attempts to change a deaf person, so that he/she can assimilate into the majority population by getting a cochlear implant and only using spoken language, are not the desired approach one can find in deaf identity politics and activism. Just because it is possible to get a CI, it is not always the desired solution. Instead it is demanded that deafness is seen as a biological characteristic that led to the development of a specific culture.¹⁹⁷

Analysing actors like the ÖGLB and other deaf associations or deaf activists, who act as 'translators' in the sense of Merry's concept on the localisation process of human rights, shows the practice of deaf human rights activism and how specific issues are translated into transnational human rights issues. It is their task to find the right arguments and ways to represent and fight for deaf human rights. The arguments should fit the specific context and still refer to ideas intended by human rights documents.¹⁹⁸ The ÖGLB refers to the CRPD, emphasising the respect for differences and human diversity. The prevailing arguments in discussions on the topic of CI and whether this is a solution or threat to deafness allude to deaf culture. Thanks to the social model of disability,

¹⁹⁴ Lane, 2005, p. 303.

¹⁹⁵ Ibidem.

¹⁹⁶ Ravaud & Stiker, 2001, p. 498.

¹⁹⁷ Lane, 1984.

¹⁹⁸ Merry, 2006, p. 49.

‘translators’ can refer to the CRPD and at the same time stress the importance of cultural and social aspects. I want to emphasise that the Austrian deaf community and ÖGLB do not generally reject the use of CI, but they demand a balanced and extensive consultation by doctors. Disability studies and activists keep on presenting disability as an acceptable form of human variation and suggest that society can ‘learn from the disability experience about the appreciation of human diversity.’¹⁹⁹ If society’s perception of deaf people and deafness changes, it might not be such a frightening moment for hearing parents to learn about their child’s deafness and they might not feel the need to try to normalise their child by the means of a medical intervention.

A linguistic and cultural understanding of deaf people consequently leads to resistance to cochlear implants and to genetic screening to identify for termination a fetus with a likely hearing impairment.²⁰⁰ However, the opinions also differ within the deaf community in Austria. I have met deaf parents who decided to get CIs for their deaf children. But their children still grew up learning and using sign language additionally to lip reading and speaking. If we are talking about the ‘best interest of the child’ in consideration of the social and cultural context, it will make a difference whether the parents are deaf themselves or not. Their own experiences influence their expectations of their children’s life and future. In any case, decisions should not be made because of pressure by medical staff and social workers, but after thorough consultations including a medical and sociocultural perspective on deafness.

Another issue often arising in deaf communities in connection to ‘struggles to avoid assimilation within a “oralist” culture and retain their separate cultural identity’ is the issue of education and schools. Disability movements campaign for inclusive school systems, whereas some members of deaf communities demand support for special deaf schools. Historically, these schools constituted an important arena for the development and maintenance of deaf culture. Additionally, the focus lies on teaching and learning

¹⁹⁹ Asch, 2001, p. 320.

²⁰⁰ Barnes & Mercer, 2001, p. 527.

through sign language.²⁰¹ Today, these arguments are sometimes still made, but it cannot be said that there is a global deaf community with the same demands. The following example of Austria will give an insight into the complexity of deaf people's demands and expectations concerning education.

5. The Case of Deaf Education

5.1 Deaf Schools and Inclusive Education in Austria

On 22 May 2013, the Austrian National Council came together to discuss the 2012 national report on education. Helene Jarmer, the third culturally deaf person to be elected to a national parliament worldwide²⁰², presented her matter of concern in sign language. The first seconds, it was unusually quiet in the assembly; not even the translator spoke. This was Jarmer's intent; she had instructed the translator to start only after the first sentences, because she wanted to give her colleagues an example of how everyday life and situations of communication in speech feel like for deaf persons. Helene Jarmer, who besides her political position is also the ÖGLB president, then addressed the education system in special schools and integration classes, which is not legitimate anymore and should be no longer the way of education for deaf children. In her presentation, she explained why the right to language for deaf children in Austria is still not existent. Even though deaf children learn sign language in a natural way, the necessity of sign language is often not recognised. Instead it is assumed that it would be better for them to learn German, but learning sign language is the foundation needed to learn more languages. Although children have the formal right, the laws on education do not obtain the right to language as sign language. Consequently, deaf children in the age of six have a vocabulary of a hearing two-year-old child. After finishing the time of compulsory education, their vocabulary equals the vocabulary of hearing children at the

²⁰¹ Ibidem, pp. 527-528.

²⁰² Helene Jarmer was inaugurated on 10 July 2009.

age of eight. The schooling is bad and according to Jarmer, it is even possible to speak of an illiteracy rate of 80 to 90 percent.²⁰³

One of the problems is based in the education for teachers. Even though inclusive education is a common topic and approach, it is not compulsory for teachers, who teach deaf children, to learn sign language. The only requirement for them is to prove attendance of 70 hours of sign language classes, but no exams are necessary. About five percent of the teachers know sign language, but they managed to learn it through their own initiative.²⁰⁴

In the meeting of the Austrian National Council Helene Jarmer also talked about a case in Carinthia where a deaf child attends an integration class in high school. In the child's class a supporting teacher is present, but this teacher does not know sign language. This shows how education offered for deaf children is limited; sign language competent teachers are an exception. Jarmer regards the overall situation as unfair and calls it a human rights violation. Finally, she demands that the national report on education's current lacking investigation on children with disabilities and their success in learning a language will be better explored and that in future, children with disabilities will not be forgotten.²⁰⁵

From Helene Jarmer's report we can see that the current problems are that the law still leaves room for differences in the practical realisation, even though sign language is recognised by federal constitutional law in Austria. This is why in June 2013, several draft laws for a reform of the school system were discussed in the Austrian parliament. Two members of parliament, Walter Rosenkranz and Dagmar Berlakowitsch-Jenewein (oppositional party FPÖ), demanded the recognition of sign language as language of instruction in school²⁰⁶, but the demand was adjourned. ÖVP (one of the ruling parties)

²⁰³ Jarmer, 2013.

