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Agnes Heinrici

Handle with Care

How to Improve Access to Healthcare for Deaf People in a Pandemic

EMA, The European Master's Programme
in Human Rights and Democratisation

AGNES HEINRICI

HANDLE WITH CARE.
HOW TO IMPROVE ACCESS TO HEALTHCARE FOR DEAF
PEOPLE IN A PANDEMIC

FOREWORD

The European Master's Degree in Human Rights and Democratisation (EMA) is a one-year intensive programme launched in 1997 as a joint initiative of universities in all EU Member States with support from the European Commission. Based on an action- and policy-oriented approach to learning, it combines legal, political, historical, anthropological and philosophical perspectives on the study of human rights and democracy with targeted skills-building activities. The aim from the outset was to prepare young professionals to respond to the requirements and challenges of work in international organisations, field operations, governmental and non-governmental bodies, and academia. As a measure of its success, EMA has served as a model of inspiration for the establishment of six other EU-sponsored regional master's programmes in the area of human rights and democratisation in different parts of the world. Today these programmes cooperate closely in the framework of the Global Campus of Human Rights, which is based in Venice, Italy.

Up to 90 students are admitted to the EMA programme each year. During the first semester in Venice, they have the opportunity to meet and learn from leading academics, experts and representatives of international and non-governmental organisations. During the second semester, they relocate to one of the 42 participating universities to follow additional courses in an area of specialisation of their own choice and to conduct research under the supervision of the resident EMA Director or other academic staff. After successfully passing assessments and completing a master's thesis, students are awarded the European Master's Degree in Human Rights and Democratisation, which is jointly conferred by a group of EMA universities.

Each year the EMA Council of Directors selects five theses, which stand out not only for their formal academic qualities but also for the originality of topic, innovative character of methodology and approach, potential usefulness in raising awareness about neglected issues, and capacity for contributing to the promotion of the values underlying human rights and democracy.

The EMA Awarded Theses of the academic year 2020/2021 are:

- Boatright, Katie, *Re-imagining Truth and Redress: Racial Injustice against African Americans in the United States and the Current Push for Transitional Justice*. Supervisor: Stephan Parmentier, KU Leuven.
- Boeren, Annelie, *Refugees' Experiences in Sites of Prolonged Displacement, Liminality, and Exception: A Case Study of the Diavata Refugee Camp in Northern Greece*. Supervisor: Georgios Agelopoulos, Aristotle University of Thessaloniki.
- Heinrich, Agnes, *Handle with Care. How to Improve Access to Healthcare for Deaf People in a Pandemic*. Supervisors: Kalliope Agapiou-Josephides, Aristotelis Constantinides, University of Cyprus.
- Lombardi, Federica, *From Myanmar to The Hague. A Feminist Perspective on the Search for Gender Justice by Rohingya Women before the International Criminal Court*. Supervisor: Dolores Morondo Taramundi, University of Deusto, Bilbao.
- McCall Magan, Ríon, *Idir Eatarthu is Achbrann. The Framing of Women's Agency in Northern Ireland's Counterterrorism Legislative Discourse during the Troubles (1968-1998)*. Supervisor: Martin Kahl, University of Hamburg.

The selected theses demonstrate the breadth, depth and reach of the EMA programme and the passion and talent of its students. We are particularly proud of EMA's 2020/21 students: as teachers and students across the world can testify, the COVID-19 pandemic brought many different challenges for teaching and learning. It is fair to say that our students researched and wrote their theses in turbulent times. On behalf of the Governing Bodies of EMA and of all participating universities, we applaud and congratulate them.

Prof. Manfred NOWAK
Global Campus Secretary General

Prof. Thérèse MURPHY
EMA Chairperson

Dr Orla Ní Cheallacháin
EMA Programme Director

This publication includes the thesis *Handle with Care. How to Improve Access to Healthcare for Deaf People in a Pandemic* written by Agnes Heinrici and supervised by Kalliope Agapiou-Josephides, Aristotelis Constantinides, University of Cyprus.

BIOGRAPHY

Agnes Heinrici is a medical doctor who has always been passionate about human rights. As a junior doctor she practiced in a specialised clinic for the Deaf. Additionally, she has numerous years of working experience in supporting persons with disabilities. Soon after her medical studies she completed the European Master's Programme in Human Rights and Democratisation. Her research is focused on the rights of persons with disabilities, gender rights and the right to health with a special interest in the Deaf community.

ABSTRACT

The Deaf community faces many barriers in the access to healthcare and is underrepresented both in politics and research. Although legislation in European countries such as Austria, Switzerland and Germany provide the basis for the fulfilment of human rights including equal access to healthcare, there is a big implementation gap. In the Covid-19 pandemic, additional new challenges like the use of face masks, daily changing information and a higher mental health burden affected the Deaf. This thesis aims to investigate how Covid-19 policies concerning access to healthcare were experienced within the Deaf communities of Austria, Switzerland and Germany, and to identify potential areas of improvement.

Based on the review of theoretical materials and existing research, an online survey was distributed to 120 participants within the Deaf community in Austria, Switzerland and Germany. Overall, 85.3% study participants stated that Deaf persons generally have more difficulties in the access to healthcare than people with average hearing. In addition, 75.7% reported that the access to healthcare became even more difficult during the Covid-19 pandemic. Face masks, lack of awareness and insufficient information availability were identified as major challenges. The survey participants named concrete improvement measures like transparent face masks, more sign language interpreters, telehealth, education for medical staff and increasing the amount of official information in sign language.

These findings raised a series of issues concerning equal access to healthcare during the pandemic due to the limited availability of resources and information as well as limited representation of Deaf people in policy making. The current findings could help to guide future adaptations regarding the Covid-19 policies of Austria, Switzerland and Germany as well as of other countries and to enhance human rights compliance.

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*I couldn't have written this thesis without the care and help of the people around me.
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Finally Georgios, who supported me at countless coffee meetings, being the best honorary third supervisor I could have wished for. His care reminded me to embrace every mess mindfully and helped me to write a thesis I believe in.

Thank you for your care.

TIME TO CARE - PROLOGUE

January 2016, Linz (Austria)

Visiting the general practitioner at the healthcare centre for the Deaf. He speaks sign language and works differently than every other doctor I have ever seen before. For the first time as a medical student, I experience medicine practiced how I imagined it. Full of humanity and genuine care for the patients.

March 2020, Linz (Austria)

Starting my career as a doctor in exactly this same healthcare centre for the Deaf. In the waiting room there are many Deaf patients who I ask to come in by welcoming them individually. Some of them already know me and we have a little conversation in sign language. A few minutes later I receive an email telling me that I am accepted to the European Master's programme in human rights.

June 2020, Klagenfurt (Austria)

Founding a clinic for the Deaf in another Austrian city while globally there is only one concern – the pandemic. I wear a transparent protective face shield when I talk to the very first patient. She is a Deaf woman who has not been to the doctor in ten years – because qualitative communication was not possible so far. Finding out that she actually has a treatable disease is another reminder how important the engagement for equal access to healthcare is.

July 2021, Limassol (Cyprus)

Caring for human rights and medicine, I completed my Master's thesis that made it possible to combine these two passions. I look back to an inspiring year, expanding my horizon and learning so much in so many ways. The pandemic is still going on, with the urgency of human rights becoming more important and undeniable every day. My research should hopefully contribute to the improvement of healthcare, drawing attention to Deaf people and their rights.

TABLE OF ABBREVIATIONS

CRPD	UN Convention on the Rights of Persons with Disabilities
EASPD	European Association of Service Providers for Persons with Disabilities
ECHR	European Convention on Human Rights
ECtHR	European Court of Human Rights
EDF	European Disability Forum
EU	European Union
FRA	EU Agency for Fundamental Rights
ICESCR	International Covenant on Economic, Social and Cultural Rights
NGO	Non-governmental organisation
SDG	Sustainable Development Goal
The Committee	The Committee on the Rights of Persons with Disabilities
UK	United Kingdom
UN	United Nations
US	United States

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1.

INTRODUCTION

Medicine and human rights are two interconnected fields. If a Deaf person is unable to communicate with medical staff in the hospital or is not able to make an emergency call and get help, quality treatment is impossible and equality still missing. Access to healthcare is a human right of great importance and room for improvement. It needs a lot of **care**.

My personal experience from working as a doctor in a clinic for Deaf people gave me practical insights in the challenges and possibilities of non-discriminatory healthcare. With the European Master's programme in human rights I could gain additional academic background knowledge. This thesis aims to combine both disciplines and develop new considerations about the access to healthcare for Deaf people.

The topic is inadequately covered in literature and thus is in urgent need of more research. Most of the few studies have their origin in the United Kingdom (UK) or the United States (US). This limitation lacks diversity and global representation. Apart from a more international approach, a particular focus on human rights is needed. The Deaf community is a vulnerable group, often disregarded in society and politics. This has its roots in their relatively small number of people and the lack of a common language. Therefore, research must make special efforts to raise awareness and look through the holistic lenses of human rights when it approaches the sensitive issue of fighting for substantive equality.

Especially at a time when the world is fighting a global pandemic, the right to health is a fundamental one that should be available and accessible for every human being. However, persons with disabilities still suffer from multiple barriers and disadvantages. When in the beginning of 2020 the Covid-19 virus suddenly became the main concern of every politician and healthcare professional, in many cases the Deaf population was forgotten. Associations had to fight for information to be made available in sign

language and for transparent face masks that would make communicating still possible for them. There was very little awareness which is also seen in the lack of literature about these challenges. There is little research about the situation of the Deaf in the pandemic yet. Therefore, this thesis aims to give insights and knowledge about an underrepresented group and highlight their perceptions and needs during the pandemic.

The research consists of two parts. The first part presents the theoretical background and discusses the topic from different angles. It analyses primary sources such as conventions and EU legislation as well as secondary sources such as commentaries and journal articles. Furthermore, it includes a chapter about Deaf health and how it changed in the pandemic. A comparative analysis presents the differences and similarities of the situation in Switzerland, Germany and Austria. The second part is the empirical one. An online survey asked Deaf persons about their access to healthcare before and during the pandemic. 120 participants from various backgrounds gave insights into their perceptions and suggested improvement ideas. Descriptive statistics and thematic analyses are an important part of the study results. Through the questionnaire the opinions of many Deaf people could be heard and thus present new and detailed insights of their up-to-date situation in the pandemic.

About the theoretical part

Generally, Deaf persons face many challenges in a world oriented around hearing people. They are a special group within the designation of persons with disabilities that not only has their own language but also their own culture. Many do not even want to be considered as having a disability, because the only distinction is the difference of the spoken language. The differences of the medical and social approach to disability as well as the attribution of disability will be discussed at the beginning of this thesis. Following the motto of the thesis – ‘Handle with care’ – this first chapter is tenderly called **Care instructions**. It introduces the reader to the topic and gives an overview of different ways to look at it. The approach chosen in this thesis is a socio-cultural model of disability that also respects the culture of the Deaf community and aims to fully respect their human rights.

These distinctions and definitions at the outset of the thesis are particularly important since the law that applies to Deaf people is tailored to persons with disabilities. Therefore, the second chapter starts with an analysis of the most relevant international treaty, the United Nations (UN)

Convention on the Rights of Persons with Disabilities (CRPD).¹ This chapter is called **Care provision**, because it analyses the legal framework and thus the necessary basis for the implementation of human rights. The official documents and treaties are needed in the first place, so governments can make use of this legal foundation in their national healthcare systems. A special focus is placed on the principles of equality and non-discrimination and reasonable accommodation. Considering access to healthcare, other treaties and soft law instruments are discussed. Given that the thesis is written for the European Master's programme, it sheds light on the CRPD implementation in the EU. The focus on the current strategies for the rights of persons with disabilities within the EU gives clarity about up-to-date political priorities.

Following this, the third chapter approaches the practical core of the topic by looking at the implementation of these laws. The characteristics of access to healthcare for the Deaf are considered from different angles. The review of research materials covers both challenges and room for improvement, including hands-on experiences of empirical studies. This part is named **Intensive care**. It then goes into even more detail by analysing the corresponding situation in the healthcare systems of Germany, Switzerland and Austria. The comparison of these three European countries and CRPD signatories is especially interesting, because they have different approaches in aiming at equality for Deaf persons. They also reacted differently in the current and most challenging public health crisis: the Covid-19 pandemic. The subsequent review of writings presents an overview over the few pieces of research about persons with disabilities and the pandemic that has already been published. To sum up, this chapter discusses the access to healthcare for Deaf persons before and during the pandemic. In the end it highlights the special challenges that emerged in the last months due to the Corona virus. A comparative analysis gives an overview of the differences and similarities between Switzerland, Germany and Austria.

At the end of the theoretical part of the thesis, the research questions are presented. They emerged from the preceding findings and are focussed on the access to healthcare before and during the pandemic. The main issue discussed is to what extent the Covid-19 policies of Germany, Switzerland and Austria regarding access to healthcare for the Deaf complied with human rights.

¹ Convention on the Rights of Persons with Disabilities (adopted 13 December 2006, entered into force 3 May 2008) 2515 UNTS 3 (CRPD).

About the empirical part

In order to answer the research questions that evolved from the theoretical part, fieldwork was conducted to learn from Deaf persons directly. The investigation part of the thesis is called **Handle with care**. The means chosen to reach as many Deaf persons as possible was an online survey. With the help of the national associations of the Deaf it was distributed to Germany, Switzerland and Austria. Although the Deaf community is a hard-to-reach population group, 120 participants from various regions and occupational backgrounds were recruited. They explained their perceptions of the access to healthcare before and during the pandemic.

The questionnaire consisted of seven questions, both quantitative and qualitative. The mixed methods approach gives even more possibilities for the research evaluation. On the one hand, quantitative questions give clear results and distinct numeric comparisons between the countries. On the other hand, qualitative questions increase the diversity of opinions and detailed insights. The thematic analysis was then able to highlight common challenges and rooms for improvement as well as to show new learnings about the needs of Deaf people. The empirical part's structure contains an extensive explanation of the methodology and presentation of results.

The discussion then combines the knowledge from the theoretical parts of the thesis with the findings of the current survey. It also states limitations of the conducted survey and makes future recommendations. One part of the recommendations is addressed to governments and draws from the concrete suggestions of the Deaf survey participants. The second part of the recommendations concerns future research and includes the perspective of possible progress in digitalisation and how it could support Deaf people.

Finally, the conclusion sums up the necessity and peculiarity of the research and answers the research questions in a concise way. This final chapter is called **What do we care?**. Ultimately, it gives a summary of both parts of the thesis and enables an outlook into the future.

HANDLE WITH CARE

I.
THEORETICAL PART

2.

CARE INSTRUCTIONS – BACKGROUND

2.1. DISABILITY AND THE DEAF

According to the definition of disability as an impairment exacerbating activities and interaction with the world around, Deaf people clearly belong to the group of persons with disabilities.² The history of this label is diverse and brings many challenges with it. The medical and social model are two different approaches that both seek to be considered in the most important legal document for this concern, the CRPD.

2.2. DIFFERENT UNDERSTANDINGS OF DISABILITY

Clapton and Fitzgerald analysed disability in the historic context, starting with the religious model.³ Especially in the Christian-Judea society, evil spirits and witchcraft were seen as the cause and disabled people encountered both extremes, exorcism on the one side and being provided with devoted care on the other.⁴ In some parts of Africa, the birth of a child with disabilities was perceived as punishment for adultery and confronted the whole family with this stigma.⁵ In the industrialisation era, the ideal of a healthy and working body led to the depreciation of

² Erica R Harvey, 'Deafness: A Disability or a Difference' (2008) 2 Health L & Pol'y 42; Centers for Disease Control and Prevention, 'Disability and Health Overview' (*Centers for Disease Control and Prevention*, 2020) <<https://cdc.gov/ncbddd/disabilityandhealth/disability.html>> accessed 14 May 2021.

³ Jayne Clapton and Jennifer Fitzgerald, 'The history of disability: A history of "otherness"' (1997) 7(1) *New Renaissance Magazine* 1.

⁴ *ibid.*

⁵ Julie Livingston, 'Insights from an African history of disability' (2006) 2006(94) *Radical history review* 111.

unproductive and incapable persons.⁶ The authors furthermore point out that with increasing scientism the medical understanding of ‘disability’ and the focus on the individual, who has the problem, not the society, was born in the post- industrial era. Only in recent times has the focus changed again to a rights-based approach and politics that aim for participation and inclusion.⁷ Buettgen and Gorman point out that disability is ‘always about culture’. This is underlined by not only the different understanding and approach, but also by diverse definitions in different countries.⁸ Buettgen and Gorman give the example that in some states the focus is mainly on physical disabilities and mental health is not included at all. Often it also is a question of range that makes disability difficult to define. One example would be the many different skin colours world-wide, but albinism is considered a disability, and another one the different heights of individuals, but persons who are ‘too short for social norms’ are called disabled.⁹

An important concern is also the phrasing. In the English language, many people and scholars tend to prefer the term impairment. It rather implies the physical dysfunction than the missing ability to be part of a social culture.¹⁰ In New Zealand for example, the Maori’s holistic understanding of health also leads to another perception of disability, recognising both interdependence and spiritual connectedness.¹¹ Looking at the many possible angles and different approaches, a global definition of disability seems difficult if not impossible. The landmark CRPD does not define disability, but persons with disabilities. An important factor is to not define a person’s identity by its disability when calling them disabled persons, but to rather choose the phrasing of the CRPD, namely persons **with** disabilities. It is different when you **are** something than when you **have** something.

⁶ Jayne Clapton and Jennifer Fitzgerald, ‘The history of disability: A history of “otherness”’ (1997) 7(1) *New Renaissance Magazine* 1.

⁷ *ibid.*

⁸ Alexis Buettgen and Rachel Gorman, ‘Disability Culture’ in Masood Zangeneh and Alean Al-Krenawi (eds), *Culture, Diversity and Mental Health - Enhancing Clinical Practice* (Springer International Publishing 2019) 39 <https://doi.org/10.1007/978-3-030-26437-6_3>.

⁹ Harlan Lane, ‘Do deaf people have a disability?’ (2002) 2(4) *Sign language studies* 356.

¹⁰ Dimitris Anastasiou and James M Kauffman, ‘The social model of disability: Dichotomy between impairment and disability’ (*J Med Philos* 2013) 38(4)441.

¹¹ Keri Ratima and Mihi Ratima, ‘Māori Experience of Disability and Disability Support Services’ in Robson B, Harris R (eds), *Hauora: Māori standards of health IV, A study of the years 2000-2005* (Te Rōpū Rangahau Hauora a Eru Pōmare: Wellington, New Zealand 2007) 189–208.

The CRPD describes persons with disabilities as having ‘long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others’.¹² There are many critics about this definition that was decided after long discussions and considerations. It is said to be solely medical and excluding many persons with the phrase of ‘long-term’ disabilities.¹³ On the other hand, the definition also mentions barriers that hinder the participation and thus implies the role and responsibility of society as well. The question when participation can be full and effective is another one. This leads to Deaf people, who have a long-term impairment but theoretically could fully participate in society on an equal basis. The Deaf community has sign language to communicate and not being able to hear is the only deficit that prevents them from engaging with others who speak. However, also the definition of Deaf people is difficult.

2.3. WHERE DO DEAF PEOPLE FIT?

Medically a Deaf person cannot hear, either from birth or a later point in their life on. A more inclusive term is ‘hard of hearing’ which contains hearing impairment of different categories and degrees. The Hearing Loss Association of America for example suggests the wording ‘people with hearing loss’.¹⁴ There is a controversial debate within the Deaf community itself whether the members want to be seen as persons with disabilities. On the one hand, it connects them to a very diverse group of people who are all considered different from ‘normal society’, when the main distinction for themselves is the different language and culture. On the other hand, this definition gives them access to a broader range of rights and enhances their implementation and possibilities.

Another problem is that the definition of ‘Deaf’ does not come from the Deaf community itself, but rather from hearing people that see the ‘others’ as missing not only a sense, but also the ability to participate

¹² Convention on the Rights of Persons with Disabilities (adopted 13 December 2006, entered into force 3 May 2008) 2515 UNTS 3 (CRPD).

¹³ M Leonardi and others, ‘The definition of disability: what is in a name?’ (2006) 368(9543) *Lancet* 1219.

¹⁴ Katherine Bouton, ‘Deaf? Hard of Hearing? Hearing Impaired? Be Careful What You Call Us’ (*AARP*, 11 July 2016) <<https://aarp.org/health/conditions-treatments/info-2016/deaf-disabled-hearing-loss-kb.html>> accessed 20 March 2021.

in every-day life.¹⁵ This attitude and audio-centric supremacy is known under the term ‘audism’.¹⁶ Hearing people can judge Deaf people to not be intelligent and even correlate spoken language to human dignity, and thus discredit Deaf persons.¹⁷ This misjudgement and discrimination widen the gap between hearing and Deaf persons and make it even more difficult to overcome deeply rooted prejudices on both sides. Another reflection of this issue is the saying ‘dialogue de sourds’ – ‘dialogue of the deaf’ – that describes two parties talking to each other but not understanding each other.¹⁸ This stigmatisation reinforces the wrong image that the Deaf lack language and understanding, when in reality it is the contrary: They have their own language that theoretically could be learnt by anyone like any other language.

The Deaf community does not see itself as missing something, it is rather proud of its own culture. The community has linguistic, social and political significance.¹⁹ The members are proud of their language, common values and culture. Many of them consider themselves as a linguistic minority. The Deaf community fulfils the minority criteria, and different legal implications considering education and communication would follow from this angle.²⁰ However, in this thesis focussing on healthcare, the linguistic model will not be discussed further. The topic will rather be approached from the social lens of the legal framework for persons with disabilities.

For someone standing outside of this culture, not speaking the language and seeing deafness as disability, it may be hard to focus on the social approach and understand the need to not only respect the community, but also fight for equality at the same time. In recent years Deaf persons from different countries are progressively cooperating and are very well connected internationally. This helps to increase both the awareness and the community spirit. Furthermore, it enhances their power and capacities to overcome barriers and challenges together.

¹⁵ Harlan Lane, ‘Do deaf people have a disability?’ (2002) 2(4) *Sign language studies* 356.

¹⁶ Richard Clark Eckert and Amy June Rowley, ‘Audism: A theory and practice of audiocentric privilege’ (2013) 37(2) *Humanity & Society* 101.

¹⁷ H-Dirksen L Bauman, ‘Audism: Exploring the metaphysics of oppression’ (2004) 9(2) *Journal of Deaf Studies and Deaf Education* 239.

¹⁸ Marleen Easton and Stanny De Vlioger, ‘Belgian reflections on the dialogue of the deaf’ (2018) 5(3) *European Journal of Policing Studies* 36.

¹⁹ Carol Padden, ‘The deaf community and the culture of deaf people’ [2000] *Readings for diversity and social justice: An anthology on racism, antisemitism, sexism, heterosexism, ableism, and classism* 343.

²⁰ Anastasia Chatzopoulou, ‘The dilemma in the deaf community: linguistic minority or persons with disability?’ (Master’s thesis, EIUC 2014).

2.4. APPROACH OF THIS MASTER'S THESIS

Discussing the access to healthcare, both the medical and the social model of disability have their justification. But since this thesis is coming from a human rights perspective, special attention is given to the social approach. Not only on international level with the CRPD, but also in EU politics the social model has gained more and more attention and acknowledgement in recent years.²¹ This thesis aims to investigate if the two models are compatible and if the social model can be applied and is helpful for the medical world as well. An integrated approach could even open new considerations enabling respect for human rights at the political and individual levels. Thinking even beyond the still evolving social model, it could develop into a socio-cultural model that takes a holistic mindset into account, especially in the field of medicine. It should acknowledge the culture and social background of persons with disabilities and fully recognise their human rights in a non-discriminatory way. To acknowledge the social approach and respect for the Deaf community and culture, the word 'deaf' will be written with capital D throughout the thesis.²²

To me it is an inclusive approach that can make substantive equality possible. With the social model one does not reduce persons to their physical deficit but instead appreciates their culture and community. In recent years there is also a visible change in the healthcare system that supports a more holistic and open-minded medicine. Going away from historic academic medicine, an increasing number of patients ask for alternative practices. Intercultural differences confront many doctors and nurses with new challenges and hospitals eventually have to adapt. This also gives a new impetus to the healthcare situation of Deaf people. Questions about their relationship to the healthcare system are not only centred on their medical condition anymore but are also human rights-based, discussing equal access and social participation. Deaf patients should be treated with the same respect for their privacy and dignity as every other patient.

²¹ Anna Lawson and Mark Priestley, *The social model of disability: Questions for law and legal scholarship?* (Routledge 2016).

²² Jamie Berke, 'Self-Identification in the Deaf Community' (*Verywell Health*, 8 January 2020) <<https://verywellhealth.com/deaf-culture-big-d-small-d-1046233>> accessed 5 June 2021.

3.

CARE PROVISION – THE LEGAL FRAMEWORK

3.1. THE LEGAL LANDSCAPE

The legal framework that applies to the Deaf community is that for persons with disabilities, although there are also rights for linguistic minorities that could apply. This thesis focusses on the social model of disability and the representation of Deaf people in law-making as persons with disabilities.

The legal framework on the rights of persons with disabilities has witnessed a big evolution in recent years. The first UN documents covering this topic were the Declaration on the Rights of Mentally Retarded Persons²³ of 1971 and the 1975 Declaration on the Rights of Disabled Persons²⁴. Both documents were following the medical model of disability and already show a big difference and progression in their title. It took until 2006, when the UN made persons with disabilities the focus of one of their main conventions. After multiple human rights treaties covering very diverse topics, this treaty finally raised awareness for persons with disabilities and set new standards of equality. The CRPD was seen as a breakthrough following the social model of inclusion and being the first legally binding treaty on the topic. Moreover, already the document name shows the major difference to the preceding papers and leaves the stigmatising phrasing behind. Among the general principles of the CRPD, stated in article 3, are non-discrimination,

²³ UN General Assembly, 'Declaration on the Rights of Mentally Retarded Persons' (1971) resolution 2856 (XXVI).

