EUROPEAN UNION OF THE DEAF

A European Non-Governmental Organisation in official liaison with
European Parliament, European Commission and the Council of Europe

Policy Recommendations on Access to Healthcare for Deaf Persons in the EU

Executive Summary

The European Union of the Deaf (EUD) produced this paper to highlight the main barriers and obstacles that hinder deaf people's highest attainable standard of health. After researching and consulting with EUD member organisations – the National Association of the Deaf (NADs) - EUD identified the origin of such issues in the lack of measures and instruments within four main categories:

1. Accessibility to healthcare information in national sign languages;
2. Awareness of medical practitioners on the cultural and linguistic identity of deaf people;
3. Awareness of medical practitioners on national sign language interpreters, its shortage and lack of funding;
4. Recognition by the EU of EU national sign languages as full languages on an equal footing with spoken languages.

This paper aims to tackle these issues by providing both the legal and policy basis on which the final recommendations are based. The policy recommendations are also based on the input from NADs. Firstly, this paper analyses the legal framework ensuring highest attainable standard of health to the same extent and quality as persons without disabilities. These include the several international and European legal frameworks such as the UN Convention on the Rights of Persons with Disabilities and the Treaty on the Functioning of the European Union. In addition, this paper reviews policy initiatives of several European and international bodies such as the World Health Organization Global Report on health equity for persons with disabilities, the European Health Union, the European Global Health Strategy, the European Disability Strategy 2021 – 2030, as well as others.

Finally, this publication offers concrete guidance to bridge the gap between the living situation of deaf people in healthcare and the existing legislation and policies through evidence-based policy recommendations. Importantly, a human rights-based approach is employed throughout the paper as it is the pivotal perspective to achieve the highest attainable standard of health for deaf people. The achievement of this objective will contribute to the implementation of the EU Disability Rights Strategy 2021-2030 to reach a Union of Equality.

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Accordingly, EUD calls Member States and EU institutions to implement the following recommendations and ensure that:

- **Inclusive national sign language healthcare environments** are put in place in order to ensure full accessibility for deaf people. While in the pursuit of this goal, professional sign language interpretation needs to be ensured to facilitate the communication between healthcare professionals and deaf people;
- **An EU anti-discrimination legal framework** protecting deaf people's access to healthcare services and the use of national sign language in a healthcare context is implemented on the broadest scale possible to ensure equal and non-discriminatory access;
- **Affordable healthcare** is needed so as not financially burdensome for deaf people – this means the provision of free and professional sign language interpretation in all healthcare settings to ensure accessibility of communication and information in healthcare settings and with service providers;
- **deaf-inclusive healthcare policies** - NADs are included in the health-policies legislation and programming making process, starting from the designing process to the monitoring phase;
- **Data collection** - disaggregated data on healthcare access of deaf people, with a focus on deaf women and girls, are collected at the national and EU levels, in collaboration with NADs, for the implementation of improved health policies responding to accessibility requirements for deaf people.

I. Introduction

Access of deaf people to the highest standard of health is a fundamental right enshrined in several international and European legal and political instruments and is crucial to ensuring the physical and mental wellbeing of deaf people. However, persons with disabilities, including deaf people, are often disregarded in the design, planning and implementation of multisectoral public health interventions and therefore do not benefit equally to others[1]. Consequently, there is a continuous issue of systematic disability-based discrimination in healthcare sectors. This is further exacerbated by the EU's lack of recognition of all European national sign languages at EU level despite its ratification of the United Nations Convention on the Rights of Persons with Disabilities (UN CRPD) and recommendations made by the UN Special Rapporteur on the Rights of Persons with Disabilities. Therefore, healthcare practitioners are not familiar and aware of the rights of deaf people to impart information and communicate in the national sign languages[2], as well as the linguistic and cultural identity of deaf people. In addition to this, lies the systemic shortage of professional national sign language interpreters and its lack of funding by the EU and its Member States, further excluding deaf people from participation and involvement in public and political life.

[1]The World Health Organisation, *WHO Global Report on the health equity of persons with disabilities*, 02/12/2022, page 33, URL: https://www.who.int/publications/i/item/9789240063600
[2] Ibid, page 33.

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Consequently, deaf people continue to be deprived of critical information and quality healthcare to which they are entitled. Importantly, national sign languages play a critical role in ensuring deaf persons' optimal mental, physical and social health during their lives.[3] However, the absence of quality and accessible health information, in national sign languages, puts the health of deaf people at risk.