²⁰⁴ Ibidem.

²⁰⁵ Ibidem.

²⁰⁶ Republik Österreich, Parlament, Umsetzung des Rechts auf bilingualen Unterricht, (2318/A[E]), 20 June 2013, available at: http://www.parlament.gv.at/PAKT/VHG/XXIV/A/A_02318/index.shtml (consulted on 24 June 2013).

mandatory, Franz-Joseph Huainigg was not present on that day; however he had called beforehand for a remembrance of the government's National Action Plan on Disability, which envisages bilingual teaching in speech and sign language by 2020.²⁰⁷ Several members of parliament voiced their anger about the adjournment, such as Helene Jarmer and Stefan Markowitz. Jarmer emphasised the recognition of sign language as a minority language in the Austrian constitution and referred to its use in class as a human right.²⁰⁸

This section of the thesis will mainly focus on compulsory education, because then deaf children are at an age that is influential for the development of their identity; and also including higher education and vocational training would be too lengthy for the scope of this research. According to the ÖGLB president and deaf Member of Parliament, the current goals and needs in education of deaf children in Austria are bilingual instructions in class and the deployment of teachers who are competent in sign language. One measure of Austria's National Action Plan on Disability is the promotion of competency in sign language among Austria's population, addressing areas like school, adult education, and vocational training.²⁰⁹ The issue of education is also covered separately in the National Action Plan, which recognises the importance of equal participation in the education sector 'for equal participation in the life of society. Inclusive accessible education is important for people with disabilities for their participation in working life, their financial security and the possibility to lead an autonomous life.'²¹⁰ Subsequently, the overall quality of education would not only be more beneficial for disabled children but for the society in general. Based on the EU Disability Strategy 2010-2020²¹¹ the promotion of inclusive education becomes a key area of focus for actions.

²⁰⁷ BMASK, 2012.

²⁰⁸ Bizeps Info, Opposition bezweifelt Reformwillen bei System der Schulverwaltung, 20 June 2013, available at: <http://www.bizeps.or.at/news.php?nr=14140> (consulted on 24 June 2013).

²⁰⁹ BMASK, 2012, p.41.

²¹⁰ Ibidem, p.61.

²¹¹ COM(2010) 636 final, 15 November 2010.

We can already see the differences between policies and political decisions that are pursued in deaf and in disability approaches. The official goal of inclusive education and bilingual instructions does not necessarily reflect the constitution of deaf education as we learned in the section on deaf culture. Demands for deaf education traditionally included instructions in sign language in class and experiences with other deaf students; both were stressed as very influential for the maintenance and development of deaf culture. Many culturally deaf people also stressed the significance of their experiences at deaf schools that contributed to the strengthening of their own identity and increased confidence.²¹² Thus this example of education for deaf students in Austria is fascinating when having a closer look at the tension between disability and cultural approaches to deafness as well as investigating the implications of self-identification as being part of a deaf culture on human rights activism.

In 2006 and 2007, Verena Krausneker and Katharina Schalber²¹³ conducted a thorough study on Austria's education offered for deaf and hard of hearing children in schools and students at the University of Vienna. One of their main findings is that deaf education in Austria is not adequate to the needs and does not allow deaf and hard of hearing children access to equal education. Underlying reasons for this seem to be language and language acquisition as well as the acceptance of deafness. Evidence from special school and mainstream classes show that sign language is substantial in education for deaf and hard of hearing students, but is not treated suitably in the respective curricula in Austria. Training for teachers and insufficient school resources, such as staff, budget, teaching material, and technical facilities, contribute to the problematic situation of education.²¹⁴

The quality and form of education offered differs across Austria, depending on whether it takes place in special schools or in integrative school settings; altogether six deaf schools exist in Austria. There have been cases where families moved to other federal states so that their deaf child could attend a certain school; also deaf teenagers tend to

²¹² E.g. in Preston, 1994.

²¹³ Krausneker & Schalber, 2007.

²¹⁴ Krausneker & Schalber, 2007.

move to Vienna in order to have the possibility of finishing high school. Schools analysed in the study have different approaches to education for deaf children. Some emphasise the use of sign language, attach importance on sign competency among the teaching personnel, and provide information on extracurricular deaf possibilities (like deaf clubs), others regard deafness as a deficiency and therefore put the focus on speech and German in class, sometimes also using a Total Communication²¹⁵ approach.²¹⁶

Austria's biggest educational institution for deaf and hard of hearing children, the 'Bundesinstitut für Gehörlosenbildung' (BIG), is located in Vienna. According to the school's website, there are approximately 240 hard of hearing or deaf students and around 100 hearing students. Education is offered starting from pre-kindergarten until high school. The school is focused on hearing and speech oriented instructions; out of 16 integration classes in elementary and high school level, attended both by hearing and by deaf students, three have a bilingual focus.²¹⁷ Among teachers at the BIG the opinion regarding the use of sign language is rather critical; some state that sign language is incompatible in cases where children have a CI.²¹⁸

Overall, education in sign language in elementary and high schools is an exception across Austria; it almost does not matter if students attend a deaf school or integrative school settings. This might lead to difficulties for deaf students in keeping up with their hearing peers. Beyond the aspect of learning, Krausneker and Schalber also stress the importance of the process of finding their own identity for students. Deaf teachers can serve as role models and interaction with deaf peers provides opportunities to exchange experiences and concerns. Through contact with deaf adults in school, deaf children can improve their language skills both in German and sign language, but in Austria's practice of education corresponding consequences are still missing.²¹⁹

²¹⁵ Total Communication: Using signs in conjunction with speech in spoken language word order (Ladd, 2003, p. xix).