²⁴ UN General Assembly, 'Declaration on the Rights of Disabled Persons' (1975) resolution 3447 (XXX).

full and effective participation in society and accessibility.²⁵ The CRPD establishes the Committee on the Rights of Persons with Disabilities (the Committee) and provides for the state parties to submit periodic reports. The Committee has already issued many general comments and statements. There is also an Optional Protocol to the CRPD considering individual complaints.²⁶

The CRPD entered into force in 2008 and has been ratified by 182 countries so far.²⁷ Deaf persons are mentioned explicitly only in the context of education and participation in cultural life. The use of sign language is included in article 9 which relates to accessibility and in article 21 concerning freedom of expression and opinion, and access to information. Article 25 entails equal standards of health for all persons with disabilities and prohibits any discrimination in this concern.

The connection of the CRPD with Europe is far-reaching. First, the Council of Europe took part in the negotiations of the CRPD, while the European Convention on Human Rights²⁸ (ECHR) can also be seen as interconnected with the CRPD.²⁹ There are no conclusive references to persons with disabilities in the ECHR, but this can be explained historically due to the drafting year being 1950.³⁰ Especially in recent years, there have been many initiatives for persons with disabilities by the Council of Europe, as well as cases before the European Court of Human Rights (ECtHR). The Disability Strategy 2017-2023 is one of these initiatives by the Council of Europe. It is called 'Human rights: A reality for all'. It focusses on five priority areas such as equality and non-discrimination.³¹ The implementation of the strategy aims to be interconnected with the CRPD, the ECHR and the European Social Charter.³² In the field of healthcare, it calls for inclusion and the education

²⁵ Convention on the Rights of Persons with Disabilities (adopted 13 December 2006, entered into force 3 May 2008) 2515 UNTS 3 (CRPD).

²⁶ UN General Assembly, Optional Protocol to the Convention on the Rights of Persons with Disabilities (2006) A/RES/61/106.

²⁷ United Nations Treaty Collection, 'Human Rights' (2021) <https://treaties.un.org/Pages/ViewDetails.aspx?src=TREATY&mtldsg_no=IV-15&chapter=4&clang=en> accessed 28 March 2021.

²⁸ Convention for the Protection of Human Rights and Fundamental Freedoms (European Convention on Human Rights, as amended) (ECHR).

²⁹ Silvia Favalli, 'The United Nations Convention on the Rights of Persons with Disabilities in the case law of the European Court of Human Rights and in the Council of Europe Disability Strategy 2017–2023: "From zero to hero"' (2018) 18(3) Human Rights Law Review 517.

³⁰ *ibid.*

³¹ Council of Europe, *Human rights: A reality for all* (Disability Strategy 2017-2023).

³² Council of Europe, European Social Charter (1961) ETS 35.

of professionals, as well as awareness creation. Furthermore, it requests the use of sign language to increase accessibility multiple times within the document.³³ Some years earlier, in 2005, the Council of Europe had already published a report about the status of sign languages in Europe. It gives an overview of the different legislation in the member countries and shows that only a few countries have recognised sign language in their constitution.³⁴ 46 out of the 47 members states of the Council of Europe have ratified the CRPD so far.³⁵ The most important difference between the Disability Strategy 2017-2023 and the CRPD is that the CRPD is a legally binding document and thus the parties have to implement its provisions in their domestic law.

3.2. THE PRINCIPLE OF EQUALITY AND NON-DISCRIMINATION

Non-discrimination, one of the fundamental principles of the CRPD as well as focus of the Council of Europe strategy, shall be highlighted. The concept has been essential for persons with disabilities already before the CRPD and still is of great importance in various areas and treaties. In many documents it goes together as the term ‘equality and non-discrimination’ since these values are strongly interconnected. In order to reach substantive equality and non-discrimination, states have to take special measures for persons with disabilities. This is known as reasonable accommodation and also ensured through article 2 of the CRPD.³⁶

In the founding statute of the UN, its Charter from 1945, there are already some references to human rights and non-discrimination. But the only areas of discrimination that are specifically mentioned are ‘race, sex, language, or religion’.³⁷ Three years later in the Universal Declaration of Human Rights, more factors of possible distinction are

³³ Council of Europe, *Human rights: A reality for all* (Disability Strategy 2017-2023).

³⁴ Nina Timmermans, *The status of sign languages in Europe* (Council of Europe Publishing 2005).

³⁵ Karolina Kozik, ‘What Does the Council of Europe Have Against People with Disabilities?’ (*Human Rights Watch*, 4 November 2020) <<https://hrw.org/news/2020/11/04/what-does-council-europe-have-against-people-disabilities>> accessed 1 June 2021.

³⁶ Convention on the Rights of Persons with Disabilities (adopted 13 December 2006, entered into force 3 May 2008) 2515 UNTS 3 (CRPD).

³⁷ Charter of the United Nations (26 June 1945, entered into force 24 October 1945) 1 UNTS XVI.

added, whereas disability again is not among them.³⁸ The two important other parts of the International Bill of Human Rights both refer to non-discrimination multiple times, each starting with this principle already in their respective article 2.³⁹ The International Covenant on Civil and Political Rights even includes a specific non-discrimination clause in article 26, concerning equality before the law.⁴⁰ Regarding the International Covenant on Economic, Social and Cultural Rights (ICESCR) the first general comment specifically about disability was published in 1994. It requires state parties to take positive actions with the maximum of resources at their hand, to fulfil equality for persons with disabilities.⁴¹

General Comment No 5 of 2009 is dedicated to non-discrimination. It not only explains different kinds of discrimination, like formal/substantive, direct/indirect or the systemic one, but also confirms disability as being included in the phrasing of ‘other status’ that many human rights documents use when they list various discrimination grounds they prohibit.⁴² Following from the distinctions of General Comment No 5, substantive equality is especially important for persons with disabilities. It underlines that equality does not necessarily mean the same (identical) treatment. De facto equality often requires additional positive action to protect the rights of vulnerable groups.⁴³ The need for these special measures is called reasonable accommodation. The CRPD clarifies that the denial of reasonable accommodation is a form of discrimination and consequently prohibited.⁴⁴ In regards to the access to healthcare it implies for example that hospitals have to take special measures to ensure equal treatment of Deaf patients and thereby reach substantive equality.

³⁸ Universal Declaration of Human Rights (adopted 10 December 1948) UNGA Res 217 A(III).

³⁹ Abdulrahim P Vijapur, ‘The Principle of Non-Discrimination in International Human Rights Law: The Meaning and Scope of the Concept’ (1993) 49(3) *India Quarterly* 69 <<https://doi.org/10.1177/097492849304900303>>.

⁴⁰ International Covenant on Civil and Political Rights (adopted 16 December 1966, entered into force 23 March 1976) 999 UNTS 171 (ICCPR).

⁴¹ UN Committee on Economic, Social and Cultural Rights (CESCR), ‘General Comment No 5: Persons with Disabilities’ (1994) UN Doc E/1995/22.

⁴² *ibid.*

⁴³ Abdulrahim P Vijapur, ‘The Principle of Non-Discrimination in International Human Rights Law: The Meaning and Scope of the Concept’ (1993) 49(3) *India Quarterly* 69 <<https://doi.org/10.1177/097492849304900303>>.

⁴⁴ Convention on the Rights of Persons with Disabilities (adopted 13 December 2006, entered into force 3 May 2008) 2515 UNTS 3 (CRPD).

Non-discrimination as a basic concept in the legislation of democracies becomes more and more applied. It is widely accepted now that the principles of equality and non-discrimination are considered as forming part of customary international law.⁴⁵ Although there are so many treaties concerned with and committed to the principle of non-discrimination, it still happens on a daily basis. In the social model of disability, discrimination is even seen as the main way of oppression.⁴⁶ Deaf persons face discrimination when information in daily life is not accessible for them or for example when other people make fun of a child that cannot hear.⁴⁷

Another big field of disadvantage is the job market. Job interviews via the phone are not possible and employers are not willing to take more time or work with an interpreter.⁴⁸ Morris says that although less than 40% of people with a hearing disability work full-time and unemployment rates are striking, discrimination can be difficult to prove. However, the principle of reasonable accommodation provides an important legal foundation for persons with disabilities to claim substantive equality at the working place.⁴⁹ Coming to the current situation, the World Federation of the Deaf issued a particular statement on equality and non-discrimination during the Covid-19 pandemic. It highlights that Deaf people are even more vulnerable to be discriminated against in access to healthcare, education and information in general.⁵⁰ Furthermore it points out the increasing issue of intersectional discrimination and that everyone should ‘respect Deaf people as citizens’.⁵¹

⁴⁵ Abdulrahim P Vijapur, ‘The Principle of Non-Discrimination in International Human Rights Law: The Meaning and Scope of the Concept’ (1993) 49(3) *India Quarterly* 69 <<https://doi.org/10.1177/097492849304900303>>.

⁴⁶ Ilias Bantekas, Michael Ashley Stein and Dimitris Anastasiou, *The UN Convention on the Rights of Persons with Disabilities: A Commentary* (OUP 2018).

⁴⁷ Simon Stallworthy, ‘Reproductive liberty and deafness: Outlawing selection is move against discrimination’ (2008) 336(7654) *BMJ* 1148 <<https://pubmed.ncbi.nlm.nih.gov/18497387/>>; <<https://ncbi.nlm.nih.gov/pmc/articles/PMC2394606/>>.

⁴⁸ Amanda Morris, ‘Deaf And Unemployed: 1,000+ Applications But Still No Full-Time Job’ (*NPR*, 12 January 2019) <<https://npr.org/2019/01/12/662925592/deaf-and-unemployed-1-000-applications-but-still-no-full-time-job?t=1619869872836>> accessed 20 May 2021.

⁴⁹ Pamela S Karlan and George Rutherglen, ‘Disabilities, discrimination, and reasonable accommodation’ (1996) 46 *Duke Law Journal* 1.

⁵⁰ World Federation of the Deaf, *Equality & Non-Discrimination during the global Covid-19 pandemic* (World Federation of the Deaf 2020).

⁵¹ *ibid.*

3.3. ACCESS TO HEALTHCARE IN INTERNATIONAL HUMAN RIGHTS LAW

According to article 25 of the CRPD, ‘Persons with disabilities have the right to the enjoyment of the highest attainable standard of health without discrimination on the basis of disability’.⁵² Article 25 also provides that state parties have ‘to ensure access for persons with disabilities to health services that are gender-sensitive’. The right to health is interconnected with many different human rights. If a person is not healthy, this can influence their private life, education or work. Altogether the fulfilment of article 25 can be seen as essential for every single right established in the CRPD,⁵³ the importance and phrasing of the right is also interconnected with other human rights treaties. Its basis roots in the ICESCR, where article 12 covers the human right to health. Its General Comment No 5 requires states to provide the same level of healthcare for persons with disabilities ‘within the same system as other members of society’.⁵⁴ This implies removing barriers of access and ensuring the same quality of medical care for everyone.

General Comment No 14 reiterates that health services have to be in safe physical reach, especially for persons with disabilities. It also states that such accessibility must be fulfilled both by the open health sector and private suppliers of medical care.⁵⁵ Coming back to the drafting process of the CRPD that was inspired by the ICESCR, the travaux préparatoires show different discussion points. One contentious issue was the question whether the right to health and the right to rehabilitation should be separate, whereas another one was the necessity to specifically mention mental health or to see it as included in the term health.⁵⁶ The decision for the mentioning of ‘sexual and reproductive health’ in the CRPD is particularly relevant and important, since it is the first such declaration in an international legally binding instrument.⁵⁷ Reproductive health is also

⁵² Convention on the Rights of Persons with Disabilities (adopted 13 December 2006, entered into force 3 May 2008) 2515 UNTS 3 (CRPD).

⁵³ Ilias Bantekas, Michael Ashley Stein and Dimitris Anastasiou, *The UN Convention on the Rights of Persons with Disabilities: A Commentary* (OUP 2018).

⁵⁴ UN Committee on Economic, Social and Cultural Rights (CESCR), ‘General Comment No 5: Persons with Disabilities’ (1994) UN Doc E/1995/22.

⁵⁵ UN Committee on Economic, Social and Cultural Rights (CESCR), ‘General Comment No 14: The Right to the Highest Attainable Standard of Health (Art 12 of the Covenant)’ (2000) UN Doc E/C.12/2000/4.

⁵⁶ Ilias Bantekas, Michael Ashley Stein and Dimitris Anastasiou, *The UN Convention on the Rights of Persons with Disabilities: A Commentary* (OUP 2018).

⁵⁷ *ibid.*

considered as an especially important dimension of accessibility in the CRPD's General Comment No 2. It also regards barrier-free transport to healthcare services as well as the necessity of accessible information, for example in sign language.⁵⁸ Apart from accessibility, the quality of healthcare should also be addressed. Bantekas, Stein and Anastasiou highlight that persons with disabilities often face for example delayed diagnoses, but the CRPD aims for an equal quality of healthcare and services.⁵⁹

Another important principle for the right to health is reasonable accommodation, as per article 2 of the CRPD. It requests states to take positive actions like removing barriers and give both attention and resources to necessary adjustments, in order to make substantive equality happen for persons with disabilities.⁶⁰ One of these adjustments could be specific education for healthcare workers about the rights of persons with disabilities and how to fully respect them. This would also contribute to raising awareness. Although article 25(d) provides for the training of healthcare professionals, generally medical staff education seems to be more focused on the contact with ethnic minorities.⁶¹ This is especially striking, since persons with disabilities are the biggest minority group counting the number of people who are included. Furthermore, article 25(d) calls on healthcare staff to work with persons with disabilities on the basis of free and informed consent. General Comment No 1 emphasises the importance of direct engagement with the patients, instead of a substitute.⁶² This also underlines the connection between article 25 and article 12 which covers the equal recognition before the law. A decision of a substitute can be against the individual's will and might violate the autonomy and independence of the person.⁶³ Considering the monitoring of the CRPD, the UN Human Rights Office of the High Commissioner points this out specifically. To see whether the right to health is fulfilled

⁵⁸ UN Committee on the Rights of Persons with Disabilities, 'General comment no 2 on Article 9, Accessibility' (2014) UN Doc CRPD/C/GC/2.

⁵⁹ Ilias Bantekas, Michael Ashley Stein and Dimitris Anastasiou, *The UN Convention on the Rights of Persons with Disabilities: A Commentary* (OUP 2018).

⁶⁰ *ibid.*

⁶¹ Michael Ashley Stein, Penelope J Stein and Raymond Lang, 'Health care and the UN Disability Rights Convention' (2009) 374(9704) *Lancet* 1796.

⁶² UN Committee on the Rights of Persons with Disabilities, 'General comment on Article 12, Equal recognition before the law' (2013) UN Doc CRPD/C/11/4.

⁶³ Anna Arstein-Kerslake and Eilíonóir Flynn, 'The General Comment on Article 12 of the Convention on the Rights of Persons with Disabilities: A roadmap for equality before the law' (2016) 20(4) *The International Journal of Human Rights* 471.

does not only require an exploration of the access to medicine, but also an evaluation of the free consent of persons with disabilities.⁶⁴

In conclusion, article 25 has many facets and is interconnected both with other rights of the CRPD as well as for example the right to health in the ICESCR. Based on this, the CRPD concedes that the right to health, being part of economic, social and cultural rights, has to be realised progressively.⁶⁵ This means that states should gradually take steps according to their available resources, with the aim of a full realisation of the right in the future.

The CRPD does not mention language or health literacy, let alone the situation of Deaf patients. Access to healthcare is discussed and elaborated by various actors in various instruments and contexts, as shown below.

One example is the annual report of the Special Rapporteur on persons with disabilities. In 2018, Catalina Devandas Aguilar elaborated on the right to health and communication barriers for example due to the lack of sign language interpreters that cause accessibility barriers.⁶⁶ She reminds countries to ensure full accessibility to all healthcare services and elaborates that all relevant information has to be accessible, including through sign language. In her subsequent report focussing on the impact of ableism in medical and scientific practice, Catalina Devandas Aguilar emphasises the necessity to train healthcare professionals in human rights issues and discusses bioethical challenges such as research about imminent gen-repair of Deafness.⁶⁷

Another important document is General Comment No 14 of the UN Committee on Social, Economic and Cultural Rights. It discusses the right to health as stated in article 12 of the ICESCR. This legally binding treaty is part of the International Bill of Human Rights and thus fundamental for international human rights law. The general comment reemphasises the need for accessibility to healthcare without discrimination. Furthermore, it clarifies that accessibility also includes

⁶⁴ United Nations Human Rights Office of the High Commissioner, 'Monitoring the Convention on the Rights of Persons with disability: Guidance for HR Monitors' vol HR/P/PT/17 (2010).

⁶⁵ Michael Ashley Stein, Janet E Lord and Dorothy Weiss Tolchin, 'Equal access to health care under the UN Disability Rights Convention' [2012] *Medicine and social justice: Essays on the distribution of health care* 245.

⁶⁶ Catalina Devandas Aguilar, *Report on the rights of persons with disabilities to the highest attainable standard of physical and mental health* (United Nations General Assembly 2018).

⁶⁷ Catalina Devandas Aguilar, *The impact of ableism in medical and scientific practice* (United Nations General Assembly 2019) UN Doc A/HRC/43/41.

the right both to look for healthcare information and to receive it.⁶⁸ This is especially relevant for the situation of Deaf persons, who might not have a chance to get information and knowledge they need, because it is not provided in sign language.

The UN General Assembly took another important step with the 2030 Agenda for Sustainable Development in 2015. In contrast to its predecessor, the Millennium Development Goals, the new agenda provided for multiple references to persons with disabilities.⁶⁹ It particularly mentions vulnerable groups and has pronounced good health and well-being as its third Sustainable Development Goal (SDG). All UN member countries adopted the goals and committed to the agenda. ‘We must achieve universal health coverage and access to quality healthcare. No one must be left behind’,⁷⁰ says the text of the landmark document. The agenda’s principle ‘leave no one behind’ also reverberates the disability movement’s motto ‘nothing about us without us’.⁷¹ The CRPD can be seen as a framework that guides the implementation of the SDGs.⁷² The International Disability Alliance for example relates SDG number 3 about health to CRPD articles 10 (right to life), 11 (risk and humanitarian emergencies), 23 (respect for home and the family), 25 (health) and 26 (habilitation and rehabilitation).⁷³ The two documents cover many cross-cutting issues, and thus their implementation can be reinforced from both approaches. Not only should actions that foster inclusion of persons with disabilities be sustainable, but it also makes clear that our common global goal is a world where no one is left behind. This is reaffirmed in the UN Disability Inclusion Strategy, launched in 2018. One of its goals is creating an accountability framework as well as mainstreaming the inclusion of persons with disabilities as one of the priorities of the UN.⁷⁴

⁶⁸ UN Committee on Economic, Social and Cultural Rights (CESCR), ‘General Comment No 14: The Right to the Highest Attainable Standard of Health (Art 12 of the Covenant)’ (2000) UN Doc E/C.12/2000/4.

⁶⁹ World Federation of the Deaf, *Know and Achieve Your Human Rights Toolkit* (World Federation of the Deaf 2016).

⁷⁰ UN General Assembly, *Transforming our world : the 2030 Agenda for Sustainable Development* (21 October 2015) UN Doc A/RES/70/1.

⁷¹ International Disability Alliance (IDA), *The 2030 Agenda. The Inclusion of Persons with Disabilities: Comprehensive Guide* (IDA 2016).

⁷² World Federation of the Deaf, *Know and Achieve your Human Rights Toolkit* (World Federation of the Deaf 2016).

⁷³ International Disability Alliance (IDA), *The 2030 Agenda. The Inclusion of Persons with Disabilities: Comprehensive Guide* (IDA 2016).

⁷⁴ United Nations, *UN Disability Inclusion Strategy* (2019).

3.4. EU LEGISLATION AND STRATEGIES FOR PERSONS WITH DISABILITIES

3.4.1. CRPD implementation in the EU

Although on the global level the CRPD is the most important common legal document, there are still many differences in national legislations. For example, in 2009 less than 50 states had systematic laws for the rights of persons with disabilities.⁷⁵ This means that most countries had to change their domestic laws to comply with the CRPD. Individual countries also have their own statutes about persons with disabilities. In the US it is the famous Americans with Disabilities Act of 1990 and in the UK the more recent Equality Act of 2010.⁷⁶ The European Union (EU) with its supranational power has overarching norms that apply to each of its member states. Some individual member states have their own strategies, but they must be compliant with EU law. Several countries have domestic bodies that examine this compliance and raise awareness for disparities. One example is the comprehensive evaluation of Wayne and others. That working group analysed the Mental Capacity Act of England and Wales in its compliance with the CRPD in great detail. They found definition discrepancies and suggested amendments of the national legal text.⁷⁷ A thorough analysis like this can make an impactful improvement of the legislation possible. Moreover, the transparency of the publication allows other states with similar laws to learn from the conclusions. In the future, more European states should conduct such evaluations about their own domestic legislation in order to improve their human rights situation progressively. Looking at the CRPD, article 33 is devoted to the establishment of national mechanisms that monitor the implementation of the treaty provisions. They should be independent and have persons with disabilities participating in the process.⁷⁸ States are also required to submit periodical reports to the Committee of the CRPD.

⁷⁵ Michael Ashley Stein, Penelope J Stein and Raymond Lang, 'Health care and the UN Disability Rights Convention' (2009) 374(9704) *Lancet* 1796.

⁷⁶ Audrey Laur, 'Healthcare access for deaf patients – The legal and ethical perspectives' (2018) 86(1) *Med Leg* 36 <<https://doi.org/10.1177/0025817217743416>>.

⁷⁷ Wayne Martin and others, 'Achieving CRPD compliance' Essex autonomy project (2014).

⁷⁸ Convention on the Rights of Persons with Disabilities (adopted 13 December 2006, entered into force 3 May 2008) 2515 UNTS 3 (CRPD).

Exactly ten years ago, in January 2011, the CRPD entered into force for the EU.⁷⁹ This was amongst other things historically significant because it was the first time the EU became a ‘High Contracting Party to a human rights treaty’.⁸⁰ Hoefmans also mentions that initially mainly the EU Commission acted as a focal point concerning CRPD issues. But following its article 33, the EU established the EU Framework for the UN Convention on the Rights of Persons with Disabilities. It consists of the European Parliament, the European Ombudsman, the EU Agency for Fundamental Rights (FRA) and the European Disability Forum (EDF).⁸¹ These very diverse bodies coordinate and monitor the CRPD implementation together and on top of that review it regularly. In 2017, the Council of the EU revised the framework.⁸²

The FRA provides information about the national mechanisms of coordination and implementation in specific EU countries. These can differ very much on the local level. For example, in Cyprus the coordination mechanism is the Pancyprian Council for Persons with Disabilities, whereas the framework is fulfilled by the Independent authority for the promotion of the rights of persons with disabilities.⁸³ In Austria, the Federal Ministry of Labour, Social Affairs and Consumer Protection together with the Federal Disability Advisory Board care for the coordination and there is a specifically designated CRPD monitoring committee. Furthermore, the nine Austrian federal states appointed their own monitoring mechanisms as well.⁸⁴ Generally, combatting discrimination of persons with disabilities is a shared competence between the EU and its member states.⁸⁵ This can sometimes lead to

⁷⁹ European Commission, ‘United Nations Convention on the Rights of Persons with Disabilities’ (*European Commission*, 2021) <<https://ec.europa.eu/social/main.jsp?langId=en&catId=1138>> accessed 15 May 2021.

⁸⁰ Alexander Hoefmans, ‘The EU disability framework under construction: New perspectives through fundamental rights policy and EU accession to the CRPD’ (2012) 3 *Eur YB Disability L* 35.

⁸¹ European Union Agency for Fundamental Rights (FRA), ‘EU Framework for the UN Convention on the Rights of Persons with Disabilities’ (*FRA*, 2021) <<https://fra.europa.eu/en/cooperation/eu-partners/eu-crpd-framework>> accessed 12 May 2021.

⁸² Council of the European Union, ‘Revised EU-level Framework Required by Article 33.2 of the UN Convention on the Rights of Persons with Disabilities’ (2017) 6710/17.

⁸³ European Union Agency for Fundamental Rights (FRA), ‘Structures set up for the implementation and monitoring of the CRPD’ (*FRA* 2020).