As the only organisation representing the rights of deaf people in the European Union, with this paper, EUD aims to offer a comprehensive explanation on what the highest attainable standard of health means for deaf people, as outlined in Article 25 UN CRPD. Further, it provides concrete, evidence-based policy recommendations for the EU's implementation of this legal provision.

The paper will first make a presentation of the barriers to accessing the highest attainable standard of health for deaf people before outlining the existing legislative corpus at both the international and European levels. Then, it presents existing international and European policies before making a presentation on, based on the legislation and policies, what these should ensure for deaf people in practice with regards to healthcare.

EUD will use this paper as a tool to advocate for equal access for deaf people to the highest attainable standard of health in the EU by disseminating it to policymakers, academics, Organisations of Persons with Disabilities (OPDs), and other relevant stakeholders. EUD will also disseminate this publication to the National Associations of the Deaf (NADs) for them to utilise for the same purpose at the national level.

II. Barriers to the highest attainable standard of health for deaf people

Following a consultation organised with National Associations of the Deaf (NADs) - EUD member organisations – it was reported that deaf people continue to face barriers to accessing healthcare across the EU. The most significant barriers pertain to a lack of accessibility of information and communication and can be grouped into four categories, namely:

1) Lack of accessibility to healthcare information in national sign languages
2) Lack of awareness of medical practitioners on the cultural and linguistic identity of deaf people
3) Lack of awareness by medical practitioners on national sign language interpreters, its shortage and lack of funding
4) Lack of recognition by the EU of EU national sign languages as fully fledged languages on an equal footing with spoken languages.

1. With regards to the first barrier, deaf people often face communication challenges as healthcare staff, including consultants and doctors, do not know their national sign language. Therefore, a national sign language interpreter must be hired for deaf people to receive information in their natural language, which is the absolute precondition to achieve the human right to quality healthcare. This is

[3] World Federation of the Deaf, *Position paper on access to national sign language as a health need*, 21/04/2022, page 1, URL: https://wfdeaf.org/news/resources/position-statement-on-access-to-sign-languages-as-a-health-need/

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an obligation outlined in both Articles 21 and 25 of the United Nations Convention on the Rights of Persons with Disabilities (UN CRPD).

2. Secondly, health practitioners lack awareness of deaf people, their culture and national sign languages and automatically assimilate them as persons with disabilities who need to be fixed. For instance, the Finnish NAD reported this being the case.

Deaf people and their communities present a unique situation compared to other persons with disabilities. In addition to belonging to the disability movement, deaf people also belong to the cultural and linguistic minority movement. Deaf people belong to the disability movement due to the numerous challenges they face in accessing inclusive societies and communities, causing further marginalisation. Yet, deaf people differ from other disability constituencies through the use of their preferred languages, the national sign languages. Conversely, persons with disabilities can benefit from information from their surrounding environment by sharing the common spoken language; deaf people and their communities face additional linguistic barriers.[4]

3. Most healthcare facilities do not automatically provide national sign language interpreters; the funding for this is not covered by national governments or national sign language interpreters are often unavailable due to a systemic shortage despite the existence of national accessibility legislation, as is the case in Spain. The shortage of interpreters brings dire consequences to the health of deaf people. They often miss their medical appointments as their names are only called verbally in the waiting room, causing delay and risk for their health.

Medical staff often offer to communicate using notes in lieu of interpretation which results in imparting less information than with the presence of an interpreter. Deaf people are also encouraged to either book an interpreter with their own fund or to bring family members to interpret for them, placing a considerable responsibility and burden on their families. This goes as far as deaf parents bringing their own children to interpret the psychotherapeutic treatment of their deaf parents and being exposed to their mental health issues and traumas, breaching several ethical practices in the health sector, as reported by our member from Finland. Moreover, as highlighted in a study in Spain, the lack of knowledge of national sign language by mental healthcare professionals leads to misdiagnosis and systematic therapeutic failures when treating deaf patients. This causes a difference of treatment with their hearing counterparts that is discriminatory as it is not of the same quality.

For instance, as with all the other countries EUD consulted in the development of this paper, in Belgium there is a shortage of sign language Interpreters, and, in the limited pool of interpreters, few are specialised in medical settings. There are several associations accompanying deaf people (social workers) who are bilingual and often support deaf people in medical settings by further explaining all the information. Further to this, Belgium reported the issue that there is a lack of clarity of who is responsible for bearing the cost of sign language interpreters in medical settings. It is often expected that deaf people should cover the cost themselves and this is not compliant with the UN CRPD.