²¹⁶ Krausneker & Schalber, 2007, pp. 42-75.

²¹⁷ Bundesinstitut für Gehörlosenbildung, at: <http://www.big-kids.at/sites/startseite.html> (consulted on 15 June 2013).

²¹⁸ Krausneker & Schalber, 2007, pp. 67.

²¹⁹ Ibidem, p. 212.

In 2003 – a time before the CRPD was adopted and also before sign language was constitutionally recognised in Austria –, the ÖGLB started a citizen initiative concerning the quality of education for deaf people. The demand was that the quality of education has to be raised; no matter if education takes place in an integrative or special school setting. School curricula should include subjects like ‘Deaf Studies’ and ‘Sign Language Studies’. Not only the content was addressed, but also bilingual teaching methods were asked for, meaning that both sign language and written/spoken German are used as languages of instruction and are taught as a subject, preferably by ‘native speakers’. Therefore, the initiative also asked for deployment of deaf teachers in classes with deaf students.²²⁰

Since then, the Austrian deaf community definitely made education a number one priority in their current policy efforts and human rights activism. For the occasion of its hundredth anniversary, the Austrian Deaf Association is organising, besides a big ceremony, an international Education Congress themed “Gebärdensprache macht stark – Empowerment durch Mehrsprachigkeit” (Sign language makes strong – empowerment through multilingualism). The event takes place in July 2013 in Vienna and will bring together international and national experts who will provide participants with information on topics like regulatory framework, political engagement, media and accessible information, networking and inclusion in education and work.

The focus of the event will be inclusion in society in general and particularly inclusion in education, which is regarded as creating potentials that need to be promoted and used in the right way. For personal development and full participation in society and in working life, equal access to education and a process of lifelong learning are very important. Deaf people continuously had and have to face barriers in access to adequate schooling. The Education Congress aims to highlight the current situation and work on possible improvements and innovations. To do so, it will build on the CRPD.²²¹

²²⁰ ÖGLB, 2003.

²²¹ Österreichischer Gehörlosenbund (ÖGLB), at: <http://www.oegl.at/> (consulted on 12 June 2013).

Inclusion is an approach to education prevalent in the disability movement; a culturally deaf movement, as we learned in the historical developments, aims for a deaf school where social exchanges take place and the language of instruction is sign language. It cannot be said that an inclusive approach does neglect deaf culture altogether, because the use of sign language in class continues to be the essential demand. The following sections will portray and analyse the current reasoning and goals of deaf human rights activism concerning education against the background of deaf culture.

5.2 Disability Perspective

Article 24 of the CRPD intends that States Parties ensure that ‘persons with disabilities are not excluded from the general education system on the basis of disability, and that children with disabilities are not excluded from free and compulsory primary education.’ The article further states the need for appropriate measures in order to facilitate ‘the learning of sign language and the promotion of the linguistic identity of the deaf community’ and to ensure that

the education of persons, and in particular children, who are blind, deaf or deafblind, is delivered in the most appropriate languages and modes and means of communication for the individual, and in environments which maximize academic and social development. [...] In order to help ensure the realization of this right, States Parties shall take appropriate measures to employ teachers, including teachers with disabilities, who are qualified in sign language.²²²

The goal for education for deaf children is both, learning to effectively communicate in sign language and to read and write in the language of their country of residence. The CRPD regards this as crucial for deaf people’s ability to participate effectively in society. The educational environment should contribute to a child’s social and academic development.

Logistically it would seem to be the easiest way to make a school for deaf children where teachers can focus on sign language and the promotion of a deaf identity. But the

²²² A/RES/61/106 (CRPD), 13 December 2006, art 24 paras 3 (c) - 4.

disability movement and supporters of inclusive school systems regard separate schools for certain people as a problem; '[c]hildren, young people, and adults experience exclusion when they are debarred entry to ordinary educational settings on the grounds of disability, learning difficulty, or difference.'²²³ Separate schools have several functions; they are supposed to protect those identified as different, but they also remove these people 'from public gaze, preventing participation in ordinary social life, and denying the wider community the opportunity of knowing them.'²²⁴ To avoid segregation and marginalisation of people with disabilities, the CRPD calls on state parties to 'ensure an inclusive education system at all levels.'²²⁵

There is almost no information on deaf people's perspective regarding their experiences at school in Austria. Krausneker and Schalber mention a study conducted in 2002 by Breiter on this topic, in which deaf women report their experiences of attending a deaf school. The majority of these women had a lot to criticise about their school; the main discontent regards the oral focus and use of speech for instructions, for which reason they could not understand everything, rather memorised than understood the content, and felt like class was boring and the level of education was too low for their real capacities.²²⁶ This is in accordance with other deaf people's stories about their experiences at deaf schools, who mention 'lost opportunities that were a result of the poor outcome of their education', but nevertheless they talk about positive experiences regarding their social life at the deaf school.²²⁷ On the other hand, deaf children who attended mainstream schools and were the only deaf child, or even deaf person, in their social environment at school, often tell of loneliness and feelings of exclusion.²²⁸ This feeling of isolation leads us to one of the main arguments of the cultural approach to deaf education; bringing together deaf students to promote and maintain deaf culture and experiences of solidarity.

²²³ Barton & Armstrong, 2001, p. 704.

²²⁴ Ibidem.

²²⁵ A/RES/61/106 (CRPD), 13 December 2006, art 24 para 1.

²²⁶ Breiter, 2005.

²²⁷ Kermit, 2009, p. 147.

²²⁸ Oliva, 2004 as quoted in Krausneker & Schalber, 2007, p.213 ; Kermit, 2009, p. 147.; Ladd as quoted in Campbell & Oliver, 1996, p. 121.