⁸⁴ *ibid.*

⁸⁵ Lisa Waddington and Andrea Broderick, *Combatting disability discrimination and realising equality: A comparison of the UN CRPD and EU equality and non-discrimination law* (European Commission 2018) <<https://cris.maastrichtuniversity.nl/en/publications/1c68b378-50cb-47ff-a9d5-2860828c3706>>.

the ambiguous question about who is responsible for the realisation of the postulated changes. However, not only the EU as an organisation, but also every single member state has ratified the CRPD. Thus, each signatory must take positive actions to fulfil the postulated rights within the scope of their capacity. Waddington and Broderick analysed that on the one hand EU law even goes beyond the CRPD in some concerns, especially in the different kinds of discrimination it prohibits and elaborates in great detail. On the other hand, the EU does not fulfil the CRPD laws in other areas such as non-discrimination in occupation.⁸⁶

Another body that scrutinises the implementation is the High-Level Group on Disability. It is organised by the European Commission and includes experts, various non-governmental organisations (NGOs) as well as organisations of persons with disabilities.⁸⁷ This follows the inclusive approach of the CRPD, which means that the EU had not only to rearrange its intra-institutional settings, but also to work together with civil society, in order to fulfil the monitoring requirements.⁸⁸ In 2014, the European Commission published a report on the implementation of the CRPD. It covers the first two years after the EU's accession to the treaty and is based on consultations with various stakeholders.⁸⁹ The report analyses every article in a detailed matter. For the right to health, it states that the founding treaty of the EU in its article 168 already 'provides that the definition and implementation of all Union policies and activities must ensure a high level of human health protection'.⁹⁰ There are many factors of health, but one focus of the CRPD implementation in the EU was mental health. Furthermore, the FRA did research on intersectional discrimination which showed that being a member of another minority increased the inequality persons with disabilities already faced.⁹¹ The

⁸⁶ Lisa Waddington and Andrea Broderick, *Combatting disability discrimination and realising equality: A comparison of the UN CRPD and EU equality and non-discrimination law* (European Commission 2018) <<https://cris.maastrichtuniversity.nl/en/publications/1c68b378-50cb-47ff-a9d5-2860828c3706>>.

⁸⁷ European Commission, 'United Nations Convention on the Rights of Persons with Disabilities' (European Commission, 2021) <<https://ec.europa.eu/social/main.jsp?langId=en&catId=1138>> accessed 15 May 2021.

⁸⁸ Alexander Hoefmans, 'The EU disability framework under construction: New perspectives through fundamental rights policy and EU accession to the CRPD' (2012) 3 Eur YB Disability L 35.

⁸⁹ European Commission, *Report on the implementation of the UN Convention on the Rights of Persons with Disabilities (CRPD) by the European Union* (2014) SWD(2014) 182 final.

⁹⁰ *ibid.*

⁹¹ *ibid.*

report addressed additional barriers like financial problems, lack of informed consent and forced treatment. It also encourages further action in the area of occupation. In order to properly implement the CRPD, more measures for security and health as well as the reintegration of employees in the working place have to be taken.⁹²

NGOs and other independent stakeholders regularly publish their own evaluation as well. Sometimes they are called shadow reports. These can give very different insights than the view from official politicians and monitoring instruments. In the course of the above discussed report of the European Commission, the European Association of Service Providers for Persons with Disabilities (EASPD) published an alternative version. Regarding the right to health, it points out the exclusive competence of the member states to decide over their national health systems.⁹³ The EU on the other hand should support research on healthcare and health of persons with disabilities as well as assist in adequate training of staff members. Another proposal is the promotion of the EU's role as an instrument to give and take information between member states considering the access to healthcare.⁹⁴ Furthermore, the report provides advice on funding and emphasises the necessity of sustainability. A shadow report of the Hungarian Disability Caucus especially criticises the issues around guardianship and lack of affordable healthcare services for persons with disabilities. It once more emphasises the essential training for healthcare workers that should focus both on communication and the treatment of women with disabilities.⁹⁵

Moreover, the High-Level Group on Disability analysed the CRPD implementation of the individual member states in great detail. For example, it summed up the reservations of Lithuania, Malta and Poland around the phrasing sexual and reproductive health that eventually was used in the CRPD.⁹⁶ Another big health topic it covers are the restrictive

⁹² European Commission, *Report on the implementation of the UN Convention on the Rights of Persons with Disabilities (CRPD) by the European Union* (2014) SWD(2014) 182 final.

⁹³ European Association of Service Providers for Persons with Disabilities (EASPD), 'EASPD Alternative report on the implementation of the UN CRPD by the European Union' (EASPD 2015).

⁹⁴ *ibid.*

⁹⁵ Hungarian Disability Caucus, *Disability Rights or Disabling Rights? CRPD Alternative Report* (Hungarian Association of the Deaf and Hard of Hearing (SINOSZ), Mental Disability Advocacy Centre (MDAC) and Committee of Disabled Persons' Organisations (FESZT) 2010).

⁹⁶ High Level Group on Disability, 'Eight Disability High Level Group Report on the Implementation of the UN Convention on the Rights of Persons with Disabilities' (2016).

means used in Czech health facilities as well as the issue of informed consent. These alternative sources should be taken into account when looking at the implementation of international policies. They not only give a practical understanding of the situation, but also provide an outlook of which areas have to be improved in the future and how this could be done.

Generally, organisations of persons with disabilities can be powerful instruments to make governments comply with the treaties they signed. An important tool in this concern is the EDF,⁹⁷ that as already mentioned, is also part of the EU Framework for the UN Convention on the Rights of Persons with Disabilities.

3.4.2. *EU strategies*

Along with the ratification process of the CRPD, the EU Commission published its European Disability Strategy 2010-2020. One of its aims was to put the requirements of the CRPD into practice both at national and EU level.⁹⁸ The EU has chosen ‘A Renewed Commitment to a Barrier-Free Europe’ as the caption for its strategy and focuses on eight main areas, health being among them.⁹⁹ In this field of action it requires the member states to fight inequalities in access to healthcare and assures that the EU will support measures to provide non-discriminatory health facilities as well as to raise awareness in the education of healthcare professionals.¹⁰⁰ Another area the strategy especially wants to enforce is the promotion of assistive technologies, in order to increase accessibility.¹⁰¹

For most EU member states the approach of the supranational policies are very different to their traditional national disability law.¹⁰²

⁹⁷ Anna Lawson, ‘The EU Rights Based Approach to Disability: Strategies for Shaping an Inclusive Society’ (2005) 6(4) *International Journal of Discrimination and the Law* 269 <<https://doi.org/10.1177/135822910500600402>>.

⁹⁸ European Commission Press corner, ‘EU ratifies UN Convention on disability rights’ (*European Commission*, 5 January 2011) <https://ec.europa.eu/commission/presscorner/detail/en/IP_11_4> accessed 30 March 2021.

⁹⁹ European Commission, ‘European Disability Strategy 2010-2020: A Renewed Commitment to a Barrier-Free Europe’ (2010) COM (2010) 636 final.

¹⁰⁰ *ibid.*

¹⁰¹ Stelios Charitakis, ‘An introduction to the disability strategy 2010-2020, with a focus on accessibility’ (2013) 1 *Ars aequi* 28.

¹⁰² David L Hosking, ‘Staying the Course: The European Disability Strategy 2010-2020’ (2013) 4 *Eur YB Disability L* 73.

Therefore, the European Disability Strategy 2010-2020 together with the CRPD accession was an important step to improve national legislations for persons with disabilities within the EU. The official evaluation shows that many objectives of the strategy have been successfully achieved in the given timeframe, but the measures in the fields of health, equality and external action were less effective.¹⁰³ In 2021, the new Strategy for the Rights of Persons with Disabilities was published, called 'Union of Equality'. It is more detailed than the previous one and sets new goals until 2030. It takes the Covid-19 pandemic into account and amongst other things attests that the Commission will offer support to stakeholders to decrease the mental health burden caused by it.¹⁰⁴ Other health focuses of the strategy are cancer prevention and improving access to the whole healthcare portfolio for persons with disabilities. Within one year, a monitoring framework for the implementation of the strategy shall be established.

Another important step into the direction of equality is the European Accessibility Act of 2019. It requires EU member states to improve the accessibility of services and products in various concerns.¹⁰⁵ The area of healthcare is not explicitly mentioned, but the realisation of the directive can and should have a positive impact on this field as well. The member states have to implement it until June 2022, obtaining equal accessibility of for example technical devices, public transport and emergency calls via 112.¹⁰⁶ Since accessibility is such a crucial issue for persons with disabilities and especially the Deaf, the European Accessibility Act is a meaningful document to make this topic more known and to ensure states comply in their legislation.

The most recent EU policies established already in the time of the Covid-19 pandemic are the European Health Union and the European Pillar of Social Rights. The European Health Union sets the goal of giving the EU greater responsibility in common public health. This issue has gained highest priority in politics and everyday life since the

¹⁰³ European Commission, 'Evaluation of the European Disability Strategy 2010-2020' Commission Staff Working Document (2020) SWD(2020) 289 final/2.

¹⁰⁴ European Commission, 'Union of Equality: Strategy for the Rights of Persons with Disabilities 2021-2030' (2021) COM(2021) 101 final.

¹⁰⁵ European Parliament and the Council, European Accessibility Act 2019 L 151/70.

¹⁰⁶ Julia Wadoux, 'The European Accessibility Act published in EU Official Journal' (*AGE Platform Europe*, 4 July 2019) <<https://age-platform.eu/policy-work/news/european-accessibility-act-published-eu-official-journal>>.

beginning of the pandemic in 2020. The European Commission wants to unite medical data collection, reporting and coordination and thus strengthen preparedness for any health crisis.¹⁰⁷ It states that it wants to learn from the challenges of the Covid-19 pandemic for the future and includes an own pharmaceutical strategy. Organisations like the EDF ask for the direct recognition of rights of persons with disabilities in this currently forming strategy.¹⁰⁸ In regard to access to healthcare, it is important that the EU not only mentions vulnerable groups but also gives them special attention and emphasis in its new framework. This could be a guidepost for future health politics as well.

The Social Summit in May 2021 was the most recent landmark meeting of the EU and again an important commitment to economic, social and cultural rights. The European Pillar of Social Rights was reaffirmed, and 20 key principles defined. Principle 16 reinforces the right to healthcare and principle 17 the inclusion of persons with disabilities to especially be protected and taken care of.¹⁰⁹ It is also linked to the 2030 Agenda for Sustainable Development and wants a Union of Equality, keeping exactly in line with the name of the 2021-2030 EU strategy for persons with disabilities.¹¹⁰

Following this comprehensive discussion of the legal landscape and European legislation the practical challenges in the access to healthcare for the Deaf shall be highlighted.

¹⁰⁷ European Commission Press corner, 'Building a European Health Union: Stronger crisis preparedness and response for Europe' (*European Commission*, 11 November 2020) <https://ec.europa.eu/commission/presscorner/detail/en/ip_20_2041> accessed 21 March 2021.

¹⁰⁸ European Disability Forum, 'European Health Union Package' (*European Disability Forum*, 8 February 2021) <<https://edf-feph.org/publications/european-health-union-package-2/>> accessed 21 March 2021.

¹⁰⁹ European Commission, 'The European Pillar of Social Rights Action Plan' (2012) COM(2021) 102 final.

¹¹⁰ *ibid.*

4.

INTENSIVE CARE – PRACTICAL CHALLENGES

4.1. IMPLEMENTATION: ACCESS TO HEALTHCARE FOR DEAF PEOPLE

Before coming to the impact of the Covid-19 on the access to healthcare for the Deaf, the situation prior to the pandemic should be addressed as well. Deaf persons face many challenges in daily life and have to adapt to a world which is currently oriented around persons who can hear. This also affects the far-reaching area of medical services. In order to improve this lack of equality, persons with disabilities should be included in the planning process of healthcare institutions and procedures from the beginning on.¹¹¹ It would be ideal if they are also employed as medical staff, not only because it would promote inclusion, but also based on studies that prove that there is a direct connection between disability and poverty.¹¹² The employment rate of persons with disabilities is distinctly lower than the average since many employers prefer to not hire persons with disabilities.¹¹³ A change of attitude especially in the healthcare sector could be an important step. The clientele of any medical clinic is very diverse, and therefore a diverse staff makes it even more relatable and trustworthy. Furthermore, persons with disabilities can feel understood better and as equal part of the workplace and society. In the case of Deaf people, Deaf employees could not only promote the use of sign language for everyone, but also increase the quality and equality of communication in healthcare.

¹¹¹ Murthy Venkata S Gudlavalleti and others, 'Access to health care and employment status of people with disabilities in South India, the SIDE (South India Disability Evidence) study' (2014) 14(1) BMC Public Health 1.

¹¹² Michael Ashley Stein, Penelope J Stein and Raymond Lang, 'Health care and the UN Disability Rights Convention' (2009) 374(9704) *Lancet* 1796.

¹¹³ Purvi Sevak and others, 'Individual characteristics and the disability employment gap' (2015) 26(2) *Journal of Disability Policy Studies* 80.

4.1.1. *Communication*

The first big barrier that Deaf people face in healthcare is communication. Up to 80% of diagnoses can already be made through an extensive anamnesis alone.¹¹⁴ Therefore, the physician-patient talk is not only essential for a trusting and beneficial professional relationship, but also significant for the therapeutic success. However, most doctors or nurses do not speak sign language and thus do not share a common language with Deaf patients. Generally, if communication is difficult or impossible, the hospital administrator is responsible for ensuring it, in order to safeguard the quality of the healthcare services provided. Many medical professionals still consider lip-reading and writing information down to be a sufficient method of exchanging relevant details.¹¹⁵ Especially when hidden aspects of the patient history or the elaborate explanation how to take medication correctly are crucial, doctors have to make sure that no detail is lost. But when they rely on lip-reading as means of communication, this is a major source of error and misinterpretation. On average, only 30% of spoken words are understood when lip-reading, hence this method can have serious consequences for the patient's health.¹¹⁶

Likewise, written communication carries a high risk for misdiagnosis and loss of information. Because of the lack of time in the healthcare system, the writing is usually limited to only a few words which most Deaf persons cannot fully comprehend when reading, which leads again to misunderstandings and mistakes.¹¹⁷ Correspondingly, Deaf people often do not comprehend medical reports of findings that concern

¹¹⁴ MC Peterson and others, 'Contributions of the history, physical examination, and laboratory investigation in making medical diagnoses' (1992) 156(2) *West J Med* 163.

¹¹⁵ British Deaf Association, 'Accessing public services: issues for deaf people' (British Deaf Association 2014).

¹¹⁶ CC Lieu and others, 'Communication strategies for nurses interacting with deaf patients' (2007) 16(4) *Medsurg Nurs* 239; R Campbell and T-JE Mohammed, 'Speechreading for information gathering: a survey of scientific sources' (University College London 2010); A Alexander, P Ladd and S Powell, 'Deafness might damage your health' (2012) 379(9820) *Lancet* 979; Audrey Laur, 'Healthcare access for deaf patients – The legal and ethical perspectives' (2018) 86(1) *Med Leg* 36 <<https://doi.org/10.1177/0025817217743416>>.

¹¹⁷ CC Lieu and others, 'Communication strategies for nurses interacting with deaf patients' (2007) 16(4) *Medsurg Nurs* 239; Robert Q Pollard Jr and Steven Barnett, 'Health-related vocabulary knowledge among deaf adults' (2009) 54(2) *Rehabilitation Psychology* 182; A Alexander, P Ladd and S Powell, 'Deafness might damage your health' (2012) 379(9820) *Lancet* 979.

them, especially when they are complicated by scientific terms.¹¹⁸ It takes extensive time to explain the results to them in sign language, as well as empathy when replying to their questions, so that trust and compliance can be developed during the course of the treatment.¹¹⁹

4.1.2. *Room for improvement in communication*

There are many possibilities to face these communication challenges. Different countries have various approaches in their national healthcare systems. The most common way is the provision of sign language interpreters. A vanguard in this concern is for example the US, where health services are obliged to ensure communication support not only for Deaf patients, but also for family members, visitors or any other clientele.¹²⁰ In Germany, the legislation in form of the social security code makes health insurances pay fully for the employment of sign language interpreters.¹²¹ But the legal preconditions are not enough. Even if this communication assistance through translators would be available, education and detailed knowledge are needed. On the one hand, the medical staff has to be informed about the legal situation and must be aware of its obligations and possibilities. On the other hand, the patients have to be educated about their rights and which kind of support they are entitled to. A recent study showed for example, that out of 841 German Deaf people 31% were not informed about their right to an interpreter.¹²²

In general, the translating can be done in person or, with limitations, also remotely via video.¹²³ However, direct communication one-on-one is recommended for the development of a trusting physician-patient

¹¹⁸ Helen Margellos-Anast, Melanie Estarziou and Gary Kaufman, 'Cardiovascular disease knowledge among culturally Deaf patients in Chicago' (2006) 42(3) *Prev Med* 235.

¹¹⁹ Johannes Fellingner, 'Patient gehörlos - Medizin unter vier Augen' (2007) 21(77) *Das Zeichen* 386.

¹²⁰ Zachary Duffly, 'Deaf and Hard of Hearing Persons' Right to Effective Communication in Health Care Settings' (*Nolo*, 2021) <<https://nolo.com/legal-encyclopedia/deaf-hard-hearing-persons-right-effective-communication-health-care-settings.html>> accessed 17 May 2021.

¹²¹ BDÜ Infoservice, 'Gebärdensprache - Ein Leitfadens' (BDÜ Infoservice 2017.)

¹²² JT Höcker, S Letzel and E Münster, 'Sind gehörlose Patienten in Deutschland über ihren gesetzlichen Dolmetscheranspruch informiert?' (2012) 74(12) *Das Gesundheitswesen* 818.

¹²³ Audrey Laur, 'Healthcare access for deaf patients – The legal and ethical perspectives' (2018) 86(1) *Med Leg* 36 <<https://doi.org/10.1177/0025817217743416>>.

relationship.¹²⁴ Especially in psychosocial and psychiatric settings, patients prefer healthcare workers who are able to speak sign language.¹²⁵ Austria is a vanguard in this respect, having specialised health centres for Deaf people that are located in five different cities. There the medical staff speaks sign language and the clinical procedures are tailored to Deaf patients. In France, specialised primary care models for the Deaf have been established, too, and their amount is gradually increasing throughout the country.¹²⁶ A big advantage is the close connection of the patients to these healthcare centres. As a result, the compliance increases and diseases are often detected early, which allows a timely intervention. Furthermore, a trusting physician-patient relationship can develop and make support in social issues possible. Since many Deaf people suffer from mental illnesses, medical staff should give psychosocial aspects special attention, and if necessary, offer support and guidance in this concern as well.¹²⁷ Psychotherapy methods can also be modified for the Deaf, particularly because therapeutic success is possible via video communication, too.¹²⁸ In general, the already collected data about the advancing field of telehealth are very promising.¹²⁹

But so far not every clinic has the consciousness or resources to take special care of the accessibility of their services for the Deaf. In particular, clinicians who rarely deal with hearing-impaired patients need more awareness and background knowledge for dealing with this group of patients.¹³⁰ Education can not only give them a better understanding of the needs in communication, but also improve their approach,

¹²⁴ Johannes Fellingner and others, 'Psychosoziale Merkmale bei Gehörlosen' (2005) 76(1) *Nervenarzt* 43.

¹²⁵ David M Feldman and Amber Gum, 'Multigenerational perceptions of mental health services among deaf adults in Florida' (2007) 152(4) *Am Ann Deaf* 391.

¹²⁶ Thomas Amoros and others, 'A dedicated ambulatory system for the primary healthcare of the deaf people' (2014) 26(2) *Sante Publique* 205; B Drion and L Buhler, 'Access to care in sign language: the French experience' (2016) 137 *Public Health* 200.

¹²⁷ Johannes Fellingner and others, 'Psychosoziale Merkmale bei Gehörlosen' (2005) 76(1) *Nervenarzt* 43.

¹²⁸ Amanda O'Hearn and Robert Q Pollard Jr, 'Modifying dialectical behavior therapy for deaf individuals' (2008) 15(4) *Cognitive and Behavioral Practice* 400; Michael John Gournaris and Irene W Leigh, 'Comparison of face-to-face and video-mediated communication with deaf individuals: implications for telepsychotherapy' (2019) 37(2) *JADARA* 5.

¹²⁹ Alexa Kuenburg, Paul Fellingner and Johannes Fellingner, 'Health care access among deaf people' (2016) 21(1) *The Journal of Deaf Studies and Deaf Education* 1.

¹³⁰ A Middleton and others, 'Communicating in a healthcare setting with people who have hearing loss' (2010) 341 *BMJ* c4672; Audrey Laur, 'Healthcare access for deaf patients – The legal and ethical perspectives' (2018) 86(1) *Med Leg* 36 <<https://doi.org/10.1177/0025817217743416>>.

anamnesis and therapeutic success. For example, medical facts should best be shown to the Deaf by using plastic models or drawings instead of explanations with words. Through this visual way of presentation their understanding can be substantially improved.

Some countries already offer a cultural competency training for healthcare workers. In North America for instance, medical students received a two-year course that covered sign language as well as information about the Deaf culture. Afterwards, they significantly showed better knowledge and skills in working with hearing-impaired patients.¹³¹ In Austria and Germany, there are also free sign language courses offered at medical universities. Students generally appreciate this possibility, and the demand is gradually increasing.

4.1.3. *Health literacy*

Another big obstacle for therapy success and Deaf health is the lack of education in health issues. Finding and understanding medical information, as well as using it as a basis for actions relevant to one's health, is known as health literacy.¹³² This is a big problem for many Deaf persons. Since they do not have access to health information on the radio, television, or public conversations, there is usually a low level of knowledge about medical issues.¹³³ For example, in an American study (n=203) from 2006, 60% of Deaf people could not name a single stroke symptom, whereas among hearing people only 30% did not know any symptoms at all.¹³⁴ Following this, in addition to establishing a trusting and functioning communication between medical personnel and Deaf patients, the lack of health consciousness and medical knowledge is a major challenge for Deaf health.¹³⁵

¹³¹ Lisa Hoang and others, 'Assessing deaf cultural competency of physicians and medical students' (2011) 26(1) *Journal of Cancer Education* 175.

¹³² Thomas Abel and Kathrin Sommerhalder, 'Gesundheitskompetenz/Health Literacy' (2015) 58(9) *Bundesgesundheitsblatt - Gesundheitsforschung - Gesundheitsschutz* 923 <<https://doi.org/10.1007/s00103-015-2198-2>>.

¹³³ Robert Q Pollard Jr and Steven Barnett, 'Health-related vocabulary knowledge among deaf adults' (2009) 54(2) *Rehabilitation Psychology* 182.

¹³⁴ Helen Margellos-Anast, Melanie Estarziou and Gary Kaufman, 'Cardiovascular disease knowledge among culturally Deaf patients in Chicago' (2006) 42(3) *Prev Med* 235.

¹³⁵ Alexa Kuenburg, Paul Fellingner and Johannes Fellingner, 'Health care access among deaf people' (2016) 21(1) *The Journal of Deaf Studies and Deaf Education* 1.

4.1.4. *Room for improvement in health literacy*

The access to health information for Deaf persons is very limited. Common sources like books, written articles on the internet and TV reports might be difficult to follow and understand. These limitations are also non-compliant with human rights, since they violate not only the right to health, but also the right to education and the right to information. Innovative and various visual ways of promoting medical education are necessary for hearing-impaired persons. The success of individual measures has already been scientifically proven. For example, study participants showed a significant improvement in their knowledge after watching videos on cancer screening that had been prepared specifically for the Deaf.¹³⁶ In Ecuador, a social network for Deaf women provides them with information on sexuality, pregnancy, STDs and reproductive medicine and has already been very well received.¹³⁷

In Linz, Austria, there is an annual event for Deaf people that is organised by the health centre for Deaf people. At this meeting, a wide variety of medical topics such as diabetes, cancer screening and vaccinations are explained in Austrian Sign Language and afterwards discussed among the experts and participants.¹³⁸ Furthermore, they organise education programmes for hearing-impaired diabetics to learn about a healthy lifestyle. In Japan, pharmacists gave lectures about the details of medication use especially adapted for the Deaf, who showed a significant increase in knowledge afterwards.¹³⁹ Another important way to learn and talk about medical topics for Deaf people is through the interaction with their peers in sign language.¹⁴⁰

¹³⁶ Sommer R Kaskowitz III and others, 'Bringing prostate cancer education to deaf men' (2006) 30(5) *Cancer Detect Prev* 439; Sun Choe and others, 'The impact of cervical cancer education for deaf women using a video educational tool employing American sign language, open captioning, and graphics' (2009) 24(1) *Journal of Cancer Education* 10.

¹³⁷ Yaroslava Robles-Bykbaev and others, 'A Bespoke social network for deaf women in Ecuador to access information on sexual and reproductive health' (2019) 16(20) *International journal of environmental research and public health* 3962.

¹³⁸ Johannes Fellingner, 'Public Health of Deaf People' in Benito Estrada Aranda and Ines Sleeboom-van Raaij (eds), *Mental Health Services for Deaf People* (Gallaudet UP 2015) 111.

¹³⁹ Naomi Hyoguchi and others, 'Effects on deaf patients of medication education by pharmacists' (2016) 21(4) *Journal of deaf studies and deaf education* 416.

¹⁴⁰ Poorna Kushalnagar and others, 'Critical health literacy in American deaf college students' (2018) 33(5) *Health Promot Internation* 827.

4.1.5. *Increased burden of symptoms and disorders*

Apart from the restricted access to the healthcare system in communication and information, Deaf people experience an increased burden of disorders and medical symptoms.¹⁴¹ Multiple studies show that Deaf persons have a significantly higher symptom burden (headaches, back pain or digestive problems) and suffer from a subjectively higher stress burden as well as elevated mental distress.¹⁴² In an Austrian research for example, 45% of the hearing population said to feel nervous and overburdened, but out of the Deaf study participants 69% reported these mental health complaints.¹⁴³ Deaf patients also suffered six times more often from headaches than the average population.¹⁴⁴ Furthermore, a Norwegian study showed that Deaf persons significantly have more symptoms of anxiety disorder or depression.¹⁴⁵ Regardless of whether their parents were hearing or not, Deaf people face many difficulties throughout their whole life. These can be communication problems from childhood on, experiences of abuse or the lack of accessibility in daily life, which are seen as partly responsible for the high level of suffering.¹⁴⁶ Furthermore, the constant dependency on others, the stigma of persons with disabilities and treatment without informed consent can increase the suffering of Deaf people additionally.¹⁴⁷

The discussion of the improvement of this elevated burden is rather difficult. On the one hand, a better inclusion in society and a support in

¹⁴¹ Johannes Fellingner, Daniel Holzinger and Robert Pollard, 'Mental health of deaf people' (2012) 379(9820) *The Lancet* 1037.