[4] World Federation of the Deaf, "Complementary or Diametrically opposed: Situating Deaf Communities within 'disability' vs 'cultural and linguistic minority' constructs – Position paper", August 2019, http://wfdeafnew.wpenginepowered.com/wp-content/uploads/2019/09/LM-and-D-Discussion-Paper-FINAL-included-IS-7-August-2019.pdf

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4. The European Union is yet to recognise the 31 European national sign languages as full EU languages. The 1958 European Economic Community's Council Regulation No 1 recognises 24 spoken languages as EU official languages[5]. Yet, no mentions are made of the 31 national sign languages co-existing in the European Union, bringing the consequences that the provision, promotion, and development of national sign languages are overlooked in public policies by both the EU and its Member States.

The EU as a State Party to the UN CRPD, is obliged to ensure the recognition of all 31 national sign languages, on an equal footing with its spoken languages, at EU level. However, this is not yet the case, and deaf people are marginalized in their fundamental rights to use of their national sign languages in all areas of life, including in accessing healthcare, within the European Union. Importantly, this lack of legal recognition of national sign languages had been highlighted by the UN Special Rapporteur on Disability, Mr Gerard Quinn, in his report on the implementation of the UN CRPD by the EU, who underlined that "*obvious issues of law reform, like the granting of official European Union language status to sign language (which already has official status in all the member States) ought to be contemplated and put on the agenda for change*" [6].

III. Legal and policy grounds

The right of deaf people to the highest attainable standard of health is legally and politically enshrined in several international and European legal instruments and policies. The purpose of this section is to compile and list these legislations and policies to equip the reader with understandable concepts to ensure deaf people benefit from the highest attainable standard of health. Before being a matter of public policies, this right is a matter of fundamental human rights that the EU and its Member States must implement.

1) International legal framework

Firstly, the 1948 **Universal Declaration of Human Rights (UDHR),** in its article 25, recognises that everyone, including deaf people, has the right to a standard of living adequate for the health and well-being of themselves and their families. This non-binding fundamental provision has been transposed into several legally binding instruments. For the relevance of this paper, we will only keep two: the International Covenant on Economic, Social and Cultural Rights and the Convention on the Rights of Persons with Disabilities.

Article 12 of the **International Covenant on Economic, Social and Cultural Rights (ICESCR)** obliges its State Parties to recognise the right of everyone to the enjoyment of the highest attainable

[5] European Economic Community CouncilEC, Regulation 1958R0001, p.385, October 6th 1958, https://eur-lex.europa.eu/LexUriServ/LexUriServ.do?uri=CONSLEG:1958R0001:20130701:EN:PDF

[6] UN Human Rights Council, Report A/HRC/52/32/ - Visit to the European Union Report of the Special Rapporteur on the rights of persons with disabilities, Gerard Quinn", Point 12, 27 February – 31 March 2023, https://www.edf-feph.org/content/uploads/2023/02/UNSR-Report-on-visit-to-Europe.pdf

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standard of physical and mental health. Yet, many persons with disabilities, including deaf people, have been left out in the application of international human rights treaties. To bridge this gap, the UN General Assembly adopted the **United Nations Convention on the Rights of Persons with Disabilities (UN CRPD)** in 2006, with the European Union ratifying the Convention on 23 December 2010, making it the first regional organisation to be a State Party to the UN CRPD and to be bound by an international human rights treaty[7]. By becoming a State Party to the UN CRPD, the EU must implement the CRPD into its legislative corpus.

2) The Convention on the Rights of Persons with Disabilities

The right of deaf people to the highest attainable standard of health is found in article 25 UN CRPD to be read in conjunction with article 5 UN CRPD.

1. Equality and non-discrimination

Article 5.2 UN CRPD establishes the principle of Equality and Non-Discrimination and forbids any discrimination on the basis of disability. Discrimination on the basis of disability is defined in article 2 of the Convention as *any distinction, exclusion or restriction on the basis of disability which has the purpose or effect of impairing or nullifying the recognition, enjoyment or exercise, on an equal basis with others, of all human rights (…). It includes all forms of discrimination, including denial of reasonable accommodations"*.[8] In essence, it is the deprivation of persons with disabilities, including deaf people, to the enjoyment of their human rights simply because they have a disability. The crucial and innovative concept here is that the denial of reasonable accommodation constitutes discrimination on the basis of disability.

Article 5.3 UN CRPD recognises the obligation of States Parties to the Convention to provide measures of reasonable accommodation to persons with disabilities.