5.3 Cultural Perspective

Two elements are crucial from a deaf perspective on education; bilingual instructions using sign language in class and possibilities of social interaction with other deaf people. The WDF and the deaf anthropologist Hilde Hauland published a report on 'Deaf People and Human Rights'²²⁹, in which they stress the necessity of possible communication with peers and teachers. They suggest a school for deaf children, because there the natural language would be sign language, used both by pupils and teachers; therefore the best environment for a deaf child.²³⁰

In current debates, it is again the relevance of a deaf and sign language using environment that is highlighted. Education and experiences in school have been a very important characteristic of deaf culture since its origins in the eighteenth century. They contributed to the formation of deaf culture and to the enhancement and strengthening of sign languages. Deaf schools are strongholds of culturally deaf people. They provide a place to meet people who are in the same situation and the use of a common language facilitates communication without limitation; 'separate schooling for deaf children is regarded as central to maintaining deaf identity and consciousness.'²³¹ The WDF connects its human rights perspective with the cultural and linguistic character of deaf students, but they seem to differentiate between primary and secondary education and higher education as well as vocational training. Primary education takes place at a time in life which is very important for a person's process of finding their identity and confidence with who they are. For all other education, the WDF demands the following;

Deaf people shall also have access to secondary and higher education as well as vocational training; and the education and/or training must be provided in a mode that is accessible to Deaf people. Access to further education and vocational training is important to being able to find and hold a job to earn a salary that allows independent living.²³²

²²⁹ Hauland & Allen, 2009.

²³⁰ Ibidem, p. 28.

²³¹ Campbell & Oliver, 1996, p. 121.

²³² Hauland & Allen, 2009, p. 46.

Then the focus does not lie on the cultural aspect anymore, but is instead emphasising the accessibility (linguistic aspect) and the desired empowerment through education to facilitate independent living.

5.4 The Tension between Culture and Disability

Obviously, the debates on education are very complex and different approaches to the topic emphasise different aspects in practice. The arguments of deaf human rights activists – again keeping in mind Merry’s thoughts on ‘translators’ and the practice of localising human rights²³³ – reveal that the arguments of the deaf community in Austria cannot be clearly categorised as arguments stemming only from the disability approach or only from the cultural approach. This reveals once more the tension between claiming a cultural identity and refusing to be considered as people with disabilities and the actual basis for arguments made in practice.

The demands of the Austrian deaf community combine aspects of both the deaf movement and the disability movement. It is a widely represented opinion that the current situation of education for deaf people in Austria is not up to date; Krausneker and Schalber refer to Baker²³⁴ who described educational approaches in North America and Europe until the 1970s, which they consider to be continuing in Austria.²³⁵ Back then, the education was based on several assumptions, such as the benefit of deaf children’s integration into mainstream society, the requirement of majority language proficiency that led to a refusal of teaching the curriculum through sign language, and the insufficiency of sign language for full intellectual development.²³⁶ Pedagogues in Krausneker’s and Schalber’s study believe that parents decide in Austria about the form of education for their deaf child. In the end, it does not matter what experts say or how

²³³ Merry, 2006.

²³⁴ Baker, 2006.

²³⁵ Krausneker & Schalber, 2007, p. 205.

²³⁶ Baker, 2006, p.376.

children seem to feel (physically or psychologically), if parents are scared of instructions in sign language, they will decide against it.²³⁷

There are two examples of best practice of deaf education mentioned in the 2006/2007 study on the situation of deaf students in Austria; one from Vienna and one from Carinthia. Both are based on a bilingual approach; teachers argue that this form of instruction makes access to equal education possible.²³⁸ Also Haualand and the WDF consider a bilingual approach as a good basis for independent and efficient communication in all environments that leads to positive results; ‘Deaf children’s literacy level is increasing, and efficient learning is facilitated so the children can focus on studying and learning the contents of the various subjects rather than using their effort to merely try to understand what the teachers say and what the books state.’²³⁹ But instead of aiming for special deaf schools, the ÖGLB and other deaf voices in Austria demand an inclusive school system that provides deaf children with a bilingual – sign language competent – environment as well as deaf role models and peers to prevent isolation as well as to make exchange of experiences possible.

The recognition of sign language in the Austrian constitution (supporting the linguistic minority aspect) and the ratification of the CRPD (supporting the disability movement) were important first steps for an improvement of the human rights situation of deaf people. For a better situation of education more work is still needed. A current problem will probably slow down the process of attaining an inclusive school system with adequate usage of sign language; there are not sufficient sign language translators in Austria – altogether there are about 90 sign language translators in the country.²⁴⁰

²³⁷ Krausneker & Schalber, 2007, p.42.

²³⁸ Ibidem, pp. 46-48, 70-71.

²³⁹ Haualand & Allen, 2009, pp. 28-29.

²⁴⁰ OeGSDV – Oesterreichischer Gebaerdensprach-DolmetscherInnen-Verband, at: <http://www.oegsdv.at/index.php?content=4> (consulted on 20 June 2013).

6. Conclusion

Being deaf means more than not being able to hear; it implies a certain way of experiencing daily life. The use of sign language creates a community whose human rights issues are not completely covered in a disability approach to human rights. The CRPD is nevertheless a helpful tool in proclaiming and advocating deaf human rights. In the context of Austria's deaf community there is no total separation between 'deaf' and 'disability' arguments in human rights activism in practice. Even though there are common experiences of exclusion and oppression based on differences, it is still important not to subsume all of them under the category of 'disability'. To combat discrimination, assumptions behind it must be challenged and the social and cultural construction of 'deaf' and of 'disability' recognised.²⁴¹ Anthropological research is very helpful to find out about the differences between these constructions as well as the actual meaning of a 'deaf' identity and the related human rights issues. The example of Nora Groce's study on Martha's Vineyard shows which influence society's experiences can have on the perception and handling of human diversity; impairment does not necessarily have to be a disability too. On the island, deaf people are remembered as individuals and full members of the community, because the community made efforts to include them. Consequently, societal barriers differ in their respective contexts and should be challenged in order to achieve equal opportunities of participation for all persons.