¹⁴² Johannes Fellingner and others, 'Mental distress and quality of life in a deaf population' (2005) 40(9) *Soc Psychiatry Psychiatr Epidemiol* 737; Johannes Fellingner and others, 'Psychosoziale Merkmale bei Gehörlosen' (2005) 76(1) *Nervenarzt* 43.

¹⁴³ Johannes Fellingner and others, 'Psychosoziale Merkmale bei Gehörlosen' (2005) 76(1) *Nervenarzt* 43.

¹⁴⁴ Johannes Fellingner, 'Patient gehörlos - Medizin unter vier Augen' (2007) 21(77) *Das Zeichen* 386.

¹⁴⁵ Marit Kvam, Mitchell Loeb and Kristian Tambs, 'Mental Health in Deaf Adults: Symptoms of Anxiety and Depression Among Hearing and Deaf Individuals' (2007) 12 *Journal of deaf studies and deaf education* 1.

¹⁴⁶ John F Knutson, Christina R Johnson and Patricia M Sullivan, 'Disciplinary choices of mothers of deaf children and mothers of normally hearing children' (2004) 28(9) *Child Abuse Negl* 925; MH Kvam, 'Sexual abuse of deaf children. A retrospective analysis of the prevalence and characteristics of childhood sexual abuse among deaf adults in Norway' (2004) 28(3) *Child Abuse Negl* 241; Johannes Fellingner and others, 'Correlates of mental health disorders among children with hearing impairments' (2009) 51(8) *Developmental Medicine & Child Neurology* 635.

¹⁴⁷ Office of the United Nations High Commissioner for Human Rights and World Health Organization, 'The Right to Health - Fact sheet No 31' (2008) United Nations GE 08-41061.

mental health from early childhood on could help. On the other hand, the proposed improved access to healthcare generally enables an earlier detection and prevention of diseases in the first place. However, more specific research has to be done in this field. Although the importance of mental health was known already thousands of years ago, its significance only seems to gain interest and focus in research nowadays, especially fostered through the events of the pandemic. The poet Juvenal wrote the famous quote '*Mens sana in corpore sano*' – a healthy soul in a healthy body.¹⁴⁸ Both mental and physical health are equally important and responsible for a happy life. Thus, both parts have to be addressed in healthcare. However, medical care often focusses only on the physical health of the patients when mental health would need special attention as well. In regard to Deaf patients, this field is even more outstanding. Because of the already mentioned reasons and risk factors they are more prone to psychological diseases. Doctors should take a full holistic approach in their treatment and researchers have to keep the field of mental health in mind when discussing Deaf health.

To sum up, Deaf persons still have many challenges in the access to healthcare, but there are also possibilities for solutions and turning medical services into inclusive settings. Improved communication, education of medical staff and the consultation of sign language interpreters can be a great help. Considering health literacy, information tailored for Deaf people has to be provided to improve both their knowledge and autonomy. The increased suffering and mental health problems of the Deaf should be another focus of research in the future.

4.2. DEAF HEALTH IN SWITZERLAND, GERMANY AND AUSTRIA

In this Master's thesis the focus shall be on the three German speaking countries of Europe, Austria, Germany and Switzerland. The situation for the Deaf in the different states, as well as the different approaches of the national healthcare systems, will be discussed. Subsequently in the methodology part, they will be analysed in practice on the grounds of a survey conducted exactly in these countries.

¹⁴⁸ David Young, 'Mens sana in corpore sano? Body and mind in Ancient Greece' (2005) 22(1) The international journal of the history of sport 22.

4.2.1. Switzerland

Switzerland is a country very diverse in itself. It consists not only of various cantons equalling federate states, but also has four national languages. Furthermore, there are different sign languages in the German-, Italian- and French-speaking regions.¹⁴⁹ However, only in 2 out of the 26 cantons sign language is recognised in the constitution.¹⁵⁰ The Swiss Federation of the Deaf is a very active and representative association fighting for the rights of Deaf persons in Switzerland. It urges the government to ‘recognise the three regional sign languages, namely Deutschschweizer Gebärdensprache (DSGS), Langue des Signes Française (LSF) and Lingua Italiana dei Segni (LIS) as national languages’.¹⁵¹ Apart from that, the existing discrimination in Switzerland mainly is not attributable to the law – especially since the adoption of the Disability Equality Act – but rather to the lack of implementation.¹⁵² Binggeli explains that there are no representatives of persons with disabilities in Switzerland who advocate for the healthcare interests of this group. Although there are around 650,000 hearing-impaired Swiss persons, with approximately 10,000 Deaf ones among them, there are still many unsolved barriers and challenges.¹⁵³

For example, one issue is the national emergency telephone, where migrants can access an interpreting service since 2011, but there is no assistance at all for sign language and the Deaf.¹⁵⁴ The Swiss foundation ‘Procom’ at least offers an 24h emergency helpline via SMS, but especially in emergency situations important time can be lost that

¹⁴⁹ European Union of the Deaf, ‘Switzerland’ (*European Union of the Deaf*, 2021) <<https://eud.eu/eud-members/full-members/switzerland/>> accessed 15 May 2021.

¹⁵⁰ Swiss Federation of the Deaf (SGB-FSS), ‘Parallel report of the Swiss Federation of the Deaf (SGB-FSS) Regarding the situation of deaf and hard of hearing persons in Switzerland To the United Nations Committee on the Rights of Persons with Disabilities’ (SGB-FSS 2018).

¹⁵¹ *ibid.*

¹⁵² Tatjana Binggeli and Christiane Hohenstein, ‘Deaf Patients’ Access to Health Services in Switzerland: An Interview with Dr. Tatjana Binggeli, Medical Scientist and President of the Swiss Federation of the Deaf SGB-FSS’ in Christiane Hohenstein and Magdalène Lévy-Tödter (eds), *Multilingual Healthcare: A Global View on Communicative Challenges* (Springer Fachmedien Wiesbaden 2020) 333 <https://doi.org/10.1007/978-3-658-27120-6_13>.

¹⁵³ Tatjana Binggeli, Adrian Lussi and Brigitte Zimmerli, ‘Der gehörlose Patient – Informationen für ein barrierefreies Patienten-gespräch in der Zahnarztpraxis’ (2009) 119(8) *Schweiz Monatsschr Zahnmed* 795.

¹⁵⁴ Tatjana Binggeli and Christiane Hohenstein, ‘Deaf Patients’ Access to Health Services in Switzerland: An Interview with Dr. Tatjana Binggeli, Medical Scientist and President of the Swiss Federation of the Deaf SGB-FSS’ in Christiane Hohenstein and Magdalène Lévy-Tödter (eds), *Multilingual Healthcare: A Global View on Communicative Challenges* (Springer Fachmedien Wiesbaden 2020) 333 <https://doi.org/10.1007/978-3-658-27120-6_13>.

way.¹⁵⁵ ‘Procom’ generally is an important stakeholder that facilitates the distribution of sign language interpreters and other services for the Deaf in whole Switzerland. Legally, in Switzerland the invalidity insurance covers the costs of sign language interpreters in workplace, education and private life, but with a maximum sum of money for each insurant.¹⁵⁶ In the healthcare sector, the providers of the services are responsible for recruiting and paying for the sign language interpreters.¹⁵⁷

In the field of practical healthcare, medical experts have to learn more about the needs of the Deaf and adjust accordingly.¹⁵⁸ Binggeli conducted a Swiss study that showed that the majority of Deaf persons is unsatisfied with healthcare, but the vast majority of medical staff on the other hand perceives themselves to cooperate well with hearing-impaired patients.¹⁵⁹ She is the President of the Swiss Federation of the Deaf and a medical scientist. In her dissertation she found out that 80% of persons with hearing-disability are dissatisfied with the access to the healthcare system in Switzerland.¹⁶⁰ For example, despite the explicit provision by law there is no psychiatric service that meets the specifications for the Deaf, which is especially striking since they have a higher mental health burden and it is also a sensitive area of physician-patient-relationship.¹⁶¹ Overall, more sign language interpreters and medical staff who are hearing-impaired themselves should be employed, to improve the accessibility and communication in healthcare.¹⁶² Another challenge is

¹⁵⁵ Schweizerischer Gehörlosenbund SGB-FSS, ‘Zugänglichkeit bei Notrufen: Wir suchen Erfahrungsberichte’ (SGB-FSS, 2021) <<https://sgb-fss.ch/news/zugaenglichkeit-bei-notrufen/>> accessed 21 May 2021.

¹⁵⁶ Schweizerischer Gehörlosenbund SGB-FSS, ‘Video-News: Das Recht auf Gebärdensprachdolmetscher*innen’ (SGB-FSS, 2018) <<https://sgb-fss.ch/news/das-recht-auf-gs-dolmetscher/>> accessed 18 May 2021.

¹⁵⁷ *ibid.*

¹⁵⁸ Schweizerischer Gehörlosenbund SGB-FSS, ‘Gehörlosigkeit und Gesundheit’ (2017) 01/2017 ganz OHR.

¹⁵⁹ Tatjana Binggeli and Christiane Hohenstein, ‘Deaf Patients’ Access to Health Services in Switzerland: An Interview with Dr. Tatjana Binggeli, Medical Scientist and President of the Swiss Federation of the Deaf SGB-FSS’ in Christiane Hohenstein and Magdalène Lévy-Tödter (eds), *Multilingual Healthcare: A Global View on Communicative Challenges* (Springer Fachmedien Wiesbaden 2020) 333 <https://doi.org/10.1007/978-3-658-27120-6_13>.

¹⁶⁰ Hans-Martin Jermann, ‘Portrait - Tatjana Binggeli: „Ich möchte gar nicht hören wollen“’ *bz Basel* (2017).

¹⁶¹ Tatjana Binggeli and Christiane Hohenstein, ‘Deaf Patients’ Access to Health Services in Switzerland: An Interview with Dr. Tatjana Binggeli, Medical Scientist and President of the Swiss Federation of the Deaf SGB-FSS’ in Christiane Hohenstein and Magdalène Lévy-Tödter (eds), *Multilingual Healthcare: A Global View on Communicative Challenges* (Springer Fachmedien Wiesbaden 2020) 333 <https://doi.org/10.1007/978-3-658-27120-6_13>.

¹⁶² Schweizerischer Gehörlosenbund SGB-FSS, ‘Gehörlosigkeit und Gesundheit’ (2017) 01/2017 ganz OHR.

the inequality in the health insurance system, where Deaf persons are excluded from some lower priced offers like the tele-medicine model that amongst other things works via the phone.¹⁶³

To sum up, Switzerland has a proper legislation providing for equal access to healthcare, but there are still many steps to be taken for the implementation. The Swiss Federation for the Deaf is an active stakeholder with a medical scientist as their president. They advocate for better education, more sign-language interpreters and hearing-impaired staff in the healthcare system, as well as an easily accessible emergency line and equality in health insurances.

4.2.2. Germany

Germany is the biggest of the German-speaking countries in Europe, with around 80,000 Deaf people living there.¹⁶⁴ They speak in ‘Deutsche Gebärdensprache’ (DGS) – German Sign Language – which was officially recognised as an independent language in 2002.¹⁶⁵ This happened through the coming into force of the Act on Equal Opportunities for Disabled Persons that created important legal changes fostering equality and non-discrimination.¹⁶⁶ Although the statutory situation in Germany is well established, the implementation is still deficient. In the healthcare sector, education and information are missing both for the staff and the patients.

The legal text of the Social Code – ‘*Sozialgesetzbuch*’ §17 paragraph 2 – assures that Deaf persons are entitled to the use of sign language interpreters when making use of social services.¹⁶⁷ The respective service providers are obliged to cover the expenses, whereas for out-patient procedures the health insurances come into place for the payment.¹⁶⁸ However, many people do not know about it, and bureaucratic

¹⁶³ Swiss Federation of the Deaf (SGB-FSS), ‘Parallel report of the Swiss Federation of the Deaf (SGB-FSS) Regarding the situation of deaf and hard of hearing persons in Switzerland To the United Nations Committee on the Rights of Persons with Disabilities’ (SGB-FSS 2018).

¹⁶⁴ Edanur Cüre, ‘Erfahrungen gehörloser Patienten im ambulanten Gesundheitssystem: eine qualitative Befragung von Gehörlosen und Gebärdensprachdolmetschern’ (Thesis doctor medicinae, Friedrich-Schiller-Universität Jena 2020).

¹⁶⁵ Deutscher Gehörlosen-Bund eV, *Der gehörlose Patient* 2011.

¹⁶⁶ Nina Timmermans, *The status of sign languages in Europe* (Council of Europe Publishing 2005).

¹⁶⁷ Deutscher Gehörlosen-Bund eV, *Der gehörlose Patient* 2011; Bundesvertretung der Medizinstudierenden in Deutschland eV, ‘Positionspapier Gehörlosigkeit im medizinischen Alltag’ (2013); BDÜ Infoservice, ‘Gebärdensprache - Ein Leitfaden’ (BDÜ Infoservice 2017).

¹⁶⁸ Deutscher Gehörlosen-Bund eV, *Der gehörlose Patient* 2011.

barriers or scheduling bottlenecks hinder the extensive deployment of sign language interpreters.¹⁶⁹ A clear and structured system for the distribution and generally a higher number of translators are necessary.¹⁷⁰ The European Union of the Deaf states that there are 750 working sign language interpreters in the whole of Germany.¹⁷¹ Deaf persons should be informed about their rights, such as the entitlement to translations, in a detailed and comprehensive way.¹⁷²

Furthermore, the accessibility of different kinds of assistance has to be improved. The website gesundheit.gehoerlosen-bund.de plays a big role in the availability of medical information and health literacy. Here the German Association of the Deaf provides videos in sign language about medical issues like elevated blood pressure, dementia or pregnancy. The internet page should increase the interest and understanding of Deaf persons concerning health topics. Additionally, medical personnel have to be educated about the best way to deal with Deaf persons already at the beginnings of their career.¹⁷³ Fortunately, some German medical universities already offer sign language courses for their students.¹⁷⁴ Overall, doctors should be informed about the possible recruitment of translators as well as immediately available communication assistance with apps like ISignIT or Telesign.¹⁷⁵ In Germany, there are no out-patient services specifically for the Deaf, but there are a few rehabilitation clinics that have specialised divisions for hearing-impaired patients.¹⁷⁶

¹⁶⁹ Johannes Till Höcker, ‚Sozialmedizinische Aspekte der medizinischen Versorgung gehörloser Menschen in Deutschland‘ (Dissertation Doktorgrad der Medizin, Johannes Gutenberg-Universität Mainz 2010).

¹⁷⁰ Bundesvertretung der Medizinstudierenden in Deutschland eV, ‚Positionspapier Gehörlosigkeit im medizinischen Alltag‘ (2013).

¹⁷¹ European Union of the Deaf, ‚Germany‘ (*European Union of the Deaf*, 2021) <<https://eud.eu/eud-members/full-members/germany/>> accessed 15 May 2021.

¹⁷² Johannes Till Höcker, ‚Sozialmedizinische Aspekte der medizinischen Versorgung gehörloser Menschen in Deutschland‘ (Dissertation Doktorgrad der Medizin, Johannes Gutenberg-Universität Mainz 2010).

¹⁷³ Bundesvertretung der Medizinstudierenden in Deutschland eV, ‚Positionspapier Gehörlosigkeit im medizinischen Alltag‘ (2013).

¹⁷⁴ Andreas Monning, ‚Gebärdensprachekompetenz: Barrierefreiheit in der Praxis auch für gehörlose Patienten‘ (2018) 115(19) *Deutsches Ärzteblatt* A 942.

¹⁷⁵ S Pinilla and KS Stephan, ‚Gehörlose Patienten in der Allgemeinarztpraxis‘ (2015) 12(9) *CME* 55 <<https://doi.org/10.1007/s11298-015-1214-z>>.

¹⁷⁶ Tatjana Binggeli and Christiane Hohenstein, ‚Deaf Patients‘ Access to Health Services in Switzerland: An Interview with Dr. Tatjana Binggeli, Medical Scientist and President of the Swiss Federation of the Deaf SGB-FSS‘ in Christiane Hohenstein and Magdalène Lévy-Tödter (eds), *Multilingual Healthcare: A Global View on Communicative Challenges* (Springer Fachmedien Wiesbaden 2020) 333 <https://doi.org/10.1007/978-3-658-27120-6_13>.

In 2008, the first Deaf graduate of medical school in Germany, Dr med Andreas Paulini, caused sensation and awareness in the media.¹⁷⁷ He did research about the satisfaction of Deaf patients with the healthcare system and is now both working as a doctor in a psychiatric clinic and conducting projects – like ‘*Gesundheitslotse*’, being a guide in healthcare – to raise awareness for the Deaf in medical settings.¹⁷⁸ Corinna Wagner is the first Deaf specialist for internal medicine and even works in the emergency department of a German clinic.¹⁷⁹ She has the support of a job assistance and promotes awareness and health literacy for the Deaf in her vlog and blog www.cocomedizin.de. Another positive example is Dr med Uta Simons from Munich. She is a hearing general practitioner who is able to speak sign language. Around 300 of her patients are Deaf, the other staff members were especially trained how to deal with hearing-impaired persons and appointments are possible via email or text message.¹⁸⁰ Unfortunately these are only a few outstanding examples of clinicians who speak sign language. In general, Deaf persons have to rely on interpreters or even family members who assist in the physician-patient communication.

In emergency situations, Deaf persons only had the possibility to fax up until now. There are structured templates available with graphics and fillable fields about the affected person’s name, location and type of accident.¹⁸¹ In the digitalised world of 2021 this seems not only outdated but also taking lots of time and effort, which are particularly precious in emergency situations. In Bavaria, it has already been possible for some time to reach an on-call interpreter via a hotline.¹⁸² This interpreter is available the whole day to support in emergency situations, coming directly to the spot or trying to help remotely.¹⁸³ After many years of

¹⁷⁷ Hamburger Abendblatt, ‚Der erste Arzt für Gehörlose‘ (*Hamburger Abendblatt*, 8 September 2008) <<https://abendblatt.de/ratgeber/wissen/medizin/article107447967/Der-erste-Arzt-fuer-Gehoerlose.html>> accessed 20 May 2021.

¹⁷⁸ *ibid.*

¹⁷⁹ Helios Klinikum Salzgitter, ‚Trotz Handicap erfolgreich‘ (*Helios Klinikum Salzgitter*, 2017) <<https://helios-gesundheit.de/kliniken/salzgitter/unser-haus-karriere/aktuelles/detail/news/trotz-handicap-erfolgreich/>> accessed 16 June 2021.

¹⁸⁰ Andreas Monning, ‚Gebärdensprachekompetenz: Barrierefreiheit in der Praxis auch für gehörlose Patienten‘ (2018) 115(19) *Deutsches Ärzteblatt A* 942.

¹⁸¹ S Pinilla and KS Stephan, ‚Gehörlose Patienten in der Allgemeinarztpraxis‘ (2015) 12(9) *CME* 55 <<https://doi.org/10.1007/s11298-015-1214-z>>.

¹⁸² Cornelia von Pappenheim, ‚Notsituation – wie kann ein Gehörloser den Notruf wählen?‘ (*GMU*, 5 December 2015) <<https://gmu.de/notsituation-wie-kann-ein-gehoerloser-den-notruf-waehlen/>> accessed 13 May 2021.

¹⁸³ *ibid.*

advocacy, negotiations and trials, in 2021 a suitable emergency app should finally be available for every hearing-impaired person. It is named ‘nora’ and currently in the final testing phase. According to the internal affairs ministry of North Rhine-Westphalia, the app will be officially launched at the end of July 2021.¹⁸⁴ This would be a big step of equality and safety for the Deaf community. With the approved app, they can make emergency calls independently – anywhere from their smartphones – and receive help equally fast as the hearing population.

4.2.3. Austria

In Austria, there are around 10,000 Deaf people who speak ‘*Österreichische Gebärdensprache*’ – Austrian Sign Language.¹⁸⁵ This language was recognised in the Austrian Constitution as an independent language in 2005.¹⁸⁶ Federal constitutional law bans the discrimination of persons with disabilities in every area of life.¹⁸⁷ In 2006, the additional Disability Equality Package came into force and made an important difference for the legislation regarding persons with disabilities.¹⁸⁸ Although it is such a small country, Austria is often seen as a vanguard in Deaf health. The access to healthcare is regulated differently than in other countries. Like in other countries, sign language interpreters are available and can be used for medical appointments.¹⁸⁹ Their financial coverage varies from federate state to federate state. In the federate state of Vienna for example every Deaf person receives an annual budget of around €3,000 that they can use for all private interpreting costs, which

¹⁸⁴ Corinna Wagner, ‘Nora Notruf-App Update April 2021’ (*Coco Medizin*, 2021) <<https://cocomedizin.de/medizin-blog-bibliothek/nora-notruf-app-update-april-2021/>> accessed 13 May 2021.

¹⁸⁵ European Union of the Deaf, ‘Austria’ (*European Union of the Deaf*, 2021) <<https://eud.eu/eud-members/full-members/austria/>> accessed 15 May 2021.

¹⁸⁶ Tatjana Binggeli and Christiane Hohenstein, ‘Deaf Patients’ Access to Health Services in Switzerland: An Interview with Dr. Tatjana Binggeli, Medical Scientist and President of the Swiss Federation of the Deaf SGB-FSS’ in Christiane Hohenstein and Magdalène Lévy-Tödter (eds), *Multilingual Healthcare: A Global View on Communicative Challenges* (Springer Fachmedien Wiesbaden 2020) 333 <https://doi.org/10.1007/978-3-658-27120-6_13>.

¹⁸⁷ Petra Hochreiter, ‘Die rechtliche Stellung der Gehörlosen im österreichischen Bildungsbereich’ (Thesis Magistra der Rechtswissenschaften, Johannes Kepler Universität Linz 2013).

¹⁸⁸ Michael Krispl, ‘Behindertengleichstellungspaket ist nun tatsächlich Gesetz’ (*Bizeps*, 10 August 2005) <<https://bizeps.or.at/behindertengleichstellungspaket-ist-nun-tatsaechlich-gesetz/>> accessed 14 May 2021.

¹⁸⁹ Manuela Reichhart, ‘Translationskultur in Gehörlosenambulanzen’ (Karl-Franzens-Universität Graz 2009) <<http://media.obvsg.at/AC08031616-2001>>.

also include healthcare.¹⁹⁰ But in five Austrian cities, there are additional free healthcare services especially tailored at Deaf and hearing-impaired persons.

In Linz, Vienna, Salzburg, Graz and Klagenfurt there are special clinics for the Deaf. The staff in these out-patient clinics speaks sign language and is educated and experienced in the treatment of Deaf persons. They are also supported by sign language interpreters who can accompany the patients to further examinations and interventions in other parts of the corresponding hospital.¹⁹¹ The health centre for the Deaf in Linz was the first one of its kind, founded in the 1990s.¹⁹² Since it is the most elaborate and renowned one it shall be presented in a bit more detail.

The out-patient clinic in Linz is part of the hospital of St John of God and offers many different services, following a holistic approach of health. There is not only a general practitioner and nurses, but also social counselling, a psychologist, early therapy for hearing-impaired children and work assistance as support for the labour market. The institute cares for around 2,000 to 2,500 Deaf and hearing-impaired persons who usually remain clients for years.¹⁹³ All staff members speak Austrian Sign Language and there are also employees in the multidisciplinary team who are Deaf themselves. An important service is the preventive medical check-up that is recommended and financially covered by the health insurances once a year.¹⁹⁴ Here the doctor takes blood, performs a physical examination and does a comprehensive anamnesis about current complaints. Furthermore, the general practitioner takes time to explain any external findings in sign language and organises further examinations accompanied by an interpreter. The health centre also offers education with lectures at special health events for the Deaf and leaflets with simple and visual information containing medical

¹⁹⁰ Cornelia Zacek, ‚Patient taub-keine Anamnese möglich‘ (Thesis Magistra der Philosophie, Universität Wien 2017).

¹⁹¹ Tatjana Binggeli and Christiane Hohenstein, ‚Deaf Patients‘ Access to Health Services in Switzerland: An Interview with Dr. Tatjana Binggeli, Medical Scientist and President of the Swiss Federation of the Deaf SGB-FSS‘ in Christiane Hohenstein and Magdalène Lévy-Tödter (eds), *Multilingual Healthcare: A Global View on Communicative Challenges* (Springer Fachmedien Wiesbaden 2020) 333 <https://doi.org/10.1007/978-3-658-27120-6_13>.

¹⁹² Manuela Reichhart, ‚Translationskultur in Gehörlosenambulanzen‘ (Karl-Franzens-Universität Graz 2009) <<http://media.obvsg.at/AC08031616-2001>>.

¹⁹³ *ibid.*

¹⁹⁴ Johannes Fellingner, ‚Public Health of Deaf People‘ in Benito Estrada Aranda and Ines Sleeboom-van Raaij (eds), *Mental Health Services for Deaf People* (Gallaudet UP 2015) 111.

explanations and prevention advice.¹⁹⁵ Since the focus is very much on psycho-social medicine with integrated mental health and social work services, close and trusting relationships with the patients are possible.¹⁹⁶ Generally, appointments can be made via text message, email or fax, and queries are also dealt with via video chat. The other four specialised out-patient clinics in Austria work similarly but are smaller and partly a bit more basic in their psychosocial services so far.¹⁹⁷ Moreover, the Austrian medical universities offer optional sign language courses for their students. In Vienna, there is also a pharmacy specialised in Deaf patients with a Deaf pharmacist and two Deaf assistants among the employees.¹⁹⁸

For emergencies, Deaf persons can either text or fax to an emergency number or use the mobile app DEC112 (Deaf Emergency Call 112).¹⁹⁹ Reflecting about the healthcare situation in Austria and comparing it to other countries, it seems that there are more and holistic offers available for Deaf persons. The implementation of many improvements might have been positively influenced by the presence of a Deaf politician in the Austrian parliament. Helene Jarmer from the Austrian Green Party was part of the parliament from 2009 to 2017 and currently still works as the president of the Austrian Deaf Association.²⁰⁰ Although in comparison to other countries, Austria has a proper legislation and provides many services for Deaf persons, there are still various barriers. One of them is the already mentioned unclear coverage of interpreting costs. Another issue is the location of the special clinics for the Deaf. Since they are only based in five big cities, Deaf people from the countryside still have many problems to access qualitative healthcare.

¹⁹⁵ Johannes Fellingner, 'Public Health of Deaf People' in Benito Estrada Aranda and Ines Sleebloom-van Raaij (eds), *Mental Health Services for Deaf People* (Gallaudet UP 2015) 111.

¹⁹⁶ *ibid.*

¹⁹⁷ Manuela Reichhart, 'Translationskultur in Gehörlosenambulanzen' (Karl-Franzens-Universität Graz 2009) <<http://media.obvsg.at/AC08031616-2001>>.

¹⁹⁸ Cornelia Zacek, 'Patient taub-keine Anamnese möglich' (Thesis Magistra der Philosophie, Universität Wien 2017).

¹⁹⁹ *ibid.*; Landeszentrum für Hörgeschädigte, 'DEC112 App für Gehörlosennotruf' (2019) (März 2019) LHZ-Aktuell 20.

²⁰⁰ Cornelia Zacek, 'Patient taub-keine Anamnese möglich' (Thesis Magistra der Philosophie, Universität Wien 2017); Michael Hausenblas, 'Helene Jarmer: „Natürlich fluchen auch Gehörlose“' (*Der Standard*, 21 September 2020) <<https://derstandard.at/story/2000119862471/helene-jarmer-natuerlich-fluchen-auch-gehoerlose>> accessed 3 June 2021.

After stating different perspectives on Deaf health and presenting the case studies of Switzerland, Germany and Austria, now the topic shall be addressed in the light of the big and current public health challenge - the still ongoing pandemic of the Corona virus. At the end of this subsequent chapter, the handling of Deaf health by Switzerland, Germany and Austria will be discussed as well. A horizontally structured summary will then combine the considerations from both angles, giving an overview that enables comparing the countries in a clear and concise way.

4.3. DEAF HEALTH IN THE COVID-19 PANDEMIC

The Covid-19 pandemic has changed our lives since the beginning of 2020 in many ways we could have never imagined before. Governments and individuals had to adapt fast without any preparation. After months living in a pandemic, now it already seems to be the new reality of our everyday life. Everyone has to adapt and cope with developments like social distancing or home working. But Deaf persons especially face additional obstacles in the Corona virus time.

One of the key challenges is the obligatory use of face masks. They prevent the transmission of contagious aerosols and thus the spreading of the virus. However, many Deaf or persons hard of hearing are dependent on lip-reading and facial expressions and cannot understand anything when the other person wears a face mask covering their mouth. Since the beginning of the pandemic many creative solutions and inventions have been made to make life easier. Many people worldwide profit from it. It is particularly striking that transparent face masks are not one of them. This makes Deaf healthcare workers and patients once more feel like they were forgotten.²⁰¹ Grote and Izagaren, two Deaf doctors from the UK, researched that the only company that produces transparent face masks approved for the healthcare system is seated in the US. These face masks could not be delivered to the UK, which meant that the healthcare professionals could not participate in clinical discussions anymore.²⁰²

²⁰¹ Helen Grote and Fizz Izagaren, 'Covid-19: The communication needs of D/deaf healthcare workers and patients are being forgotten' (2020) 369 *BMJ* m2372.

²⁰² *ibid.*

Another issue that shows the sidelining of Deaf and hard of hearing healthcare staff are missing guidelines.²⁰³ Williams addresses the difficulty of wearing hearing aids in the medical setting, especially in regard to compatibility with the personal protective equipment necessary in the course of the Corona measures. However, Shew points out that the Covid-19 pandemic suddenly made many changes possible that persons with disabilities had fought for for a long time. Among these are working from home, flexibility of schedules and creativity of task realisation – these are all improvements that persons with disabilities hope to be continued and to raise awareness for disability technology in the clinical setting as well as in daily life.²⁰⁴

In the US as one example of many countries, in-person medical interpreters were banned due to Covid-19 measures.²⁰⁵ McKee, Moran and Zazove discuss the importance of qualitative remote translation and the possibility of virtual care platforms. Captioning apps can help to transcribe the spoken words of healthcare professionals.²⁰⁶ Restrictions of visitors and relatives who accompany patients to the hospital affect persons hard of hearing who may be dependent on help when communicating.²⁰⁷ On the one hand they could feel very isolated, and on the other hand also information – important for the recovery – might get lost. Chang and Lipner ask healthcare institutions to make an exception for Deaf and hard of hearing patients in this concern.²⁰⁸ The same goes for elective medical measures that are decreased to a minimum during the pandemic. In the case of new-born hearing screenings and other audiologic examinations a few months can make a difference. It has to be taken into account that initial diagnoses of Deaf or hard of hearing babies were already missed in the first time of adapting to the Corona virus.²⁰⁹

²⁰³ IJM Williams, 'Covid-19: lack of guidance on PPE for hearing impaired doctors' 370 *BMJ* m2831.

²⁰⁴ A Shew, 'Let COVID-19 expand awareness of disability tech' (2020) 581(7806) *Nature* 9.

²⁰⁵ Michael McKee, Christa Moran and Philip Zazove, 'Overcoming additional barriers to care for deaf and hard of hearing patients during COVID-19' (2020) 146(9) *JAMA Otolaryngology–Head & Neck Surgery* 781.

²⁰⁶ *ibid.*

²⁰⁷ JS West, KH Franck and DB Welling, 'Providing health care to patients with hearing loss during COVID-19 and physical distancing' (2020) 5(3) *Laryngoscope Investig Otolaryngol* 396.

²⁰⁸ MJ Chang and SR Lipner, 'Caring for deaf and hard of hearing patients in dermatology during the COVID-19 pandemic' (2020) 33(6) *Dermatol Ther* e14185.

²⁰⁹ Prasanth Pattisapu and others, 'Defining essential services for deaf and hard of hearing children during the COVID-19 pandemic' (2020) 163(1) *Otolaryngology–Head and Neck Surgery* 91.

Galindo Neto and others emphasise the problem of lack of health information. Since it is difficult for Deaf persons to access Covid-19 related knowledge and up-to-date details, they become an especially vulnerable population for the virus.²¹⁰ The study analysed YouTube videos about the pandemic in Brazilian sign language and found out that most videos came from individual users. Therefore, the researchers point out the need for reliable health information from official institutions that address prevention measurements of the virus infection.²¹¹ Considering that the level of education correlates with the knowledge Deaf persons have about Covid-19, the information has to be clear and easy to understand.²¹² Authorities must take into account multi-modal communication tools and follow the principle of non-discrimination in their emergency response as well.²¹³ Another advantage of using sign language, for example in television broadcasts, is the new visibility that creates awareness for members of the public who before maybe did not have any knowledge of the Deaf community.²¹⁴ Castro points out that there is no international sign language vocabulary for the new arising issues of the pandemic. Brazil for example uses at least three different signs for the virus itself.²¹⁵ The vocabulary used can be crucial for the understanding of the progress of the disease and its prevention. There should be a consensus and guidelines that clarify the linguistics recommended for persons of different education levels.

Tagupa addresses the increasing risk of social isolation and loneliness that comes with physical distancing and diverse restrictions. For persons hard of hearing it can be especially difficult to rely on video communication and remote technologies.²¹⁶ Regarding the higher rate

²¹⁰ Nelson Miguel Galindo Neto and others, 'Information about COVID-19 for deaf people: an analysis of Youtube videos in Brazilian sign language' (2021) 74 (Suppl 1) *Rev Bras Enferm* e20200291.

²¹¹ *ibid.*

²¹² Raylene Paludneviene and others, 'Perception of COVID-19 Physical Distancing Effectiveness and Contagiousness of Asymptomatic Individuals: Cross-sectional Survey of Deaf and Hard of Hearing Adults in the United States' (2021) 23(2) *Journal of Medical Internet Research* e21103.

²¹³ Maya Sabatello and others, 'Disability, Ethics, and Health Care in the COVID-19 Pandemic' (2020) 110(10) *Am J Public Health* 1523 <<https://doi.org/10.2105/AJPH.2020.305837>>.

²¹⁴ Elena Tomasuolo and others, 'The Italian Deaf community at the time of Coronavirus' (2021) 5 *Frontiers in Sociology* 125.

²¹⁵ HC Castro and others, 'COVID-19: don't forget deaf people' (2020) 579(7799) *Nature* 343.

²¹⁶ Hyacinth Tagupa, 'Social Isolation, Loneliness, and Hearing Loss During COVID-19' (2020) 73(5) *The Hearing Journal* 46 <https://journals.lww.com/thehearingjournal/Fulltext/2020/05000/Social_Isolation,_Loneliness,_and_Hearing_Loss.16.aspx>.

of mental health problems in the Deaf community²¹⁷ care providers should pay attention to their vulnerability and consider the connection of social interaction and emotional well-being.²¹⁸ Recio-Barbero, Sáenz-Herrero and Segarra request adjusted guidelines from institutions, especially for populations at risk like Deaf patients. A study in Ethiopia found a high rate of depression, anxiety and insomnia in persons with disabilities during the pandemic. Especially the prevalence of insomnia was elevated for Deaf persons.²¹⁹ Furthermore, in the lockdown time the tendency to ruminate about one own's hearing loss increased.²²⁰

The lack of social and cultural events leads to a decrease in encountering other persons and has an impact on the psychological status of many people. Consequently, Al Majali and Alghazo found that living with family members had a good effect for the mental health of Deaf persons in the pandemic.²²¹ However, for Deaf children the lockdown can also be a problem that enhances their stigmatisation even more. For example in Ghana, they are at risk that their parents will keep them away from the community when they do not spend their time at school.²²² Swanwick and others emphasise that children who normally feel protected and connected in schools for the Deaf are at big risk of isolation and worsening of their sign language skills during the time of the pandemic.

Another burden on persons with disabilities was not only the fear of their close ones getting the virus, but also the losses of famous disability activists like Leilani Jordan, who died from an infection with Covid-19 in April 2020.²²³ Lund and others also focus on the economic and

²¹⁷ Johannes Fellingner, Daniel Holzinger and Robert Pollard, 'Mental health of deaf people' (2012) 379(9820) *The Lancet* 1037.

²¹⁸ Mar Recio-Barbero, Margarita Sáenz-Herrero and Rafael Segarra, 'Deafness and mental health: Clinical challenges during the COVID-19 pandemic' (2020) 12 *Psychological Trauma: Theory, Research, Practice, and Policy* S212.

²¹⁹ M Necho and others, 'Depression, anxiety symptoms, Insomnia, and coping during the COVID-19 pandemic period among individuals living with disabilities in Ethiopia, 2020' (2020) 15(12) *PLoS One* e0244530.

²²⁰ G Naylor, LA Burke and JA Holman, 'Covid-19 Lockdown Affects Hearing Disability and Handicap in Diverse Ways: A Rapid Online Survey Study' (2020) 41(6) *Ear Hear* 1442.

²²¹ Salwa A Al Majali and Emad M Alghazo, 'Mental health of individuals who are deaf during COVID-19: Depression, anxiety, aggression, and fear' (2021) 49(6) *J Community Psychol* 2134-2143.

²²² Ruth Swanwick and others, 'The impact of the COVID-19 pandemic on deaf adults, children and their families in Ghana' (2020) 8 *Journal of the British Academy* 141.

²²³ Emily M Lund and others, 'The COVID-19 pandemic, stress, and trauma in the disability community: A call to action' (2020) 65(4) *Rehabilitation Psychology* 313.

intersectional stress that persons with disabilities face. In the time of the pandemic, they were even more aggravated. Furthermore, the fear of ableism in healthcare and thus unequal rationing has a negative impact on the mental health of persons with disabilities and increases anxiety and mistrust.²²⁴

Another distinctiveness is the fact that the preliminary health situation of Deaf persons on average is worse. Precedent research highlighted that the Deaf and persons hard of hearing have a higher prevalence of chronic diseases like diabetes or high blood pressure which are both risk factors for adverse events of a Corona virus infection.²²⁵

4.3.1. *Surveys about Deaf health in the pandemic*

Paludneviene and others conducted a survey about the perception of social distancing and its effectiveness, as well as the knowledge about contagiousness of an asymptomatic person. The results showed a correlation of education and believing in the effectiveness of physical distancing. They furthermore highlighted the importance of social media as information source for the Deaf.²²⁶ Another study from November 2020 was in line with these results and likewise asked where people receive information about the Corona virus from. 44% of persons with a pre-existing medical condition looked for information via the internet, 24% via television and only 1% through healthcare personnel; the rest relied on friends and family.²²⁷ Kushalnagar found a similar tendency with a questionnaire among Deaf Americans, where 31.9% looked for Covid-related information for the first time on the internet, followed by 24.8% using the TV for this purpose.²²⁸ Interviews in Ghana pointed

²²⁴ Emily M Lund and others, 'The COVID-19 pandemic, stress, and trauma in the disability community: A call to action' (2020) 65(4) *Rehabilitation Psychology* 313.

²²⁵ Junghyun Park, 'Unraveling the Invisible but Harmful Impact of COVID-19 on Deaf Older Adults and Older Adults with Hearing Loss' (2020) 63(6-7) *Journal of gerontological social work* 598.

²²⁶ Raylene Paludneviene and others, 'Perception of COVID-19 Physical Distancing Effectiveness and Contagiousness of Asymptomatic Individuals: Cross-sectional Survey of Deaf and Hard of Hearing Adults in the United States' (2021) 23(2) *Journal of Medical Internet Research* e21103.

²²⁷ Christopher J Moreland and others, 'Deaf adults at higher risk for severe illness: COVID-19 information preference and perceived health consequences' (2021) 104(11) *Patient Educ Couns* 2830-2833.

²²⁸ Poorna Kushalnagar, 'Part 1 Findings from a Survey of Deaf Americans: COVID-19 Awareness and Risk Perceptions' (Gallaudet University 2020) <<https://deafthequity.com/grant-awards/covid-19-deaf-health-research/>> accessed 10 June 2021

out the problem that some Deaf persons cannot afford a computer or television and are thus even more dependent on support in receiving current and important information.²²⁹ Apart from the necessity of an electronic device or even specific social media accounts, the content of the educative material was also criticised by Swanwick and others. The information about the Corona virus was only aimed at Deaf adults, which is especially striking since Deaf schools in Ghana for example were closed during the lockdown.²³⁰

A survey focussed on Deaf persons in Glasgow did amongst other things research on behaviour and emotional change as well as practical issues. Among the negative aspects of the pandemic respondents issued that they have to go without family members to doctor's appointments and thus lack interpreting support.²³¹ Naylor, Burke and Holman also address the additional burden the Covid measures put on the psyche of persons hard of hearing. In line with that, Rosencrans and others did a survey among persons with intellectual and developmental disabilities in Chile and the US, where only a few participants stated increased health problems during the pandemic. However, 41% of the participants in the US and half of the representatives in Chile responded that they have more mental health problems.²³²

In a US survey, the majority of persons hard of hearing reported difficulties wearing both hearing aids and face masks. They furthermore responded face masks impair communication, particularly because they cannot read lips or facial cues and the masks cause muffled sounds.²³³ Considering the increasing use of videocalls, a participant of another survey suggests that one field of improvement should be the compatibility of hearing aids and video-call equipment.²³⁴

In April 2020, an online assessment of the American Association on Health & Disability reached 2,469 adults with disabilities, 182 of

²²⁹ Ruth Swanwick and others, 'The impact of the COVID-19 pandemic on deaf adults, children and their families in Ghana' (2020) 8 *Journal of the British Academy* 141.

²³⁰ *ibid.*

²³¹ G Naylor, LA Burke and JA Holman, 'Covid-19 Lockdown Affects Hearing Disability and Handicap in Diverse Ways: A Rapid Online Survey Study' (2020) 41(6) *Ear Hear* 1442.

²³² M Rosencrans and others, 'The impact of the COVID-19 pandemic on the health, wellbeing, and access to services of people with intellectual and developmental disabilities' (2021) 114 *Res Dev Disabil* 103985.

²³³ Laura Gaeta, 'Survey of Hearing Health During the COVID-19 Pandemic: Implications for Service Delivery' (2020) 29(4) *Am J Audiol* 944.

²³⁴ G Naylor, LA Burke and JA Holman, 'Covid-19 Lockdown Affects Hearing Disability and Handicap in Diverse Ways: A Rapid Online Survey Study' (2020) 41(6) *Ear Hear* 1442.

them were Deaf or hard of hearing. 44% of all the respondents said they experienced new difficulties in healthcare during the Covid-19 virus time, whereas 56% stated no new challenges.²³⁵ This is especially interesting, because persons with disabilities already had more challenges to access the healthcare system before the start of the pandemic. In this study, contrary to others, the most used source for information about the pandemic was the television, followed by the internet. 15% mainly consulted healthcare providers or relatives and only 5% preferably used social media for receiving Covid-19 information. Most participants reported to have anxiety or depression. 76% of those had access to emotional support or service, while the remainder denied having access.²³⁶

In another survey from the US, most persons with disabilities who received any medical services before the pandemic reported some service loss.²³⁷ Schwartz and others found mental health to be an exception because here it was easier to maintain access via telehealth. Counter-intuitively, in this study participants experienced the pandemic as an improvement of their own health situation thanks to new telemedicine services.²³⁸ A Nigerian study that focusses on Covid-19 also recommends the increase of telehealth for persons with disabilities in general.²³⁹

Another hopeful observation is not only the increased visibility of sign language, but also the successful lobbying of the Deaf community, for example in Ghana, where they could make an impactful change in the government's pandemic communication.²⁴⁰

4.3.2. Deaf health and the pandemic in Switzerland

In the Covid-19 pandemic, the Swiss Federation of the Deaf issued multiple position papers and updates for affected persons. On their

²³⁵ CE Drum and others, 'COVID-19 and adults with disabilities: health and health care access online survey summary report' (American Association on Health and Disability 2020).

²³⁶ *ibid.*

²³⁷ Ariel E Schwartz and others, 'Impact of COVID-19 on services for people with disabilities and chronic health conditions' [2021] *Disability and Health Journal* 101090.

²³⁸ *ibid.*

²³⁹ Dominic Samaila and others, 'Impact of Covid-19 pandemic on people with disabilities and its implications on special education practice in Nigeria' (2020) 5(6) *Int J Innov Sci Res Technol* 803-808.

²⁴⁰ Ruth Swanwick and others, 'The impact of the COVID-19 pandemic on deaf adults, children and their families in Ghana' (2020) 8 *Journal of the British Academy* 141.

website they offer videos where they translate up-to-date information into sign language and explain the necessary public health measures with infographics. Moreover, they have also published position papers and discussed the communication complications because of the use of face masks. The association strongly advocated for the inclusion of the Deaf in the government's adjustment plans and the increased need for sign language interpreters.²⁴¹ They recommend masks with transparent windows to improve the communication possibilities in the pandemic. Furthermore, they explain that – in agreement with the authorities – the Deaf can even remove the masks when they follow social distancing regulations in order to communicate. This exceptional removal of masks was officially confirmed by the Swiss health ministry in October 2020.²⁴² From April 2021 on, transparent face masks could be bought from a Swiss company that produces them.²⁴³

Thanks to the advocacy of the Swiss Federation of the Deaf, relevant information about the Corona virus was published in sign language on the website of the health ministry in the middle of March.²⁴⁴ Press conferences were also translated into the three different sign languages from that time on.²⁴⁵ The Swiss public TV has increased its offer of TV news and shows in sign language in the course of the pandemic, broadcasting six different telecasts that are translated.²⁴⁶ Another success were the vaccination events organised by the Swiss Federation of the Deaf in cooperation with other unions and the cantonal health directories.²⁴⁷ On specific days, sign language interpreters and assistance for hearing-impaired persons were available at the vaccination centres.

²⁴¹ Schweizerischer Gehörlosenbund SGB-FSS, ‚Maskenpflicht: Kommunikation mit gehörlosen und hörbehinderten Menschen muss sichergestellt werden!‘ (SGB-FSS, 2020) <<https://sgb-fss.ch/maskenpflicht-rechte-von-gehoerlosen-schuetzen/>> accessed 26 May 2021.

²⁴² *ibid.*

²⁴³ Pilatus Today, ‚Flawa produziert Schutzmasken mit Sichtfenster‘ (Pilatus Today, 30 April 2021) <<https://pilatustoday.ch/schweiz/flawa-produziert-schutzmasken-mit-sichtfenster-141734013>> accessed 4 June 2021.

²⁴⁴ Beat Hürlimann, ‚Pressekonferenzen des Bundes werden neu live in Gebärdensprache übersetzt‘ (Horizont, 24 March 2020) <<https://horizont.net/schweiz/nachrichten/corona-krise-alle-pressekonferenzen-des-bundes-werden-neu-live-in-gebaerdensprache-uebersetzt-181809>> accessed 1 June 2021.

²⁴⁵ *ibid.*

²⁴⁶ SRG Deutschschweiz, ‚«Schweiz aktuell» neu in Gebärdensprache‘ (SRGD, 29 March 2021) <<https://srgd.ch/de/aktuelles/news/2021/03/29/schweiz-aktuell-neu-in-gebardensprache/>> accessed 1 June 2021.

²⁴⁷ Schweizerischer Gehörlosenbund SGB-FSS, ‚Zürich: Freiwillig Impfen, Spezialtermin‘ (SGB-FSS, 2021) <<https://sgb-fss.ch/news/zuerich-freiwillig-impfen-spezialtermin/>> accessed 29 May 2021.

4.3.3. Deaf health and the pandemic in Germany

Especially at the beginning of the Covid-19 pandemic, the German government did not take care of the needs of Deaf persons. In contrast to other countries, they did not translate up-to-date press conferences in sign language, and it took comparatively long until they provided accessible information in video format.²⁴⁸ Multiple representatives of the Deaf community blamed the government of violating the CRPD and fought for the translation of press conferences into sign language.²⁴⁹ From 11 March 2020, the health ministry published information videos in sign language on their website and on 17 March the translation of press conferences started.²⁵⁰ Throughout the whole pandemic the German Association of the Deaf was an important stakeholder to distribute and promote updates for Deaf persons. It also raised awareness through press releases and called for the use of transparent masks coupled with the consultation of sign language interpreters.²⁵¹ In April 2020, the first German transparent face masks were available.²⁵² Furthermore, the association provides collected information about the access to Covid-19 vaccinations in the different federate states. In some regions group appointments were organised, so multiple Deaf persons could get the vaccination in the presence of a sign language interpreter on the same day.²⁵³

²⁴⁸ Leonie von Hammerstein, ‚Taube Menschen und Corona: „Ernsthaft, Deutschland?“‘ (DW, 2020) <<https://dw.com/de/taube-menschen-und-corona-ernsthaft-deutschland/a-52759680>> accessed 5 June 2021.

²⁴⁹ Ottmar Miles-Paul, ‚Coronavirus Epidemie – Informationsdefizit bei gehörlosen Menschen‘ (Kobinet Nachrichten, 5 March 2020) <<https://kobinet-nachrichten.org/2020/03/05/coronavirus-epidemie-informationsdefizit-bei-gehoerlosen-menschen/>> accessed 6 June 2021.

²⁵⁰ Deutscher Gehörlosenbund eV, ‚DGB-Stellungnahme 04/2020‘ (Deutscher Gehörlosenbund eV, 22 April 2020) <<https://gehoerlosen-bund.de/coronavirus/dgb-stellungnahme>> accessed 5 June 2021.

²⁵¹ Deutscher Gehörlosenbund eV, ‚DGB-Pressemitteilung 03/2020‘ (Deutscher Gehörlosenbund eV, 22 April 2020) <<https://gehoerlosen-bund.de/coronavirus/dgb-stellungnahme/pressemitteilung%20vom%2022.04.2020>> accessed 5 June 2021.

²⁵² Schwarzwälder Post, ‚Schneidermeisterin entwickelt Mundschutz für Gehörlose‘ (Schwarzwälder Post, 22 April 2020) <<https://schwarzwaelder-post.de/orte-im-verbreitungsgebiet/biberach/2020/04/schneidermeisterin-entwickelt-mundschutz-fuer-gehoerlose/76095>> accessed 9 June 2021.

²⁵³ Deutscher Gehörlosenbund eV, ‚Corona-Impfungen‘ (Deutscher Gehörlosenbund eV, 10 May 2021) <<https://gehoerlosen-bund.de/coronavirus/corona-impfungen>> accessed 12 June 2021.

In Germany, the implementation of the Protection against Infection Act – the applying law in the pandemic – is the responsibility of the 16 federate states.²⁵⁴ Therefore, the situation can differ in the various regions. Bavaria, for example, allows the removal of the face mask when it is necessary for communication with hearing-impaired persons.²⁵⁵ In North Rhine-Westphalia, special counselling services – also available online – were established in the time of the pandemic.²⁵⁶ In some regions the Deaf community connected even more among themselves. Deaf activists raised awareness with videos where they criticised the Covid-19 response that did not include proper information in sign-language.²⁵⁷

4.3.4. *Deaf health and the pandemic in Austria*

The Austrian Association of the Deaf and its different subdivisions in the federate states played an important role in distributing information about the Corona virus to Deaf persons.²⁵⁸ Although government services gradually tried to catch up with providing information in sign language, Deaf people needed more guidance and access to health knowledge.²⁵⁹ The special clinics for the Deaf have increased their social media presence and worked via telehealth as well. They also provided videos on Facebook explaining Covid-19 symptoms, measures and detailed information about the vaccination.