From a human rights perspective, the adoption of the CRPD and its approval of the social model of disability was a significant development for the disability movement worldwide. Recognising society's responsibility in barriers in daily life can help to find solutions and promote equal access and participation for all people. It is important to promote means and measures to reduce these barriers for all hard of hearing people. Support for the use of sign language is probably the most important one of these measures; at the same time, it is also the link to a cultural and linguistic understanding of deafness. Sign language constitutes a central aspect of deaf culture and the self-

²⁴¹ Andersson & Burch, 2010, p. 195.

identification of its members. Therefore it strongly influences deaf human rights activism in practice and distinguishes it from human rights activism based solely on a disability perspective. The two cases of ‘Cochlear Implants’ and ‘Deaf Education’ illustrate the implications of self-identification as being part of a deaf culture. The analysis of the cases also brings forward relevant aspects for the issues that might fall short when only regarding deafness as a disability.

Opinions regarding CIs are very diverse among scholars, activists and other actors worldwide. From a medical perspective, CIs are represented as a treatment that is worth pursuing in order to improve a person’s life and chances for their future. Some voices suggest making it a requirement to get the implant in order to have access to translator services. There are extremist views both on the supporting and the opposing side of CIs. An extreme deaf cultural perspective completely objects the use of implants and regards it as a serious threat to the culture and its continuation. Also the Austrian deaf community is heterogeneous, and so are its attitudes regarding the topic. For instance, it will most likely make a difference if the deaf child’s parents are deaf or hearing. Irrespective of the various opinions, the ÖGLB refers to the Articles 3 (d) and 23 (2) of the CRPD and demands respect for differences and acceptance of deaf people as well as autonomy in choosing CIs or not. This would also mean full recognition of deaf people’s rights to linguistic and cultural self-determination. In actual practice, the demands of the ÖGLB cannot be seen as entirely opposing CIs, but rather as demands for neutral and comprehensive consultations at ENT departments that include the medical opinion of the doctors as well as the sociocultural and linguistic perspective of deaf people.

Currently, education for deaf children is a very central concern in Austria and again there is not one single opinion on this issue. Unlike many remarks on the matter in deaf communities worldwide, it is not necessarily striven for special deaf schools in Austria. This form of schools has been very important in the past for the development and maintenance of deaf culture and sign language. It is still regarded as crucial for deaf children to have deaf peers or adults in their social environment at school, but this does

not mean that segregation has to take place at the same time. Instead it is aimed for an inclusive school system that takes into consideration the significance of sign language and multilingualism as a personal capacity that leads to empowerment in social and work life. Many believe that instructions in classes with deaf children are most successful, if conducted in sign language. Because there are not enough sign language competent teachers, the education offered for deaf children is limited and remains a point of criticism by the deaf community and its supporters.

Besides the emphasis on support for sign language, the arguments in discussions on education are not as strongly connected to implications of a person's identity due to their belonging to deaf culture as they are in discussions on CIs. Certainly, language and social interaction with other people identifying as members of the community fit under the umbrella of culture, but the statements in practice do not necessarily refer to this cultural aspect. It is more about personal empowerment and the strengthening of self-confidence and identity. This highlights a certain tension between the meaning of identifying as a member of deaf culture, its claim for recognition as a cultural minority, and the actual practice of human rights activism. There are some positive aspects of defining as a disability group that might assist deaf people in gaining more of their rights,²⁴² like translators at events or at school which would normally not be provided for members of other cultural minorities.²⁴³

I see it as a fact though that the use of sign language a main characteristic of deaf communities, makes them to a linguistic minority. This is also increasingly acknowledged by political actors and institutions; for example by the Council of Europe which in its recommendations does not refer to 'deaf' people anymore, but instead to 'sign language users'. In Austria and many other countries sign language has been affirmed as a minority language in the constitution. What is lacking now and needs further efforts in the future, are adequate measures to support this language and its users

²⁴² Baynton, 2002.

²⁴³ Lane, 2005, p. 296.

in daily life in order to deconstruct social barriers and facilitate equal possibilities and participation for all people.

Based on Sally Engle Merry's approach to human rights practice it can be said that the tension between disability and cultural approaches to deafness will continue to be an issue for deaf human rights activism. Local and personal contexts influence the use of arguments and pursued goals. But it seems like the 'translating' process continuously changes the perception of disability and increasingly leads to the inclusion of cultural aspects. After all, the CRPD calls for 'recognition and support of their specific cultural and linguistic identity, including sign languages and deaf culture'.²⁴⁴ Further developments in this area will be interesting to follow in the future, especially as it is most likely that more and more technical and medical innovations will come. They will pose further human rights challenges for society and its handling of human diversity.

²⁴⁴ A/RES/61/106 (CRPD), 13 December 2006, art 30 para 4.

Bibliography

Anderson, Benedict, *Imagined Communities*. London: Verso, 1983.

Anderson, Yerker & Burch, Susan, 'Deaf and Disability Studies, A Conversation with Yerker Anderson', pp. 193-203 in Susan Burch and Alison Kafer, (eds.), *Deaf and disability studies*. Washington, D.C.: Gallaudet University, Press, 2010.

Asch, Adrienne, 'Disability, Bioethics, and Human Rights', pp. 297-326 in Gary L. Albrecht, Katherine D. Seelman and Michael Bury, (eds.), *Handbook of Disability Studies*. Thousand Oaks: Sage, 2001.

Baker, Colin, *Foundations of Bilingual Education and Bilingualism*. Clevedon, Buffalo, Toronto, Sydney: Multilingual Matters, 2006.