TV news and press conferences were translated simultaneously in sign language throughout the whole pandemic and additional information in video format was available on the social ministry website from the beginning of March 2020 onwards.²⁶⁰ The problem of getting in contact

²⁵⁴ Ärzteblatt hil, 'Maskenpflicht für Gehörlose besonders belastend' (*Ärzteblatt*, 11 November 2020) <<https://aerzteblatt.de/nachrichten/118191/Maskenpflicht-fuer-Gehoerlose-besonders-belastend>> accessed 15 June 2021.

²⁵⁵ *ibid.*

²⁵⁶ Kompetenzzentrum Selbstbestimmt Leben, 'Online Beratung in Gebärdensprache' (*Kompetenzzentrum Selbstbestimmt Leben*, 2021) <<https://ksl-msi-nrw.de/de/node/2710>> accessed 18 June 2021.

²⁵⁷ Leonie von Hammerstein, Taube Menschen und Corona: „Ernsthaft, Deutschland?“ (DW, 2020) <<https://www.dw.com/de/taube-menschen-und-corona-ernsthaft-deutschland/a-52759680>> accessed 5 June 2021.

²⁵⁸ Österreichischer Gehörlosenbund, 'Corona: Ansteckung vermeiden, Verdacht abklären' (*Österreichischer Gehörlosenbund*, 11 March 2020) <<https://oeglb.at/corona-ansteckung-vermeiden-verdacht-abklaeren/>> accessed 19 June 2021.

²⁵⁹ Stadt Wien, 'Informationen zu Corona für Gehörlose' (*Stadt Wien*, 2021) <<https://coronavirus.wien.gv.at/informationen-zu-corona-fuer-gehoerlose/>> accessed 19 June 2021.

²⁶⁰ BIZEPS – Zentrum für Selbstbestimmtes Leben, 'Infos zum Corona-Virus in Gebärdensprache' (*Bizeps*, 6 March 2020) <<https://bizeps.or.at/infos-zum-corona-virus-in-gebaerdensprache/>> accessed 1 June 2021.

with the telephone help lines was faced both with relay translating services and accessibility via the emergency app DEC112.²⁶¹ The big disadvantage of this solution was the limited time frame Deaf persons could make use of these services. The relay sign language interpreters were only available for specific working hours per day. Especially when Deaf persons had immediate suspicion of an infection with Covid-19, round the clock assistance would be necessary in an emergency situation like this. Considering the obligatory use of face masks, only in November 2020 the social and health ministry announced an important amendment to the Covid-19 Emergency Measures Act: It allowed Deaf and hearing-impaired persons to remove their face masks if necessary for communicating.²⁶²

4.3.5. *Horizontal comparison of Switzerland, Germany and Austria*

To sum up, the situations in the three addressed countries shall also be viewed horizontally to get a holistic and thematic overview.

4.3.5.1. *Horizontal comparison of demographics and human rights*

The first table shows demographic and human rights related differences. Apart from the population numbers represented by the statistics from 2020,²⁶³ two other variables from global rankings are contrasted. The first is the Human Freedom Index from 2020, published by the Cato Institute and Fraser Institute. Among other things it takes the rule of law, freedom of expression and information and legal systems into account.²⁶⁴ It is said to depict a representative reflection of the democracy and human rights situation of states world-wide.²⁶⁵ The

²⁶¹ Österreichischer Gehörlosenbund, 'Corona: Ansteckung vermeiden, Verdacht abklären' (Österreichischer Gehörlosenbund, 11 March 2020) <<https://oegl.at/corona-ansteckung-vermeiden-verdacht-abklaeren/>> accessed 19 June 2021; Stadt Wien, 'Informationen zu Corona für Gehörlose' (Stadt Wien, 2021) <<https://coronavirus.wien.gv.at/informationen-zu-corona-fuer-gehoerlose/>>.

²⁶² BIZEPS – Zentrum für Selbstbestimmtes Leben, 'Novelle der COVID-19-Notmaßnahmenverordnung berücksichtigt Bedürfnisse gehörloser Menschen' (Bizeps, 26 November 2020) <<https://bizeps.or.at/novelle-der-covid-19-notmassnahmenverordnung-beuecksichtigt-beduerfnisse-gehoerloser-menschen/>> accessed 3 June 2021.

²⁶³ J Rudnicka, 'Bevölkerung in Deutschland, Österreich und der Schweiz im Jahr 2020' (Statista, 2020) <<https://de.statista.com/statistik/daten/studie/1117261/umfrage/bevoelkerung-in-den-dach-laendern/#professional>> accessed 22 June 2021.

²⁶⁴ Ian Vasquez and Fred McMahon, *Human Freedom Index 2020* (CATO Institute, Fraser Institute 2020).

²⁶⁵ *ibid.*

World Happiness Index on the other hand focuses on the quality of life in different countries. It includes inter alia the gross domestic products, healthy life expectancy at birth, perceptions of corruption and social support in its ranking.²⁶⁶ These factors can particularly be linked to economic, social and cultural rights like the right to health or the right to social security.

In both index rankings, Switzerland achieved the best position out of the three countries and very high positions in general. Germany had better results than Austria in the human rights assessment, whereas Austria did better in the happiness evaluation.

Table 1: Demographics and human rights

	Switzerland	Germany	Austria
Population in millions ²⁶⁷	8.6	83.2	8.9
Human Freedom Index ranking position ²⁶⁸	2	9	15
World Happiness Index ranking position ²⁶⁹	3	17	9

4.3.5.2. Horizontal comparison of the legal situation for the Deaf

As the previous chart showed, Austria and Switzerland have a similar population, and likewise the number of Deaf persons is estimated to be in both countries around 10,000. In the by far bigger Germany, the count is eight times more. The next table shows the relevant legal documents in the different states and the recognition status of sign language. Furthermore, the ratification dates of the CRPD are specified.²⁷⁰

²⁶⁶ John F Helliwell and others (eds), *World Happiness Report 2020* (The Sustainable Development Solutions Network 2020) 202.

²⁶⁷ J Rudnicka, 'Bevölkerung in Deutschland, Österreich und der Schweiz im Jahr 2020' (Statista, 2020) <<https://de.statista.com/statistik/daten/studie/1117261/umfrage/bevoelkerung-in-den-dach-laendern/#professional>> accessed 22 June 2021.

²⁶⁸ Ian Vasquez and Fred McMahon, *Human Freedom Index 2020* (CATO Institute, Fraser Institute 2020).

²⁶⁹ John F Helliwell and others (eds), *World Happiness Report 2020* (The Sustainable Development Solutions Network 2020) 202.

²⁷⁰ United Nations Treaty Collection, 'Human Rights' (2021) <https://treaties.un.org/Pages/ViewDetails.aspx?src=TREATY&mtdsg_no=IV-15&chapter=4&clang=en> accessed 28 March 2021.

Table 2: Legal situation

	Switzerland	Germany	Austria
Deaf population approximately	10,000	80,000	10,000
Recognition of sign language	In 2 out of 26 cantons in constitution	Officially recognised, but not in constitution	In Austrian constitution since 2005
Important legal document	Disability Equality Act	Act on Equal Opportunities for Disabled Persons	Disability Equality Package
CRPD ratification	15 April 2014 (accession)	24 February 2009	26 February 2008

4.3.5.3. Horizontal comparison of Deaf health

The healthcare systems and sign language interpreter allocation work in all three countries differently. The access to the emergency hotline operates in Germany and Austria similarly. These two countries also have sign language course offers in some of their medical universities. The following table gives an overview over the access to healthcare in the three discussed countries.

Table 3: Deaf health

	Switzerland	Germany	Austria
Sign language interpreters	Platform 'Procom' facilitates distribution, healthcare institutions cover costs	No distribution platform, Social Code assures entitlement, but lack of knowledge	No distribution platform, federate states provide budget for interpreting costs
Special clinics for the Deaf	No	Rehabilitation clinics with special departments	Out-patient clinics for the Deaf in five cities
Emergency number	24h emergency helpline via SMS carried out by 'Procom'	Via fax, but from July 2021 on new emergency app 'nora' available	Via emergency app 'DEC112'; fax also still possible
Specific features	President of Swiss Federation of the Deaf is medical scientist; difficulties in access to specific health insurances for the Deaf	Deaf Association provides health literacy website; medical universities offer sign language courses	Pharmacy with Deaf employees in Vienna, medical universities offer sign language courses

4.3.5.4. *Horizontal comparison of Deaf health in the pandemic*

The Covid-19 pandemic caused many sudden challenges and changes for every country. The ensuing table shows different reactions and handlings of the access to healthcare for the Deaf in Switzerland, Germany and Austria.

Table 4: *Deaf health in the pandemic*

	Switzerland	Germany	Austria
Sign language interpreters at press conferences	After advocacy of Deaf association, started around 17 March 2020	After advocacy of Deaf association, started 17 March 2020	After advocacy of Deaf association, started mid-March 2020
Information about Covid-19 in sign language	By Deaf associations and from mid-March 2020 onwards by ministry	By Deaf associations and from 11 March 2020 onwards by ministry	By ministry and local Deaf associations
Exceptional removal of mask for the Deaf when communicating	Yes, officially stated by health ministry in October 2020	Only in specific federate states	Yes, via legislation amendment in November 2020
Vaccination days with sign language interpreters	Yes	Yes, in some regions	No
Specific features	Swiss company producing transparent face masks	German company producing transparent face masks, in some regions: special online counselling services	Questions about Covid-19 via emergency app and relay translating in working hours, telehealth of special clinics for the Deaf

4.4. RESEARCH QUESTIONS

The main field of practical research in this thesis is focussed on the impact of the Covid-19 pandemic. The research questions emerged from the findings of the theoretical thesis part. Special attention is given to the differences between the analysed countries and correlation with their healthcare approach.

4.4.1. Main research question

To what extent did the Covid-19 policies of Germany, Switzerland and Austria – concerning access to healthcare for the Deaf – comply with human rights?

4.4.2. Sub-questions

To answer the main research question, the following sub-questions should support the analysis.

- 1) Did Deaf persons have more difficulties in the access to healthcare already before the pandemic?
- 2) Are there significant differences in the perceptions of healthcare between Germany, Switzerland and Austria?
- 3) Did access to healthcare become more difficult for the Deaf in the Covid-19 pandemic?
- 4) What were the major challenges in the access to healthcare during the pandemic perceived by Deaf persons?
- 5) What were the differences in the provided services for Deaf patients between Germany, Switzerland and Austria?
- 6) Which concrete measures are suggested by Deaf persons to improve the access to healthcare?

II.
EMPIRICAL PART

5.

TAKE CARE – EMPIRICAL RESEARCH

5.1. METHODOLOGY

5.1.1. Objective

The aim of this Master’s thesis was to present insights into Deaf health before and during the pandemic. The theoretical part gave an overview over the legal framework and led together with the comparative analysis among the different countries to the research questions. The conducted online survey among Deaf persons from Germany, Austria and Switzerland showed the perception of directly affected persons from different backgrounds. Qualitative questions were chosen to follow the socio-cultural approach of this thesis. Learning directly from Deaf people’s experiences and ideas how to improve access to healthcare in a pandemic should give both valuable knowledge and raise awareness. The study results could offer an enticement for national health politics to take human rights even more into account and thus promote substantive equality.

5.1.2. Background

Exactly ten years ago, in 2011, an Austrian research team did a global survey concerning Deaf health.²⁷¹ Kuenburg and Fellingner initiated the Health Resources Initiative to find out global challenges in healthcare for Deaf persons. They worked together with the World Federation

²⁷¹ Johannes Fellingner and Alexa Kuenburg, ‘World Federation of the Deaf (WFD) Health Resources Initiative’ (*World Federation of the Deaf*, 2011) <<https://wfdeaf.org/news/world-federation-of-the-deaf-wfd-health-resources-initiative/>> accessed 10 June 2021.

of the Deaf that also helped distributing the survey. It consisted of 14 questions and was filled in by the presidents of the national associations of the Deaf.²⁷²

The original idea for this thesis was to conduct a survey that depicts an update of the international health situation in the countries that participated ten years ago. However, on the one hand, this time the World Federation of the Deaf did not want to cooperate. Their help and contacts would have been indispensable for a hard-to-reach-population like the Deaf community. On the other hand, a sudden public health crisis has been changing people's lives in ways nobody could have imagined before. The pandemic affected healthcare and its priorities as well, and thus constituted a new and urgent research field of human rights. Therefore, the questions of the 'Health Resources Initiative' were taken as a prototype and inspired the structure of the current survey with a different focus.

5.1.3. *Design*

The methodology was designed to reach as many participants as possible. Since the Deaf community is a hard-to-reach-population and underrepresented in research panels and politics, there is a lack of existing studies.²⁷³ Especially in Germany, Austria and Switzerland, as far as it is known, there are no scientific resources about the situation of the Deaf during the pandemic available yet. To get as much as information as possible and not lose Deaf participants because of difficulty of language, the format had to be both concise, but also making room for their own considerations that a hearing person maybe could not even think of.

Germany, Austria and Switzerland were chosen as the focus of the thesis for multiple reasons. First, they are very diverse countries with different healthcare systems, but share a common German language. The according Deaf populations speak different sign languages but most of them are able to read and understand German written language. The three countries are European ones, Germany and Austria being EU members and all of them part of the Council of Europe. Each of them

²⁷² Alexa Kuenburg, 'Health Care for Deaf People - Global perspectives' (Thesis Doktorin der gesamten Heilkunde, Medical University of Vienna 2011).

²⁷³ Yoko Kobayashi and others, 'Using a social marketing framework to evaluate recruitment of a prospective study of genetic counseling and testing for the deaf community' (2013) 13(1) BMC Medical Research Methodology 1.

signed and ratified the CRPD and are committed to the rule of law and human rights. The survey should show if they handled the pandemic differently and whether they followed an inclusive approach for the Deaf or not.

The mixed methods study design is aimed at reflecting clear, comparable answers, but also showing empirical open thoughts. It combines quantitative and qualitative research. This broad approach provides for a large potential of different results.²⁷⁴ Especially in an area without preceding research it can be the starting point for future analyses that would go into more detail.

5.1.4. Measures

After the confirmation of the Austrian research team that their Health Resources Initiative survey can be used as a basis for this project the survey questions were designed.

A big issue was the choice of the language for the questionnaire. Since there are different sign languages used in the countries of interest, written German language was the most common one, although it is only the second language of Deaf persons and not their mother tongue. The likelihood of Deaf persons speaking English was even less, although in recent years more and more emphasis has emerged on German children who are Deaf to learn English as well.²⁷⁵ There are only very few sources about the reading literacy of Deaf persons in the German-speaking area.²⁷⁶ Most of them are about the education of Deaf children and show that the lack of vocabulary is the biggest barrier for the understanding of written German texts.²⁷⁷ But for the past years, educators have given increasing attention to the understanding of written language to improve accessibility for Deaf persons.²⁷⁸

²⁷⁴ Julia Brannen and Gemma Moss, 'Critical issues in designing mixed methods policy research' (2012) 56(6) *Am Behav Sci* 789.

²⁷⁵ Lena Kläser and Andreas Rohde, 'Fremdsprachenunterricht für gehörlose Schülerinnen und Schüler am Beispiel des Unterrichtsfaches Englisch' [2015] *Inklusion im Englischunterricht* 209.

²⁷⁶ Klaudia Krammer, *Schriftsprachkompetenz gehörloser Erwachsener* (Band 3 edn, Forschungszentrum für Gebärdensprache und Hörgeschädigtenkommunikation 2001).

²⁷⁷ *ibid.*

²⁷⁸ Martina Riegler, 'Deutsch als Zweitsprache für Gehörlose - Bedingungen bilingualer Förderung mit einem Fokus auf die Lesesozialisation' (Thesis Magistra der Philosophie, Universität Wien 2013).

The phrasing of the survey questions was made as simple as possible and the number of questions was kept to a minimum, in order to not lose participants because of the amount of time it would take. Multiple studies show that the shorter the survey is, the more people will respond.²⁷⁹ Therefore, the aim was to create a survey that will only take five minutes and only ask relevant questions for the research of this thesis. The value of reaching as many people as possible was higher than detailed demographic details like gender or age that would have prolonged the questionnaire unnecessarily which is why the seven questions were kept as simple as possible.

The important demographic parameter was the location of the person to distinguish between the according regions and countries. Voluntarily they could specify their connection to Deaf health or alternatively their profession. Two quantitative questions cover the difficulties in the access to healthcare before and during the pandemic. Three open questions asked about the challenges perceived, solutions provided and possible improvements for Deaf health in the Covid-19 pandemic. At the end, the participants could add something else that they wanted to say.

5.1.5. Procedure

The study was conducted via the online tool www.umfrageonline.com and completely held in written German. Altogether it consisted of nine pages. The starting page was introducing the survey, explaining the purpose and length of the questionnaire. Then the participants could click from question to question. There were no obligatory answers. It was also possible to pause the procedure and continue another time. The last page explained that the survey was done, thanked the user for their participation and told the user to close the window.

The results were directly collected in the online platform. On the one hand, they could be seen allocated to the questions as a list and overview of the answers. On the other hand, every reply could be viewed in detail and with an anonymous response-ID.

The survey was online and filled in from 17 May to 4 June 2021.

²⁷⁹ Sindre Rolstad, John Adler and Anna Rydén, 'Response burden and questionnaire length: is shorter better? A review and meta-analysis' (2011) 14(8) *Value in Health* 1101.

Statistics

For the evaluation of the quantitative questions, descriptive statistics and diagrams were created with the Excel programme (5.2.1.1., 5.2.1.3., 5.2.1.4., 5.2.4.2.1.). The statistical analysis of correlations (5.2.2., 5.2.3., 5.2.4.2.2.) was conducted by Agnes Poullikka from the University of Cyprus. She used the pairwise comparison technique within the R programme for the calculation of correlations.

Qualitative evaluation

For qualitative data, thematic analysis is one of the main tools to present a clear overview of answers to open questions, especially when there are many diverse responses.²⁸⁰ Especially in the field of health and medical research it can be a complimentary method to the mainly available quantitative data that gives very different results.²⁸¹ Following the thematic research technique, the participants' replies were read and scanned for common categories and similarities of answers.

5.1.6. Participants

The recruitment of participants was developed in two stages. The first aim was that the presidents of the national associations of the Deaf and their local delegates would fill in the survey. But since these primary sources were difficult to reach in the busy time of the pandemic and did not give much response, it led to the decision to expand the participant criteria and address members of the Deaf community from Germany, Switzerland and Austria through various ways.

In Switzerland, the representatives of the national association of the Deaf helped to distribute the survey link. In Germany, individual emails were sent to the regional associations for the Deaf. In Austria, the healthcare centre for the Deaf in Linz helped contacting the national association of the Deaf. In all countries, Facebook groups that included Deaf persons were used to publish the survey link. Moreover, Deaf individuals were contacted personally via Facebook messages

²⁸⁰ Andrew JB Fugard and Henry WW Potts, 'Supporting thinking on sample sizes for thematic analyses: a quantitative tool' (2015) 18(6) *International Journal of Social Research Methodology* 669.

²⁸¹ V Braun and V Clarke, 'What can "thematic analysis" offer health and wellbeing researchers?' (2014) 9 *Int J Qual Stud Health Well-being* 26152.

and email. Sign language clubs, doctors who speak sign language and pharmacies that offer special services for Deaf people were recruited with direct messages as well. The messages contained information about the human rights Master's programme, the research purpose and the survey link. The receivers of the message were also asked to forward the questionnaire to other affected persons, following the snowball strategy that is especially used for hard-to-reach populations like the Deaf.²⁸² In Germany, one local association published the survey link on their website. Another one published it on their Facebook page. Some recipients of direct emails responded with interest in the research and asked to afterwards receive the results as well.

Altogether, 120 participants could be recruited for the data collection, coming from various regions of the three targeted countries and diverse professional backgrounds.

5.2. RESULTS

5.2.1. *Descriptive statistics*

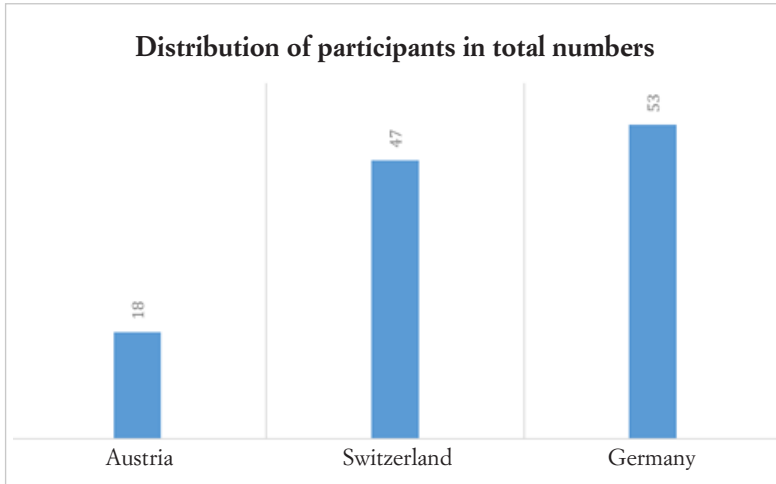
5.2.1.1. *Demographics – Countries*

120 participants filled in the survey. They came from various German-speaking regions, thus giving diverse insights into the situation at different locations. Out of the 17 German-speaking cantons in Switzerland, there were participants from 11 different cantons. The survey users from Austria represented four out of the nine federate states. Germany had the highest representation of diverse federate states, where participants contributed from 13 out of the 16 regions.

Overall, 18 survey participants said that they live in Austria, 47 in Switzerland and 53 in Germany. Two participants did not specify the country where they reside.

²⁸² Georgia Robins Sadler and others, 'Recruitment of hard-to-reach population subgroups via adaptations of the snowball sampling strategy' (2010) 12(3) Nurs Health Sci 369.

Table 5: Distribution of participants



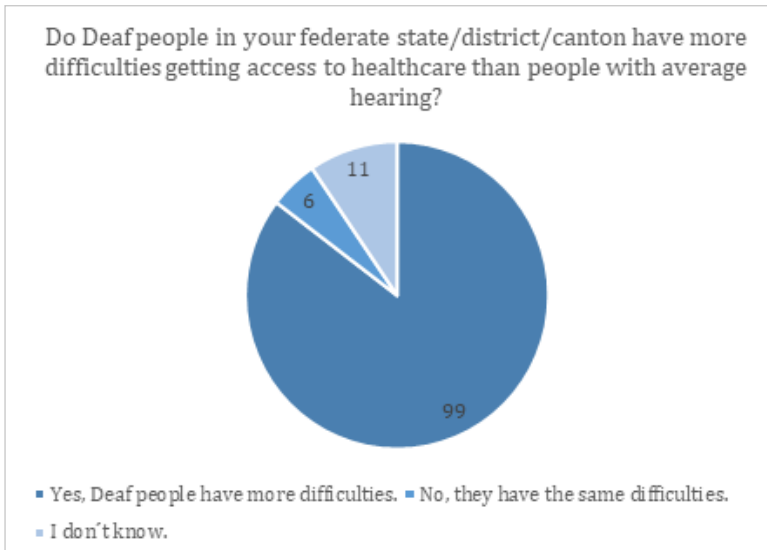
5.2.1.2. Occupation/connection to Deaf health

Voluntarily, the participants could explain their connection to Deaf health or indicate what they were working. The 85 answers to this question once again showed the broad spectrum of responders. There was a great variety of professions specified. 11 of them could be seen as connected to sign language. These participants were working as sign language interpreters and teachers or communication assistants. Nine participants indicated a connection to the associations for the Deaf in their respective regions. They either were a board member or other representatives of the Deaf community. 14 survey users had jobs related to the healthcare systems. They stated they work as pharmacists, nurses, social workers, optometrists and office workers in the healthcare system. 13 participants said they were in retirement. In the group of various professions, some were working for the public and the majority as employees in the tertiary sector. Four responders clarified in this field of the survey that they were not Deaf but hard of hearing.

5.2.1.3. *Sub-question: Did Deaf persons have more difficulties in the access to healthcare already before the pandemic?*

116 participants answered the question considering the access to healthcare before the pandemic. 85.3% said that Deaf persons generally have more difficulties in the access to healthcare than people with average hearing, whereas 5.2% reported the same difficulties. 9.5% could not give a clear answer to this question.

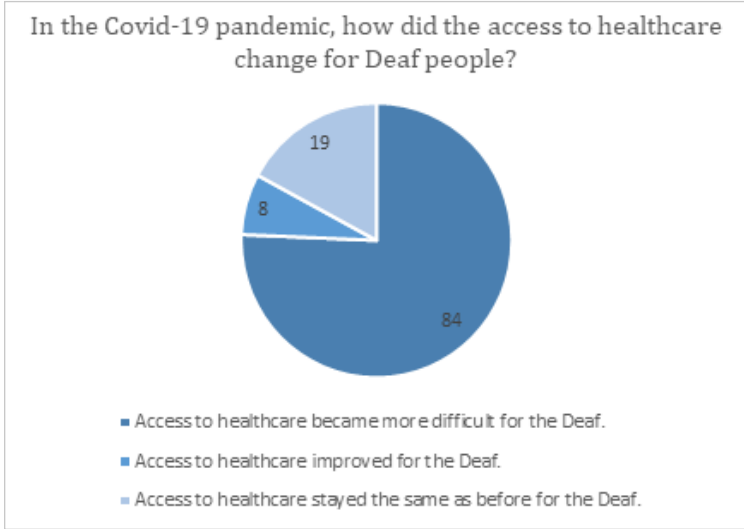
Table 6: *Sub-question 5.2.1.3.*



5.2.1.4. *Sub-question: Did access to healthcare become more difficult for the Deaf in the Covid-19 pandemic?*

111 survey participants stated their perception of the access to healthcare during the Covid-19 pandemic. 75.7% claimed that the access to healthcare became more difficult, 17.1% said that it stayed the same and 7.2% responded that access to healthcare improved for the Deaf during the pandemic.

Table 7: Sub-question 5.2.1.4.



5.2.2. Correlation of perception of access to healthcare and countries

Overall, there was no correlation between the answer to the question ‘Did Deaf persons have more difficulty in the access to healthcare already before the pandemic?’ and the country where people come from.

For Austria, the reported correlation was -0.07662246, therefore -0.08 to two decimal places.

For Switzerland, the reported correlation was 0.04552961, therefore 0.05 to two decimal places.

For Germany, the reported correlation was 0.01099976, therefore 0.01 to two decimal places.

The table shows the according numbers of participants and how they answered to this question in each country.

Table 8: Correlation 1

Do Deaf people in your federate state/district/canton have more difficulties getting access to healthcare than people with average hearing?			
Answer	Austria	Switzerland	Germany
More difficulties	14	41	44
Same difficulties	1	2	3
I don't know	3	3	5

5.2.3. *Correlation of perception of difficulties in Covid-19 pandemic and countries*

For the statistic correlation of the responses to the question ‘In the Covid-19 pandemic, how did the access to healthcare change for Deaf people?’ the following results were reported:

Overall, there was not a strong correlation between the answer to this question and the country where people come from.

For Austria, the reported correlation was 0.1408271, therefore 0.14 to two decimal places.

For Switzerland, the reported correlation was 0.01373731, therefore 0.01 to two decimal places.

For Germany, the reported correlation was -0.1456193, therefore -0.14 to two decimal places.

The following table depicts the numeric answers and basis for the statistics sorted by country.

Table 9: *Correlation 2*

In the Covid-19 pandemic, how did the access to healthcare change for Deaf people?			
answer	Austria	Switzerland	Germany
More difficulties	13	36	25
It improved.	3	2	2
Same difficulties	2	6	11

5.2.4. *Thematic analysis of qualitative data*

5.2.4.1. *What were the major challenges in the access to healthcare during the pandemic perceived by Deaf persons?*

The thematic analysis categorised the responses into four big categories: Communication, education, information and isolation. The most reported challenges considered communication and information barriers, with the obligatory face masks as the most indicated major challenge. The lack of sign language interpreters and the uncertainty about their financial coverage were also stated multiple times. Education of medical personnel was another important issue. Many survey participants reported misunderstandings and lack of both patience and time in medical settings.

One participant also stated the lower health literacy of Deaf persons as an obstacle in the pandemic. Many people mentioned the lack of information that was available in sign language. They reported uncertainty and receiving relevant news too late. Additionally, many survey participants saw isolation and the adding up of all the previously mentioned challenges as a big mental health burden.

The following table gives an overview of the different categories and the according considerations of the survey participants.

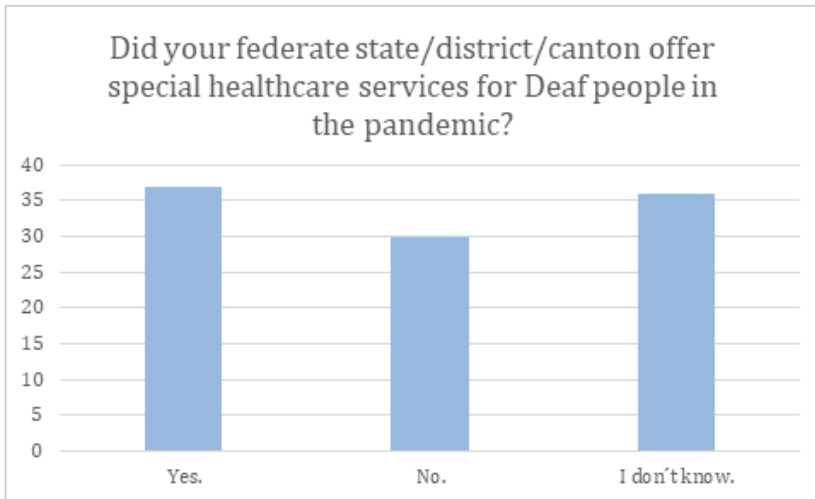
Table 10: Major challenges

Category	Theme	Examples of challenges
Communication	Masks	Barrier for lip-reading and facial expressions Lack of transparent face masks Medical staff refuses to remove mask
	Sign language interpreters	Low availability Unclear cost coverage
	Emergency hotline	Lack of other solution than calling When suspicion of infection, urgent response and instructions are needed
Education	Training	Lack of education about Deaf community for healthcare staff Most medical appointments only possible via telephone Impatience and lack of understanding
	Health literacy	Generally lower health knowledge of Deaf persons
Information	Pandemic news	Not always sign language interpreters Deaf persons need simple language Most information only available digitally, can be overwhelming Important news received too late
	Uncertainty	Often too much information and thus unclear Fake news difficult to distinguish Lack of clear information about vaccination and access to it
Isolation	Mental health	No more meetings possible Frustration because of increased communication barriers Especially old persons suffer from isolation and loneliness

5.2.4.2.1. *What were the differences in the provided services for Deaf patients between Germany, Switzerland and Austria?*

102 persons responded to the question if there were special services in the pandemic, with 35.3% saying that they did not know about it. 29.4% stated that special services for the Deaf did not exist in their regions. 36.3% reported extraordinary services for Deaf persons in the pandemic and specified them in free text fields.

Table 11: *Special services*



Half of the Austrian participants perceived that there were special services for the Deaf in the pandemic. Eight of the nine specified answers mentioned the special clinics for the Deaf in the respective federate states. One participant reported the possibility of written communication in the Covid testing sites and another one the deployment of sign language interpreters on Austrian TV.

In Switzerland, 40.4% of the survey users reported the provision of special services for the Deaf in the pandemic. 13 out of these 19 responders indicated the special vaccination days with support of sign language interpreters. Three participants mentioned the availability of information videos in sign language. Two participants also reported online Zoom meetings and one participant the work of a Swiss association that fought for the availability of transparent face masks.

In comparison, only 16.9% of the German participants stated that special services for the Deaf existed in the time of the pandemic. More people responded that there were no special services at all. In fact, most German responders answered that they did not know whether there were any new services in the pandemic or not. Out of the positive replies three survey users, all from Bavaria, reported the common vaccination appointments for Deaf people with the presence of sign language interpreters. Two participants each mentioned information videos in sign language and an online support group via Zoom. One participant indicated the support of translators via video when going to the vaccination centre or hospital. Another one said that the situation for Deaf people in Germany only improved at the second and third coronavirus wave.

5.2.4.2.2. Correlation between provided services and countries

The pairwise comparison showed that there was no correlation between the answer to the question ‘Did your federate state/district/canton offer special healthcare services for Deaf people in the pandemic?’ and the country where people come from.

For Austria, the reported correlation was 0.05457072, therefore 0.05 to two decimal places.

For Switzerland, the reported correlation was -0.03577434, therefore -0.03 to two decimal places.

For Germany, the reported correlation was -0.005782454, therefore -0.01 to two decimal places.

5.2.4.3. Which concrete measures are suggested by Deaf persons to improve the access to healthcare?

74 persons gave concise answers to the question ‘What would be ideas how to improve access to healthcare for the Deaf especially in times of the pandemic?’. The thematic analysis resulted in seven major topics that were named repeatedly. The most mentioned categories were the use of transparent face masks, general community services, political cooperation/inclusion, healthcare accessibility, education of staff, increased sign language interpreter availability and clear information offered in sign language.

In the field of general services, Deaf persons suggested sports programmes with instructions in sign language and more online offers. Some participants also had ideas directly targeted at politics. Politicians should not only cooperate between the regions, but also include Deaf people in the planning process of new strategies. In regard

to healthcare, many persons wished for clinics especially directed at Deaf persons that are experienced in the work with hearing-impaired persons. Many participants issued the need for email, video chat or text message communication to make appointments with doctors. The use of transparent face masks was stated as necessary several times as well.

The training of medical staff was another field of improvement that was addressed multiple times. Many people suggested that basic sign language courses and education about the Deaf community should be obligatory in the education of healthcare personnel. One person gave the US as an example, where every police officer, paramedic and firefighter is able to speak and understand basic American Sign Language. Another survey participant suggested graphic tables and visual scales for every hospital, so communication with hearing medical personnel is easier in emergency situations.

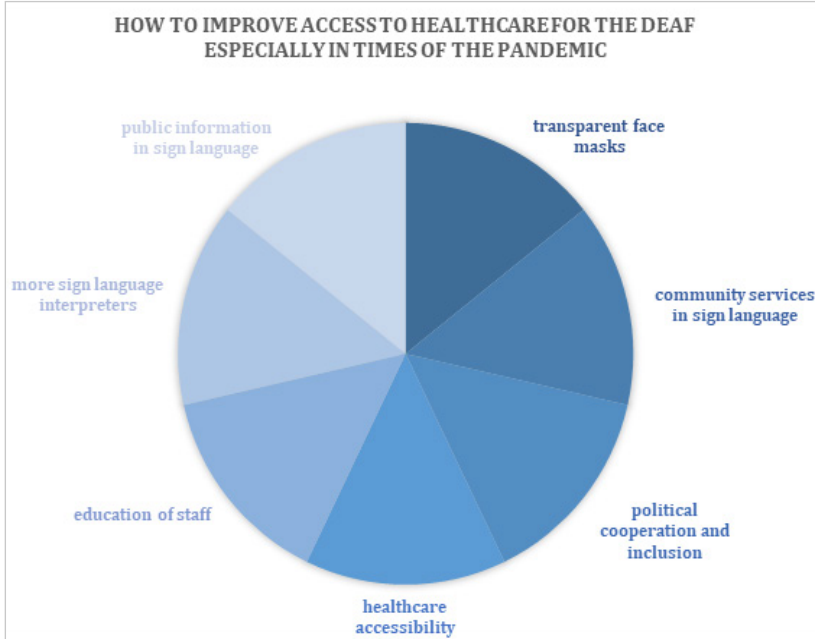
Considering sign language interpreters, the participants had different suggestions for improvement. Many addressed generally the need for a higher number and reachability. For example, more schools and education possibilities to achieve this job in the first place were mentioned. Also, remote interpreting should be improved in the time of the pandemic. Some participants explicitly asked for the improvement of technological devices and apps that assist in facilitating interpreting services and transcribe spoken language. Others said that interpreting costs always have to be covered by health insurances, and hospitals have to provide sign language interpreters from the beginning on in every interaction with Deaf patients. To achieve this, a survey user proposed a model of 'stand-in- interpreters' who are available anytime and can support wherever and whenever needed.

The last big topic of improvement that was named repeatedly was the accessibility of information. Many persons asked for a clearly indicated public channel with information in sign language where they can trust the source. They also stated that the TV programme generally needs more subtitles, and all official news should be with sign language interpreters. Survey users also pointed out the general need for visual information and simple written language.

A few participants mentioned the exclusion of Deaf persons from the obligatory face mask use and one survey user proposed the earlier admission of Deaf persons to the Covid vaccinations. Three persons explicitly wrote that they cannot think of any improvements.

The following chart shows a visual overview of the most named improvement ideas.

Table 12: Improvements



5.2.5. Additional remarks of survey participants

At the end of the online questionnaire, there was room for some additional remarks. A quarter of the participants, 30 persons in numbers, made use of this free space. Four people issued feedback and gratitude about the survey and five people stated explicitly that they had nothing to add. Multiple participants pointed out the need for a barrier-free access to healthcare once again. They asked for more understanding both in society and medical personnel. Some commented on the Covid-19 pandemic, for example that it was over soon anyway or that they were against compulsory vaccinations.

Many survey participants used the free space to mention their complaints or wishes to politics. The lack of solidarity and need for financial coverage of sign language interpreters were topics as well as the high unemployment rate among Deaf persons. In general, the need for more political awareness and inclusion were indicated several times. The following table gives an overview about the topics addressed voluntarily at the end of the survey.

Table 13: Something else I want to say

Topics of final survey question (optional): ‘Something else I want to say...’	
Theme	Number of participants who addressed it
Survey feedback	4
Pandemic	4
Nothing more to add	5
Access to healthcare	7
Awareness in politics and society	10

5.3. DISCUSSION

The discussion will contextualise the results of the online survey with the findings of the theoretical part and analyse the answers to the research questions with their consequential implications. The specification of the study’s limitations pave the way for new research possibilities and future perspectives. Recommendations could be established through the combination of already existing literature and the new findings of this survey.

5.3.1. Interpretations

The high participant number, especially from a hard-to-reach-population like the Deaf community, plays an important part in the success and peculiarity of this study. 120 people from three different countries and different occupational backgrounds replied to the online survey. Thus, the answers represent diverse views and depict multifaceted insights. To my knowledge, this is the first research giving insights to the situation of Deaf persons in Austria, Switzerland and Germany during the Covid-19 pandemic with the focus on healthcare.

The discussion is structured according to the research questions, starting with the sub-questions and ending ultimately with the answer to the main research question.

1) Did Deaf persons have more difficulties in the access to healthcare already before the pandemic?

85.3% of the study participants reported that Deaf persons generally have more difficulties in the access to healthcare than people with average hearing. Consequentially, the majority of responders acknowledged more challenges for Deaf persons in healthcare already before the start of the Covid-19 pandemic. Previous literature mainly illustrated specific difficulties Deaf persons face in access to healthcare from a qualitative perspective. Therefore, no direct comparison to the numeric percentage can be done. Namely, the findings of the existing literature can be summed up in the fields of communication, health literacy, higher burden of symptoms and mental health issues. The variety and high number of possible challenges depicted in the already published materials lead to the hypothesis that Deaf people would generally experience more difficulties. One Deaf person may only face one of these issues, but another one may experience all of them and additional ones the literature has not even discussed so far. In this survey, the quantitative results support the hypothesis, answering the research question 'Did Deaf persons have more difficulties in the access to healthcare already before the pandemic?' with a clear yes. Deaf persons perceive their access to healthcare to be more difficult than for the hearing population.

2) Are there significant differences in the perceptions of healthcare between Germany, Switzerland and Austria?

The statistic evaluation did not show any correlation between the perceptions of difficulties and the country where people came from. This is especially interesting, since Germany, Switzerland and Austria have different healthcare systems and services for Deaf people as well. The fact that there are special clinics for the Deaf in Austria could lead to the conclusion that they do not perceive as many challenges as Deaf persons in other countries where this system does not exist. But the study showed that in Austria most participants reported more difficulties as well. First, this could be explained from the location of these clinics, which are only in five Austrian cities and thus do not solve the access problem for people in the countryside. Second, these clinics only offer basic medical services in the function of a general practitioner. For further consultations at specialist doctors or stays in the hospital they still need sign language interpreters like in Germany or Switzerland. Third, the

availability of special clinics for the Deaf could even raise the awareness regarding access to healthcare and lead to more critical answers, whereas in other countries people may even lack that consciousness and do not actively deal with the subject or the claim of their rights.

Although Switzerland is the only country that has a distribution system for sign language interpreters, there is also a lack of available translators and financial coverage issues as reported in the other countries. Generally, the three countries of the study have many features in common. They are all high-income countries within Europe, states under the rule of law and CRPD signatories. Although their approaches of implementation are different, they are all committed to respect the human rights of persons with disabilities in their national legislations. Furthermore, each of these states has a very active national association of the Deaf and a connected Deaf community. These similarities could also be an explanation for the missing correlation of country and reply.

From a global perspective, it is striking that these European countries – at the top of many rankings as well as known for their excellent healthcare systems – have such a high number of Deaf people who perceive challenges in the access to healthcare. This introduces the possible assumption that the situation in countries that overall neither respect the rule of law nor human rights – or that do not have the economic capabilities – is even worse. In this concern, more international comparative studies would be of high interest in the future.

The results of the current survey answered the research question ‘Are there significant differences in the perceptions of healthcare between Germany, Switzerland and Austria?’ clearly with a no. The evaluation of the participants’ replies showed that there were no significant differences in the perceptions of healthcare between members from the Deaf communities from the three distinct countries.

3) Did access to healthcare become more difficult for the Deaf in the Covid-19 pandemic?

The discussion of Deaf people’s human rights in a pandemic is especially important and necessary because the situation is new and unknown. Thus, the topic lacks both experience and research materials. The few available resources are mainly qualitative studies from the US and the UK. Consequentially, the present results from German-speaking areas are outstanding because they represent new regions – such as two member states of the EU – and give quantitative insights as well. The

only comparable study with similar quantitative questions came from the US in April 2020, but it was broader and addressed persons with disabilities of all kinds. Deaf persons were only a small section of the questionnaire responders. Drum and others reported that 44% the total participants said that they experienced more difficulties in the access to healthcare during the pandemic.²⁸³

The results at hand show a far higher number of people who state that the access to healthcare became more difficult. Among Deaf persons in Austria, Switzerland and Germany, 75.7% replied that the access to healthcare became more difficult during the Covid-19 pandemic. Considering that Deaf people already faced many diverse barriers before the pandemic, it seems reasonable that a situation that in itself brings challenges for every person and the whole healthcare system is an additional burden for the Deaf as well. Main issues like the use of face masks and the lack of information available in sign language do not apply to other members of the big group of persons with disabilities. This could be an explanation for the overall lower number of reported difficulties in the study of Drum and others. So far as it is known, there has been no specific quantitative study addressing only Deaf persons and the pandemic.

Especially at the beginning of the Covid-19 pandemic, suddenly the whole healthcare system had to focus on the treatment and containment of the virus. Other important topics like fair and qualitative healthcare for disadvantaged groups faded into the background. Especially in countries that are committed to the fulfilment of human rights, the principles of equality and non-discrimination should have been considered in the crisis response from the beginning on. Looking at the literature, the CRPD calls for reasonable accommodation that would be especially necessary in difficult situations like a pandemic.²⁸⁴

The additional challenges in the access to healthcare were perceived only slightly different in Austria, Switzerland and Germany. In comparison, the percentage of participants from Germany who experienced more difficulties in the pandemic was rather low. Almost 30% of the German responders said that access to healthcare stayed the

²⁸³ CE Drum and others, 'COVID-19 and adults with disabilities: health and health care access online survey summary report' (American Association on Health and Disability 2020).

²⁸⁴ Ilias Bantekas, Michael Ashley Stein and Dimitris Anastasiou, *The UN Convention on the Rights of Persons with Disabilities: A Commentary* (OUP 2018).

same during the pandemic. On the one hand, this could imply that the German government took special measures to not aggravate the negative impacts of the pandemic on the access to healthcare for the Deaf. On the other hand, another interpretation takes into account the perception of healthcare before the pandemic. As the study results show, the majority of responders has already perceived it more difficult before the pandemic. It might be that German survey responders already had many difficulties in the access to healthcare before the Covid-19 virus and now did not feel that the pandemic made a big difference in this concern.

Altogether five participants perceived that the access to healthcare for Deaf people had improved during the pandemic. As previous literature shows, the popularity of telehealth or the increased awareness due to more sign language interpreters at press conferences could be reasons for this positive impact on Deaf health.²⁸⁵ This issue should be paid more attention to in future analyses. Overall, the impact of the pandemic on healthcare perceptions should be addressed in greater detail and compared globally.

4) What were the major challenges in the access to healthcare during the pandemic perceived by Deaf persons?

Face masks

The results of this study go in line with the already existing qualitative data about the challenges that Deaf persons face especially in the pandemic. In accordance with previous findings, the use of face masks was the most reported issue.²⁸⁶ The majority of responders mentioned the masks, and many explained them further as barriers for lip-reading or understanding facial expressions. The frustration about medical staff who are unwilling to make an exception and remove the mask when communicating with Deaf persons was stated frequently as well. The obligatory use of face masks was implemented within the Covid-19 measures of all three states. Accordingly, the problem was reported with similar frequency by responders from the three different countries. The outstanding specification of this issue as the most named major

²⁸⁵ Ariel E Schwartz and others, 'Impact of COVID-19 on services for people with disabilities and chronic health conditions' [2021] *Disability and Health Journal* 101090.

²⁸⁶ Helen Grote and Fizz Izagaren, 'Covid-19: The communication needs of D/deaf healthcare workers and patients are being forgotten' (2020) 369 *BMJ* m2372.

challenge reflects the failure of all three governments to take care of the production or free distribution of transparent face masks and gives a clear indication to do so in the future. One survey participant stated that transparent face masks were available on the private market but too expensive. It shows that some countries and companies in fact countered the challenge and produced them, but the governments need to find a way to make them affordable and accessible for Deaf people in their countries.

Sign language interpreters

The low availability and unclear cost coverage of sign language interpreters are problems that already existed before the pandemic. The fact that they were mentioned multiple times as a response to this question shows not only their importance but also the deterioration of this issue in the time of the crisis. Cost coverage issues might have changed due to budget displacement in the crisis responses or because the bureaucratic units changed their capacities and emphasis to Covid-19 related issues. An interesting difference to the existing literature were the restrictions considering sign language interpreters. In the US and other countries, they were banned as part of the pandemic measures, and thus made the access to medical services even more difficult in that time.²⁸⁷ In the current survey this issue was never mentioned, indicating that Austria, Switzerland and Germany did not have a discriminating legislation in this concern and sign language interpreters could still accompany Deaf persons during the pandemic.

Lack of awareness

Other general barriers in the access to healthcare for the Deaf were perceived in the pandemic. Since the whole healthcare system was suddenly busy dealing with the Corona virus, the needs of Deaf people might have been disregarded even more than before. When personal contacts were restricted in the pandemic, the only way of communicating with most doctors was the telephone. This made Deaf persons even more dependent on hearing friends or relatives and might have also added to their mental health burden. Three participants noted that the

²⁸⁷ Michael McKee, Christa Moran and Philip Zazove, 'Overcoming additional barriers to care for deaf and hard of hearing patients during COVID-19' (2020) 146(9) JAMA Otolaryngology–Head & Neck Surgery 781.

impatience and ignorance of medical staff and the public have increased in the pandemic at the cost of qualitative and respectful treatment of Deaf persons. This goes in line with many studies that show the mental health burden of the Covid-19 pandemic on the general population as well.²⁸⁸ Many people were occupied with fear and unclarity and did not pay additional attention to the needs of Deaf people. The survey responses reflect that this behaviour and lack of awareness increased the frustration of several Deaf persons.

Lack of education

The lack of cultural training and education of medical personnel should be addressed carefully. Multiple survey participants mentioned that doctors and nurses need to be better educated about the Deaf community and even learn basic sign language. This concern applies to the improvement of the healthcare system in general, but is not necessarily causally connected to the Covid-19 pandemic. However, the lack of socio-culturally educated medical staff increased the difficulties for the Deaf in the pandemic. With more awareness and background knowledge, transparent face masks and better means of communication probably would have been used from the beginning on. But discussing causality, this issue does not descend from the pandemic. Quite the contrary, in the time of a public health crisis it seems unrealistic that governments would use this time to educate their medical staff about the Deaf culture and community. They would rather need all means to instruct them about the novelties and changing measures in order to contain the virus. Therefore, this challenge did not arise newly during the pandemic, but is rather a problem rooted already in the past. Medical staff had not received proper education about the dealing with Deaf persons before and thus missed awareness and a more human rights oriented approach to Deaf patients in the pandemic.

Health literacy

An interesting observation considers the topic of health literacy. The fact that it has already been covered in several publications about Deaf health before the pandemic shows that is a well-known issue in the

²⁸⁸ A Kumar and KR Nayar, 'COVID 19 and its mental health consequences' (2021) 30(1) J Ment Health 1.

literature.²⁸⁹ However, in the current responses of the survey participants it only occurred one single time. Of course, this could be justified with the lack of connection to the pandemic. This problem already existed before the virus. Nevertheless, all of the other main healthcare challenges for the Deaf were indicated in this question of the survey multiple times. One consideration is the awareness of Deaf people about their own health literacy. It might be difficult to judge someone's own knowledge about a topic and especially compare it to others. It could also be that the responders of the survey are mainly educated Deaf persons who understand and speak German very well. This high intellectual capacity could also imply an increased health literacy. Therefore, these specific responders maybe did not face this challenge in the time of the pandemic. Only one single person mentioned the lack of health literacy when replying to the questionnaire. This low percentage is different to the comparatively high number of materials found about this topic in the literature from before the pandemic.²⁹⁰ This topic needs more in-depth research and examination in the future.

Information

One of the most reported challenges was the access to information. This difficulty for Deaf persons in the pandemic had already been highlighted in the existing literature.²⁹¹ It is interesting that access to healthcare is so strongly connected to access to information, especially for Deaf persons and in a pandemic with so frequently changing measures. If Deaf people do not receive any information, they are excluded not only from up-to-date knowledge but also from support and clarity. Without knowing what is going on, they are left behind and face discrimination on multiple levels. Access to information and access to healthcare are both human rights that are violated if Deaf persons do not receive it equally to the hearing population. Especially in an emergency like the pandemic with daily changing relevant news, governments should have addressed these challenges and rights from the beginning on. Deaf persons missed

²⁸⁹ Alexa Kuenburg, Paul Fellingner and Johannes Fellingner, 'Health care access among deaf people' (2016) 21(1) *The Journal of Deaf Studies and Deaf Education* 1.