Barnes, Colin & Mercer, Geoff, 'Disability Culture: Assimilation or Inclusion?', pp. 515-534 in Gary L. Albrecht, Katherine D. Seelman and Michael Bury, (eds.), *Handbook of Disability Studies*. Thousand Oaks: Sage, 2001.

Barton, Len & Armstrong, Felicity, 'Disability, Education, and Inclusion: Cross-Cultural Issues and Dilemmas', pp. 693-710 in Gary L. Albrecht, Katherine D. Seelman and Michael Bury, (eds.), *Handbook of Disability Studies*. Thousand Oaks: Sage, 2001.

Baynton, D.C., *Forbidden Signs: American Culture and the Campaign against Sign Language*. Chicago: University of Chicago Press, 1996.

Baynton, D., 'Bodies and environments', pp. 387-411 in P. Blanet, (ed.), *Employment, disability and the Americans with Disabilities Act*. Evanston, IL: Northwestern University Press, 2000.

Baynton, D., 'Deafness and disability', Paper presented at the Deaf Studies Think Tank, Gallaudet University, Washington, DC, July 2002.

Bell, Alexander Graham, *Upon the Formation of Deaf Variety of the Human Race*. Reprint, Washington, DC: Alexander Graham Bell Association for the Deaf, [1883] 1969.

Bickenbach, Jerome E., 'Disability, culture and the UN convention', pp. 1111–1124 in *Disability and Rehabilitation*, vol. 31, no. 14, 2009.

Bickenbach, Jerome E., 'Disability Human Rights, Law, and Policy', pp. 565-584 in Gary L. Albrecht, Katherine D. Seelman and Michael Bury, (eds.), *Handbook of Disability Studies*. Thousand Oaks: Sage, 2001.

Braddock, David L. & Parish, Susan L., 'An Institutional History of Disability', pp. 11-68 in Gary L. Albrecht, Katherine D. Seelman and Michael Bury, (eds.), *Handbook of Disability Studies*. Thousand Oaks: Sage, 2001.

Breiter, Marion, *Muttersprache Gebärdensprache. VITA: Studie zur Lebens- und Berufssituation von gehörlosen Frauen in Wien*. Mühlheim a.d. Ruhr: Guthmann-Peterson, 2005.

Breivik, Jan-Kare, *Deaf identities in the making: Metaphors and narrations in translocal lives*. Doctoral thesis, University of Oslo: 2001.

Breivik, Jan-Kare, *Deaf Identities in the Making: Local Lives, Transnational Connections*. Gallaudet University Press: 2005.

Burch, Susan & Kafer, Alison, (eds.), *Deaf and disability studies*. Washington, D.C.: Gallaudet University, Press, 2010.

Campbell, J. and Oliver, M., *Disability Politics: Understanding Our Past, Changing Our Future*. London: Routledge Kegan Paul, 1996.

Davis, L. J., *Enforcing Normalcy: Disability, Deafness, and the Body*. London: Verso, 1995.

Davis, D.S., 'Cochlear Implants and the Claims of Culture? A Response to Lane and Grodin', pp. 253-258 in *Kennedy Institute of Ethics Journal*, vol. 7, no. 3, 1997 (a).

Davis, D.S., 'Genetic Dilemmas and the Child's Right to an Open Future', pp. 7-15 in *Hastings Center Report*, vol. 27, no. 2, 1997 (b).

Eriksen, Thomas Hylland, *Languages at the margins of modernity: Linguistic minorities and the nation-state*. Oslo: International Peace Research Institute, PRIO, 1991.

Goffman, Erving, *Stigma: Notes on the Management of Spoiled Identity*. Englewood Cliffs, NJ: Prentice-Hall, 1963.

Gómez Isa, F., 'International Protection of Human Rights', pp. 21-48 in Isa F. Gómez & K. De Feyter, (eds.), *International Human Rights Law in a Global Context*. Deusto University Press, Bilbao, 2009.

Groce, Nora, *Everyone here spoke sign language: hereditary deafness on Martha's Vineyard*. Cambridge, Massachusetts and London, England: Harvard University Press, 1985.

Hastrup, Kirsten, 'The Quest for Universality: An Introduction', pp. 1-24 in Kirsten Hastrup, (ed.), *Human Rights on Common Grounds: The quest for universality*. The Hague etc.: Kluwer Law International, 2001.

Haualand, Hilde, 'The Two-Week Village: The Significance of Sacred Occasions for the Deaf Community', pp. 33-55 in Susan Reynolds Whyte & Benedicte Ingstad, (eds.), *Disability in Local and Global Worlds*. Berkeley: University of California Press, 2007.

Haualand, Hilde & Allen, Colin, *Deaf People and Human Rights*, World Federation of the Deaf and Swedish National Association of the Deaf, January 2009.

Higgins, P., *Outsiders in a Hearing World: Sociology of Deafness*. Beverly Hills: California: Sage Publications, 1980.

Ingstad, Benedicte, 'Seeing Disability and Human Rights in the Local Context: Botswana Revisited', pp. 237-258 in Susan Reynolds Whyte & Benedicte Ingstad, (eds.), *Disability in Local and Global Worlds*. Berkeley: University of California Press, 2007.

Ingstad, Benedicte & Whyte, Susan Reynolds, *Disability and Culture*. Berkeley, etc.: University of California Press, 1995.

Ingstad, Benedicte & Whyte, Susan Reynolds, (eds.), *Disability in Local and Global Worlds*. Berkeley, etc.: University of California Press, 2007.

Kayess, Rosemary & French, Phillip, 'Out of Darkness into Light? Introducing the Convention on the Rights of Persons with Disabilities', pp. 1-34 in *Human Rights Law Review*, vol. 8, no. 1, 2008.

Kermit, Patrick, 'Cochlear implants, linguistic rights and 'open future' arguments', pp. 137-153 in Kristjana Kristiansen, Simo Vehmas and Tom Shakespeare (eds.), *Arguing about Disability, Philosophical perspectives*. London and New York: Routledge, 2009.

Krausneker, Verena & Schalber, Katharina, *Sprache Macht Wissen, Zur Situation gehörloser und hörbehinderter SchülerInnen, Studierender & ihrer LehrerInnen, sowie*

zur Österreichischen Gebärdensprache in Schule und Universität Wien. Abschlussbericht des Forschungsprojekts 2006/2007. Wien: Innovationszentrum der Universität Wien Verein Österreichisches Sprachen-Kompetenz-Zentrum (mit Unterstützung der Abt I/8 des bm:ukk), 2007.

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

Lane, Harlan, *When the Mind Hears: A History of the Deaf*. New York: Random House, 1984.

Lane, Harlan, 'Ethnicity, Ethics, and the Deaf-World', pp. 291- 310 in *Journal of Deaf Studies and Deaf Education*, vol. 10, no. 3, 2005.

Lane, Harlan, 'Do Deaf People Have A Disability?', pp. 277-292 in H. Dirksen and L. Bauman (eds.), *Open Your Eyes*. Minneapolis: University of Minnesota Press, 2008.

Merry, Sally Engle, 'Transnational Human Rights and Local Activism: Mapping the Middle', pp. 38-51 in *American Anthropologist*, vol. 108, no. 1, 2006.

Messer, Ellen, 'Anthropology and Human Rights', pp. 221-249 in *Annual Review of Anthropology*, vol. 22, 1993.

Mirzoeff, N., *Silent Poetry: Deafness, Sign and Visual Culture in Modern France*. Princeton, NJ: Princeton University Press, 1995.

Mori, Soya, 'Testing the Social Model of Disability, The United Nations and Language Access for Deaf People', pp. 235-244 in Susan Burch & Alison Kafer, (eds.), *Deaf and disability studies*. Washington, D.C.: Gallaudet University, Press, 2010.

Nunn, Nicola, 'Book Review, Deaf Identities in the Making: Local Lives, Transnational Connections', pp. 65-66 in *Deafness and Education International*, vol. 9, no. 1, 2007.

Österreichischer Gehörlosenbund (ÖGLB), *BürgerInneninitiative/Petition für Chancengleichheit gehörloser Menschen im österreichischen Bildungssystem*. Wien, 2003.

Österreichischer Gehörlosenbund (ÖGLB), *Stellungnahme des Österreichischen Gehörlosenbundes zur einseitigen Beeinflussung von Eltern gehörloser Kinder zum Cochlea-Implantat (CI) durch Krankenhäuser und HNO-Abteilungen*. Vienna, February 2013.

Oliva, Gina A., *Alone in the Mainstream. A Deaf Woman Remembers Public School*. Washington, D.C.: Gallaudet University Press, 2004.

Padden, C. and Humphries, T., *Deaf in America: Voices from a Culture*. Cambridge, Massachusetts: Harvard University Press, 1988.

Porter, S., 'The Suppression of Signs by Force', pp. 169-178 in *American Annals of the Deaf*, vol. 39, 1894.

Preston, Paul, *Mother Father Deaf*. Cambridge: Harvard University Press, 1994.

Prinz, Philip M. & Prinz, Elisabeth A., 'Simultaneous Acquisition of ASL and Spoken English', pp. 283-296 in *Sign Language Studies*, vol. 25, 1979.

Prinz, Philip M. & Prinz, Elisabeth A., 'Acquisition of ASL and Spoken English by a Hearing Child of a Deaf Mother and a Hearing Father', pp. 78-88 in *Sign Language Studies*, vol. 30, 1980.

Rashid, Khadijat, 'Intersecting Reflections', pp. 22-30 in Susan Burch & Alison Kafer, (eds.), *Deaf and disability studies*. Washington, D.C.: Gallaudet University, Press, 2010.

Ravaud, Jean-François & Stiker, Henri-Jacques, 'Inclusion/Exclusion: An Analysis of Historical and Cultural Meanings', pp. 490-512 in in Gary L. Albrecht, Katherine D. Seelman & Michael Bury, (eds.), *Handbook of Disability Studies*. Thousand Oaks: Sage, 2001.

Robinson, Mary, *The Universal Declaration of Human Rights: A Living Document*, Statement made at the Symposium on Human Rights in the Asia-Pacific Region, 27 January 1998; available at <http://archive.unu.edu/unupress/Mrobinson.html> (consulted on 15 May 2013).

Sacks, Oliver, *Seeing Voices. A Journey Into the World of the Deaf*. Berkeley: University of California Press, 1989.

Stein, Michael Ashley, 'Disability Human Rights', pp. 75-121 in *California Law Review*, vol. 95, no. 75, 2007.

Tucker, B.P., 'Deaf Culture, Cochlear Implants and Elective Disability', pp. 6-14 in *Hastings Center Report*, vol. 28, no. 4, 1998.

United Nations Secretariat, Division for Social Policy and Development, *The United Nations and Disabled Persons – A Historical Overview: First Fifty Years*. New York: United Nations, 1997.

United Nations, *Minority Rights: International Standards and Guidance for Implementation*. New York and Geneva, 2010.

World Health Organisation (WHO), *World Report on Disability*, 2011.

Whyte, Susan Reynolds, 'Disability: global languages and local lives', pp. 168-181 in Conerly Casey & Robert Edgerton (eds.), *Companion to Psychological Anthropology: Modernity and Psychocultural Change*. London: Blackwells, 2004.

Whyte, Susan Reynolds, 'Health Identities and Subjectivities: The Ethnographic Challenge', pp. 6-15 in *Medical Anthropology Quarterly*, vol. 23, no. 1, 2009.