²⁹⁰ Helen Margellos-Anast, Melanie Estarziou and Gary Kaufman, 'Cardiovascular disease knowledge among culturally Deaf patients in Chicago' (2006) 42(3) *Prev Med* 235; Kuenburg, Fellingner and Fellingner *ibid*.

²⁹¹ Nelson Miguel Galindo Neto and others, 'Information about COVID-19 for deaf people: an analysis of Youtube videos in Brazilian sign language' (2021) 74 (Suppl 1) *Rev Bras Enferm* e20200291.

information in sign language or in simple language. One of the main concerns was also the credibility of information. Survey participants said that they faced fake news and did not know if they could trust even the little information they received. Once again this shows the need for clear and classified announcements in sign language by the respective governments.

Since most of the pandemic related information was to be found online, digitalisation was also mentioned as a struggle by some Deaf persons. On the one hand, this is surprising because many Deaf people are dependent on apps and video calling. Generally, they are well acquainted with technical devices and digitisation and make frequent use of modern media and the internet. On the other hand, many survey participants said that they were already in retirement. Some elderly persons are not used to the overwhelming information flood of the internet. They might find it difficult to access and classify it. Without the Covid-19 restrictions, many Deaf persons would meet with their peers in pensioners' clubs. These meetings do not only have a social purpose but are also an opportunity to exchange knowledge and information in sign language. Therefore, some members of the Deaf community who are not acquainted with modern technology lost their most important information source through the social restrictions.

Another issue that was mentioned multiple times was the delay of information. Many persons reported that they received information later than the hearing population. The reason could be the governments' lack of simultaneous sign language interpreting at press conferences. In all three countries it took until around mid-March until interpreting and online information for the Deaf were available. This shows the lack of awareness and prioritisation in politics. In this concern, as in many others mentioned above, the principle of substantive equality was not met in any of the three countries. Moreover, both the right to health and the right to information were violated.

Mental health

The last major challenge many survey participants reported were new mental health issues. This is especially striking, since the literature from before the pandemic already showed that Deaf persons have a higher

mental health burden than the hearing population.²⁹² A situation like the pandemic provokes many psychological challenges. First it is something new and scary without any personal experience. Politicians and the public can feel overwhelmed and be without a clear plan how to handle the situation. Nobody can estimate how the pandemic will continue and how long it will take. Different countries take different strategies and citizens have to trust new legislations. Measures restrict social exchange and change the daily life as people have known it before. Many people also fear for their own life or the health of their relatives. Economic worries and the increasing unemployment rates affected people from all social classes. Furthermore, in order to contain the Covid-19 virus, most people were not allowed to leave their houses anymore. Many experienced loneliness and isolation and reports of anxiety and depression increased throughout the whole population.

In the case of Deaf persons, the burden is especially severe. They did not only have more mental health disorders already before the pandemic but also had to face various new problems as listed above. Next to the fears and economic difficulties, they had to cope with many challenges on different levels. The Covid-19 pandemic allowed for many creative novelties in social life and online services that people could access from home. However, most of them were only addressed at the hearing population and not available in sign language. Particularly because the group of Deaf people is smaller than other social groups, possibilities of exchange and offered services were limited. Multiple survey responders reported feelings of isolation and loneliness. They missed social contact, communication and understanding. Since the higher mental health burden of Deaf persons was already known and discussed in various research materials, the governments should have shown more awareness of this issue throughout the pandemic. They did increase their mental health services but did not think of Deaf persons in this concern. This role had to be taken over by the national associations of the Deaf and in the case of Austria the special clinics for the Deaf. These organisations then provided information and social support. Considering the human rights commitment of Germany, Switzerland and Austria, these services should have been offered from their official side and public institutions as well.

²⁹² Johannes Fellingner and others, 'Psychosoziale Merkmale bei Gehörlosen' (2005) 76(1) *Nervenarzt* 43; Marit Kvam, Mitchell Loeb and Kristian Tambs, 'Mental Health in Deaf Adults: Symptoms of Anxiety and Depression Among Hearing and Deaf Individuals' (2007) 12 *Journal of deaf studies and deaf education* 1.

5) What were the differences in the provided services for Deaf patients between Germany, Switzerland and Austria?

The statistical evaluation showed that there was no correlation between the answer to the question ‘Did your federate state/district/canton offer special healthcare services for Deaf people in the pandemic?’ and the country where people came from. This is an interesting observation, because the three countries reacted differently to the needs of Deaf persons during the pandemic. Each country took care of the rights of Deaf persons at least to some extent or after some time. For example, all three governments added sign language interpreters to their press conferences after the urging advocacy of the respective national associations of the Deaf in mid-March 2020.

In comparison between the three countries, the percentage of participants who reported special services in the pandemic was the highest in Austria. Most of them mentioned the special clinics for the Deaf. On the one hand, these services were already available before the pandemic and not a new implementation of the government. On the other hand, these special clinics played a great role in the access to healthcare and access to information for Deaf people during the pandemic. They have a close connection to many of their patients and responded to health issues and questions via video call or email. Thus, the special clinics offered telehealth and overall were an outstanding and important service for the Deaf during the pandemic.

Other special services by the government were rather limited in Austria and not specified by the survey participants. More than a quarter of the Austrian responders stated that there were no special services at all. Especially in a country that respects the rights of Deaf persons in many other concerns, this percentage is surprisingly high. On the one hand, the well-working special clinics for the Deaf could have been an excuse for the Austrian government to put this role into their hands and not offer special public services themselves. On the other hand, the establishment of these clinics has taken years and is still in progress. Their progress is not pushed by the government, but rather by the national associations of the Deaf and other stakeholders. Moreover, most of these out-patient clinics are connected to hospitals run by a religious order and not subordinate to the state. Therefore, the government should not rely on the special clinics but rather take care of the right to health of Deaf persons independently and additionally to these clinics. Austrian politics should have been more aware of Deaf

health and special accommodation needs throughout the pandemic.

The responses in Switzerland were especially interesting, because 13 of the 19 positive replies gave the same indication of special services that were provided. They all addressed the organised vaccination days for Deaf persons. On the one hand, this result indicates the awareness about this offer. The vaccination days were well advertised and known by Deaf citizens across different Swiss cantons. On the other hand, it shows the lack of additional special services. The few other specifications mentioned information videos available in sign language, online meetings and transparent face masks. It was not the government, but a national association who advocated for the production and use of transparent face masks. One survey participant mentioned not only the fight for these masks but also specified their manufacturing in Switzerland. It is remarkable that the vaccination days have been that well received. They can be seen as a very good example for an initiative that respects and acknowledges the human rights of Deaf persons.

In some regions in Germany these vaccination events existed as well. Three persons mentioned them in their questionnaire replies. However apart from that, the survey participants gave a rather negative image of the German government's Covid-19 policy. More people said that there existed no special services than people who could think of any. Most of them did not know the answer to the question. This also shows the lack of information. There might have been services, but Deaf persons were not sure about details. It is questionable why the special vaccination days took only place in specific regions and not throughout the whole country. The similar offer in Switzerland had a far bigger representation in the answers of survey participants who came from various cantons. In Germany, this was limited to replies from the federate state of Bavaria. A more active and advocating local association of the Deaf or a proactive federate government could be an explanation for this difference. Other services that were mentioned by responders of the German Deaf community were information videos in sign language and online support groups. Considering the fact that Germany is such a big country and committed to the protection of human rights, this comparatively little amount of additional services does not meet the needs of the 80,000 Deaf persons that might be affected by the pandemic in different ways. The government should have taken more action and provision of information about the services they offer, so Deaf persons would know them and make use of them.

Overall, the maximum percentage of persons who perceived special services for the Deaf in the pandemic was 50% in Austria. In Germany, only 16.9% could name any special services. These numbers do not fit the human rights commitment of the analysed countries. Although the Covid-19 pandemic caused many challenges for the healthcare system in general, Deaf people should not have been forgotten. In order to achieve substantive equality they needed special services to be able to access healthcare in the time of the public health crisis. There were some service offers in Austria, Switzerland and Germany, but mainly only in specific regions and thanks to the advocacy and promotion of the national associations of the Deaf. The respective governments have to take more positive actions to ensure qualitative healthcare for the Deaf. They should provide them from the official public side and in the whole country, so they are accessible for every Deaf citizen.

6) Which concrete measures are suggested by Deaf persons to improve the access to healthcare?

The current study demonstrates that Deaf persons can name concrete improvement suggestions concerning the access to healthcare. 74 participants gave unique answers that showed their capacity of reflection as well as creativity, with some of the replies being very detailed. It once more speaks for the inclusion of Deaf people in political strategy planning and decision making. It is not hearing persons who should decide what Deaf people need and how to implement that, but rather the affected community themselves should be listened to. The current survey wants to be part of that inclusion by giving the voice to Deaf persons and hear their perceptions of the pandemic and improvement ideas.

Transparent face masks

The suggested improvements go very much in line with the challenges stated by the participants in the according preceding question of the survey. Again, one of the most frequent mentioned topics were transparent face masks. This issue could be processed by the governments of Austria, Switzerland and Germany very easily. They could either cover the costs of transparent face masks for Deaf persons like they do with the costs of sign language interpreters or provide them for free for example at healthcare facilities. A nationwide distribution of these masks would help Deaf people in their interactions of daily life.

In regards to healthcare, every hospital or medical institution should be equipped with these masks. If the governments consider the extensive acquisition too expensive, they could stock every health facility with a specific amount of transparent face masks that they could use when Deaf persons make use of their services. Furthermore, the more people wear transparent face masks the better the awareness in society could become.

Community services and politics

A further interesting finding are the suggestions considering social services and politics. The question in the survey that asked for improvement measures was specifically framed within the topic of healthcare. However, some participants issued suggestions from different fields that are connected to healthcare. One of them is the availability of online sports courses conveyed in sign language. This improvement could be interpreted as confirming a very broad understanding of health by the participant. Including preventive measures in the frame of healthcare is a smart consideration and could beware many Deaf persons from becoming ill in the first place. Furthermore, the inclusion of political topics in the considerations shows not only the interest of some Deaf persons, but also their willingness to have a say in the decision-making process of governments. Going in line with the recommendation of the Swiss Federation of the Deaf, especially in such a challenging situation like the pandemic, Deaf representatives should be included in the building and evaluation of political strategies.²⁹³

Specific healthcare improvements

Concerning the access to healthcare, Deaf persons could name concrete improvements as well. The education and training of staff was mentioned multiple times. If the clinic personnel could speak basic sign language, at least some direct communication would be possible and improve the physician-patient relationship. One survey participant stated that ‘doctors should know that Deaf patients exist’. This implies that a big part of education concerns the raising of awareness. Some of

²⁹³ Schweizerischer Gehörlosenbund SGB-FSS, ‚Maskenpflicht: Kommunikation mit gehörlosen und hörbehinderten Menschen muss sichergestellt werden!‘ (SGB-FSS, 2020) <<https://sgb-fss.ch/maskenpflicht-rechte-von-gehoerlosen-schuetzen/>> accessed 26 May 2021.

the suggested solutions for better access could be easy to implement. Instead of only arranging appointments via the telephone, options of email and text message should be available as well. For this service employees do not even need sign language skills or special knowledge about the Deaf community. Moreover, this could have been changed very fast, especially in the urgency of a pandemic. Telehealth and apps that support communication in medical settings were indicated multiple times by the participants. Telehealth has already been recommended by previous studies about persons with disabilities.²⁹⁴ Its frequent mentioning by Deaf persons in the survey shows not only openness to new technologies, but also trust in medical care that would work remotely. In a digitalised world this also implies a big research possibility for the future. Deaf people should be included in the development of modern devices so they can be adjusted to their needs and support them in various ways.

Sign language interpreters

Keeping in line with that, many participants issued the need for remote interpreting services in the pandemic. Others raised the problem of cost coverage and the lack of nationwide availability. These concerns should have been faced by the governments already before the pandemic, especially because the legislation in all three countries provides for the principle of non-discrimination. More schools that educate translators should be installed and advertisement and awareness for these jobs should be increased.

Information

The improvement suggestions for access to information are relatively easy to implement as well, but also underline the urgent need for more sign language interpreters. The simultaneous translation of press conferences has already been applied by all three governments. However, an official website with trustworthy and up-to-date information especially for Deaf persons would be needed in Austria, Switzerland and Germany. There it should be indicated that this information comes from the government and where and when it is valid. For elderly persons

²⁹⁴ Dominic Samaila and others, 'Impact of Covid-19 pandemic on people with disabilities and its implications on special education practice in Nigeria' (2020) 5(6) *Int J Innov Sci Res Technol* 803-808.

who are not acquainted with the internet, printed newsletters in simple language or transmission via fax could be a way to inform them. These improvements would lead to equality in the access to information as it is required in the CRPD that all three countries have ratified.

7) To what extent did the Covid-19 policies of Germany, Switzerland and Austria – concerning access to healthcare for the Deaf – comply with human rights?

The main research question can be answered through the combination of the theoretical research findings and the sub-questions answered in the online survey. The legislative landscape of all three countries is committed to human rights. They are not only all CRPD signatories but also have specific laws for persons with disabilities in their domestic legislations. However, already before the pandemic the access to healthcare was more difficult for Deaf persons than the hearing population. This violates the principles of equality and non-discrimination regarding the right to health. The right to information is very interconnected in this concern and also violated when news or other relevant issues are not available in sign language and thus not accessible for everyone. After the advocacy of the national associations of the Deaf, the governments of Austria, Switzerland and Germany provided sign language interpreting at their press conferences and also some information videos in sign language. Furthermore, in Switzerland special vaccination days for Deaf persons were a well perceived innovation. But apart from that, the main work and support for Deaf people in the Covid-19 pandemic was not implemented by the governments but rather by other stakeholders like NGOs or in Austria the special clinics for the Deaf. Despite the fact that all countries are committed to human rights in their legislation, they did not properly think of the needs of Deaf persons in the pandemic. For example, they missed out on the production and distribution of transparent face masks, availability of adjusted and current information or the special mental health support for Deaf people. Therefore, the Covid-19 policies of Germany, Switzerland and Austria did not fully comply with human rights, because the access to healthcare was more difficult for Deaf persons than persons with average hearing. In this concern, the principles of equality and non-discrimination were not respected in the time of the pandemic.

5.3.2. *Limitations*

Several limitations of the conducted survey are rooted in communication issues. The first big limitation is the language used. As already discussed in the methodology, there is not enough research about the literacy skills of Deaf persons in German-speaking areas yet.²⁹⁵ Thus, it is difficult to judge the comprehensibility of the phrasing of the questionnaire. A future study in video format with questions in the respective sign languages could give further insights, reaching an even broader representation of the Deaf population.

A very little amount of written qualitative answers was difficult to understand because it did not follow the German grammar rules. Since sign language works very differently than spoken language, the way Deaf people write sentences can be confusing for a native German speaker. Thus, special care was necessary when reading and interpreting the responses. Around three answers were not understandable at all. Consequentially, this inadequacy evokes the question how well these survey participants had understood the other questions. To counter the unclarity of comprehension, Deaf persons could be involved in the survey design from the beginning on or asked for more direct feedback after each question.

Demographic limitations that are seen in the results are for example the lack of participants of the Western part of Austria. Whereas the national associations of the Deaf in Switzerland and Germany responded and forwarded the survey, the response in Austria was rather low. Thus, this region lacks representation in the survey and should get more attention in future research.

Since the survey was kept as simple and short as possible, demographic factors of the responders like age or gender are missing. These distinctions were not seen as relevant for the purpose of this research focused on the access to healthcare. However, for future studies they could be interesting to give a better understanding of different perceptions and new distinctions.

Another consideration to make more persons fill in the survey was to make all answers voluntarily. None of them was obligatory since the user had the possibility to just click 'continue' and ignore questions.

²⁹⁵ Klaudia Krammer, *Schriftsprachkompetenz gehörloser Erwachsener* (Band 3 edn, Forschungszentrum für Gebärdensprache und Hörgeschädigtenkommunikation 2001).

Some participants made use of this option and therefore not all of the questions were answered in an equal number. However, it also shows which questions were perceived as easy and relevant by the responders and which ones need revision and more reflection for future research settings.

5.3.3. Implications

This study gives the first insights of the perceptions of access to healthcare by Deaf persons in Switzerland, Germany and Austria and therefore provides important new knowledge. Key findings were the quantitative results that clearly showed the difficulties of Deaf persons in the access to healthcare already before the pandemic. Three quarters of the participants stated that the access to healthcare became even more difficult in the Covid-19 pandemic. The qualitative answers showed Deaf persons' interest in the topic and that they can name concrete improvement measures themselves. The governments of the three countries failed in major human rights principles like equality and non-discrimination when they did not provide information in sign language for the vulnerable group from the beginning on. Furthermore, they did not arrange transparent face masks or special mental health services for the Deaf.

Recommendations

Concluding from the survey answers, the following concrete recommendations should be implemented by the governments of Austria, Switzerland and Germany to fully comply with human rights in the access to healthcare for Deaf persons in the pandemic:

- Equip healthcare facilities with transparent face masks nationwide
- Increase the number of sign language interpreters and cover their costs
- Include Deaf persons in political strategy planning and decision-making
- Educate medical staff about the needs of Deaf patients and in basic sign language
- Publish information available in sign language and classify it clearly
- Offer special mental health support for Deaf people

Future research

The current study gives insights into the situation of Deaf persons in three European countries. Future research should provide a more global view and enable the comparison between countries on different continents. Furthermore, it could focus on more demographic details and for example compare the perceptions between Deaf women and men or different age groups. It should also take into account the different sign languages and expand the research of human rights compatibility to other fields than healthcare. Since this study was conducted still during the course of the pandemic, a retrospective analysis could demonstrate a broad and detailed evaluation as well. Personal interviews with Deaf persons could teach even more detailed case studies. Another interesting area of research would be the comparison of measures among each other. It could show if there is a specific hierarchy of needs of Deaf persons or if governments should lay a specific focus or order in their implementation of improvements.

A big future field of research that is not analytical but rather practical is the development of new technologies. Especially in the pandemic, the need for remote healthcare services like telehealth and virtual sign language interpreting became urgent. Apps that match the needs of Deaf persons should be developed together with the affected group. There are already various possibilities in modern technology that could help Deaf persons. Mechanisms that transcribe spoken language or even convert it into sign language would be great ways to improve communication and accessibility. This research area is a promising field where many improvements could happen already within the next years.

6.

WHAT DO WE CARE? – CONCLUSION

This Master's thesis looked at the access to healthcare for Deaf persons with a special focus on the Covid-19 pandemic. The topic is of high relevance because it has not been covered properly in research yet. The Deaf community is an underrepresented minority and considered a hard-to-reach population. As far as it is known, this work is the first research on Deaf health during the pandemic in Austria, Switzerland and Germany. The theoretical framework showed that the rights of persons with disabilities are enshrined in the important CRPD as well as in European human rights documents. Switzerland, Austria and Germany have all ratified the CRPD and accordingly their domestic legislations are committed to the protection of human rights as well.

Nevertheless, Deaf persons face many challenges in the access to healthcare. The main issues are communication barriers, the lack of health literacy and the higher symptom burden. In the Covid-19 pandemic new challenges arose. The use of face masks, not enough information in sign language and additional fears and loneliness made the situation for the Deaf even more difficult. The main distinctions in the access to healthcare were the special clinics for the Deaf in five Austrian cities, a distribution platform of sign language interpreters in Switzerland and a health literacy website provided by the national association for the Deaf in Germany. In the pandemic, it took all countries some weeks and meetings with advocacy groups before they provided information and press conferences in sign language around mid-March. Transparent face masks were implemented in none of the states.

The empirical part of this research was an online survey with quantitative and qualitative questions about the access to healthcare. It is outstanding that altogether 120 participants from Austria, Switzerland and Germany could be acquired, especially since the Deaf community

is a minority and considered a hard-to-reach population. The national associations of the Deaf helped to distribute the questionnaire link in their regions. 85.3% of respondents said that Deaf persons have more difficulties in the access to healthcare than people with average hearing and 75.7% stated that the access to healthcare became even more difficult during the pandemic. No strong correlation could be seen between the answers and the countries participants came from.

The most frequently identified challenge in the pandemic was the use of face masks. Moreover, Deaf persons did not receive enough information in sign language or simple written language. Many healthcare professionals were not aware of the needs of Deaf persons and communication was only available via the telephone. The cumulation of these challenges also led to a higher mental health burden for the Deaf. In the study, they could name concrete improvement measures that go in line with the stated challenges. Transparent face masks, translated information, educated medical staff and more mental health support should be implemented by the governments of Austria, Switzerland and Germany. During the pandemic, healthcare services were not equally accessible for Deaf people. Thus, the states' crisis responses did not comply with the human rights of Deaf persons and the treaties Austria, Switzerland and Germany have ratified.

The conceptional approach of this thesis wanted to expand the medical and social model of disability and look at the access to healthcare from a socio-cultural lens. Respecting the rights of persons with disabilities also means respecting their culture. The case of the Deaf minority is outstanding due to their own language. The fact that most of the discussed challenges are connected to communication demonstrates not only the lack of awareness but also the need for a holistic approach. The socio-cultural model fulfils this broad frame and can be used in healthcare as well. Medical personnel should be educated in the fields of human rights, basic sign language and the needs of Deaf people, even more in a public health emergency like the Covid-19 pandemic. The thesis provided future recommendations that are based on the improvement suggestions of the survey. Governments should equip healthcare facilities with transparent face masks, increase the number of sign language interpreters, include Deaf persons in political strategy planning, educate medical staff about the Deaf community, publish information in sign language and offer special mental health support for Deaf people.

Future research is needed to compare and analyse the situation in other countries, too. Moreover, progress in technological devices and applications could also have a positive impact on Deaf health, thus more research should be done in this concern as well. Since the Deaf community is an underrepresented minority and still faces many barriers, their human rights need special protection and care. Access to healthcare is especially important not only in the pandemic but also because it is connected to multiple other human rights and life quality in general. In the current study, Deaf people named various measures that could be implemented by governments to improve Deaf health and thereby fulfil human rights. This thesis aimed to raise awareness and showed that there are concrete ways to improve the access to healthcare for Deaf people.

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ANNEX I
QUESTIONNAIRE

I.a Questionnaire (in German)

Herzlich willkommen zu unserem Fragebogen über den Zugang zum Gesundheitswesen während der Covid-19 Pandemie! Wir bitten Sie höflich um Ihre Hilfe. Das Ausfüllen wird circa 5 Minuten dauern. Vielen Dank!

1) In welchem Bundesland/Bezirk/Kanton wohnen Sie?

Freiwillige Angabe: Mein Bezug zu diesem Thema/Ich arbeite als...

2) Haben Gehörlose in Ihrem Land mehr Schwierigkeiten beim Zugang zum Gesundheitswesen als Hörende?

- a) Ja, Gehörlose haben größere Schwierigkeiten.
- b) Nein, sie haben die gleichen Schwierigkeiten.
- c) Ich weiß nicht.

3) Wie hat sich der Zugang zum Gesundheitswesen für Gehörlose in der Covid-19 Pandemie verändert?

- a) Der Zugang zum Gesundheitswesen ist für Gehörlose schwieriger geworden.
- b) Der Zugang zum Gesundheitswesen ist für Gehörlose besser geworden.
- c) Der Zugang zum Gesundheitswesen ist für Gehörlose gleich geblieben.

4) Was sind Ihrer Meinung nach die 3 größten Herausforderungen für die Gesundheit Gehörloser in der Covid-19 Pandemie?

5) Gibt es in Ihrem Bundesland/Bezirk/Kanton spezielle Angebote für die Gesundheit Gehörloser während der Pandemie?

- a) Ja, die folgenden: ...
- b) Nein.
- c) Ich weiß nicht.

6) Welche Ideen haben Sie, um den Zugang zum Gesundheitswesen für Gehörlose während der Pandemie zu verbessern?

7) Sonstiges das ich gerne sagen würde:

Die Umfrage ist beendet. Vielen Dank für die Teilnahme.
Das Fenster kann nun geschlossen werden.

I.b Questionnaire (English translation)

Welcome to our questionnaire on access to health care during the Covid-19 pandemic!

We kindly ask for your help.

It will take approximately 5 minutes to complete.

Thank you very much!

1) In which district/federal state/canton do you live?

Optional: My connection to Deaf health/I'm working as...

2) Do Deaf people in your country have more difficulties getting access to health care than people with average hearing?

a) Yes, Deaf people have more difficulties.

b) No, they have the same difficulties.

c) I don't know.

3) In the Covid 19 pandemic, how did the access to health care change for Deaf people?

a) Access to healthcare became more difficult for the Deaf.

b) Access to healthcare improved for the Deaf.

c) Access to healthcare stayed the same as before for the Deaf.

4) What do you think are three major problems/challenges concerning Deaf health and mental health in the Covid19-pandemic?

Please list them in your own words in English.

5) Does your country offer special health care or mental health services for Deaf people in the pandemic?

a) Yes. If yes, which ones:

b) No

c) I don't know.

6) What would be ideas how to improve the health care situation for the Deaf especially in times of the pandemic?

7) Something else I want to say:

The survey is over. Thank you for your participation.

The window can be closed now.

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The present thesis - *Handle with Care. How to Improve Access to Healthcare for Deaf People in a Pandemic* written by **Agnes Heinrici** and supervised by Kalliope Agapiou-Josephides, Aristotelis Constantinides, University of Cyprus - was submitted in partial fulfillment of the requirements for the European Master's Programme in Human Rights and Democratisation (EMA), coordinated by Global Campus Europe.