Whyte, Susan Reynolds & Ingstad, Benedicte, 'Introduction: Disability Connections', pp. 1-29 in Susan Reynolds Whyte & Benedicte Ingstad, (eds.), *Disability in Local and Global Worlds*. Berkeley: University of California Press, 2007.

Whyte, Susan Reynolds, 'Constructing Epilepsy: Images and Contexts in East Africa', pp. 226-245 in Benedicte Ingstad & Susan Reynolds Whyte, *Disability and Culture*. Berkeley, etc.: University of California Press, 1995 (a).

Whyte, Susan Reynolds, 'Disability between Discourse and Experience', pp. 267-291 in Benedicte Ingstad & Susan Reynolds Whyte, *Disability and Culture*. Berkeley, etc.: University of California Press, 1995 (b).

Wilson, Richard A., 'Human Rights, Culture and Context: An Introduction', pp. 1-27 in Richard Wilson (ed.), *Human Rights, Culture and Context*. Chicago, Illinois: Pluto Press, 1997.

Official Documents

BMASK (Federal Ministry of Labour, Social Affairs and Consumer Protection), 'National Action Plan on Disability 2012-2020', Vienna: BMASK, 2012.

Bundesgesetzblatt für die Republik Österreich, 'Übereinkommen über die Rechte von Menschen mit Behinderungen sowie das Fakultativprotokoll zum Übereinkommen über die Rechte von Menschen mit Behinderungen', BGBl. III 155/2008, 23 October 2008.

Bundes-Verfassungsgesetz (BVG) 2005 art 8 para (3).

Commission (EC), 'European Disability Strategy 2010-2020: A Renewed Commitment to a Barrier-Free Europe' (Communication) COM(2010) 636 final, 15 November 2010.

Convention on the Rights of Persons with Disabilities (adopted 13 December 2006, entered into force 3 May 2008), A/RES/61/106 (CRPD).

Council of Europe, Parliamentary Assembly, Rights of national minorities, Recommendation 1492 (2001), 23 January 2001.

Council of Europe, Parliamentary Assembly, Protection of sign languages in the member states of the Council of Europe, Recommendation 1598 (2003), 1 April 2003.

Declaration on the Rights of Mentally Retarded Persons, Supplement Number 30 at 93, U.N. Doc. A/8429, 1971.

Declaration on the Rights of Disabled Persons, Supplement Number 34 at 88, U.N. Doc.A/10034, 1975.

International Covenant on Civil and Political Rights (adopted 16 December 1966, entered into force 23 March 1976) 999 UNTS 171 (ICCPR).

International Covenant on Economic, Social and Cultural Rights (adopted 16 December 1966, entered into force 3 January 1976) 993 UNTS 3 (ICESCR).

OHCHR, 'General Comment No. 23: The rights of minorities' art. 27, CCPR/C/21/Rev.1/Add.5, 8 April 1994.

Proclamation of Teheran, Final Act of the International Conference on Human Rights, Teheran, from 22 April to 13 May 1968, A/CONF. 32/41 at 3, 1968.

UNGA, Declaration on the Rights of Persons Belonging to National or Ethnic, Religious and Linguistic Minorities, A/RES/47/135, 18 December 1992.

UNGA, Standard Rules on the Equalization of Opportunities for Persons with Disabilities, A/RES/48/96, 4 March 1994.

UNGA, Universal Declaration of Human Rights (adopted 10 December 1948) Res 217 A(III) (UDHR).

Vienna Declaration and Programme of Action, World Conference on Human Rights, Vienna, from 14 to 25 June 1993, A/CONF.157/23, 12 July 1993.

Internet Sites

Bizeps Info, Bundesverfassungsgesetz, available at:

<http://www.bizeps.or.at/gleichstellung/rechte/bvg.php> (consulted on 28 May 2013).

Bizeps Info, Opposition bezweifelt Refomwillen bei System der Schulverwaltung, 20 June 2013, available at: <http://www.bizeps.or.at/news.php?nr=14140> (consulted on 24 June 2013).

Bundesinstitut für Gehörlosenbildung, available at:

<http://www.big-kids.at/sites/startseite.html> (consulted on 15 June 2013).

OeGSDV – Oesterreichischer Gebaerdensprach-DolmetscherInnen-Verband, available at: <http://www.oegsdv.at/index.php?content=4> (consulted on 20 June 2013).

Republik Österreich, Parlament, Umsetzung des Rechts auf bilingualen Unterricht, (2318/A[E]), available at:

http://www.parlament.gv.at/PAKT/VHG/XXIV/A/A_02318/index.shtml (consulted on 24 June 2013).

UN enable, <http://www.un.org/disabilities/> (consulted on 30 April 2013).

UN News Centre, More people than ever have hearing loss that can be improved or treated, UN reports, 27 February 2013, available at:

http://www.un.org/apps/news/story.asp?NewsID=44245&Cr=health&Cr1=#.UWVljjeD4_w (consulted on 10 April 2013).

WFD, Theme – Equality for Deaf People, at:

<http://www.wfdsydney2013.com/theme.php> (consulted on 8 April 2013).

Filmography

ARTE, “Gehörlosigkeit – eine Behinderung?“, 2011, available at: <https://www.youtube.com/watch?v=qf422RxSx4E> (consulted on 2 June 2013).

Mertz, Reiner, ‘The Last Deaf’, Frankfurt: Mainhattan Film, 2001.

Tracy, James, ‘The End’, United Kingdom: Neath Films & British Sign Language Broadcasting Trust, 2011.

Other sources

Jarmer, Helene, 2013, Nationalratssitzung 2012 Nationaler Bildungsbericht, 22 May 2013, Vienna.

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Deaf human rights activism in practice : the tension between disability and cultural approaches to deafness

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