The concept of reasonable accommodation is defined in the same article 2 as the necessary and appropriate measures not imposing disproportionate burdens to ensure persons with disabilities can enjoy and exercise their human rights and fundamental freedoms. For deaf people, reasonable accommodation often takes the form of professional and accredited national sign language interpreters. Therefore, the denial of funding of professional and accredited national language interpreters for deaf people constitutes a discrimination on the basis of disability in light of Article 5 UN CRPD.

For deaf people, some examples of discrimination on the basis of disability in healthcare include:

[7] EDF, "10th anniversary of the CRPD in the EU and 10 reasons why we still need the Convention", January 2021, https://www.edf-feph.org/10th-year-anniversary-of-the-crpd-in-the-eu-and-10-reasons-why-we-still-need-the-convention/

[8] Convention on the Rights of Persons with Disabilities, Article 2 - Definitions, September 2006, https://www.ohchr.org/en/instruments-mechanisms/instruments/convention-rights-persons-disabilities#:~:text=%22Discrimination%20on%20the%20basis%20of,freedoms%20in%20the%20political%2C%20economic

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- The lack of funding for professional national sign language interpreters. For instance, in Germany the legislation safeguarding accessibility in hospitals is a federal law. Yet, there are more than 100 different health insurances with varying coverage, which make it complicated to fund German sign language interpreters. There is also a shortage of national sign language interpreters in Romania and Finland.
- In a doctor's or hospital waiting room, vocally calling deaf patients by their names instead of physically calling them in person, causing deaf patients to miss their appointments, as it was reported by our members from Spain and Romania.
- Imposing the presence of a family-member to ensure interpretation and communication.
- Booking appointments only through phone calls without any alternatives provided such as email, SMS or online appointment. Indeed, the Spanish NAD reported having experience and reports that medical practitioners always contact deaf people through phone calls without suggesting any alternatives such as emails or SMS.
- Imposing a treatment without their full and informed consent.
- Approaching deaf people with a purely medical approach without any considerations for their linguistic and cultural identity.
- Consultation with deaf patients taking place with the same format as for hearing people without considering their linguistic and communicational requirements. For instance, the Spanish NAD reported that, in Spain, medical consultations are short and quick without considering the cultural requirements of deaf people of having longer and more elaborated explanations.

2. ***Accessibility***

This requirement is also highlighted in article 9.2(e) UN CRPD, which recognises that States Parties to the Convention must take appropriate measures to provide professional sign language interpretation services to facilitate accessibility for deaf people. The use of "professional sign language interpreters" as stated in article 9.2(e) has been interpreted to mean *sign language interpreters who are properly trained with the participation of their deaf community, certified according to a neutral certification mechanism where deaf people are represented, and are compensated accordingly to their professional status.*[9]

A best practice example of ensuring accessibility for deaf people in the healthcare sector can be found in Sweden, where it has a partnership with different hospitals which have dedicated iPads allowing deaf people to call VRI (video remote interpreting) services in situations of emergencies at the hospital in addition to the existing accessibility features to booking medical appointments in Swedish Sign Language. This model should be mainstreamed within the EU.

3. ***Access to the highest attainable standard of health***

Article 25 UN CRPD specifically focuses on the access of persons with disabilities, including deaf people, to healthcare. More specifically, this provision recognises the right of deaf people to

[9] World Federation of the Deaf, "Statement on the right of deaf people to equal treatment in the context of the Global Covid-19 Pandemic", January 2022, https://wfdeafnew.wpenginepowered.com/wp-content/uploads/2022/01/Statement-on-the-right-of-deaf-people-to-equal-treatment-in-the-context-of-the-Global-Covid-19-pandemic-ENGLISH-Version.pdf

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the enjoyment of the highest attainable standard of health without discrimination on the basis of their disability. This article grants deaf people the right to the same range of quality and affordable healthcare as provided to hearing people including in the area of sexual and reproductive health (25(a) UNCRPD). It also grants the right to early detection and prevention to minimize and prevent further disabilities, including among children and older people (point (b)). Further, it recognises the rights of deaf people to have health services as close as possible to their communities, including in rural areas (point (c)) and healthcare professionals must provide care of the same quality to deaf people as to others including on the basis of free and informed consent through awareness raising and training (point (d)). Ultimately, this provision prohibits discrimination against deaf people on the ground of their disabilities in the provision of healthcare and life insurances (point (e)) In essence, it prevents discriminatory denial of health care or health services on the basis of disability (point (f)).

Deaf people encounter multiple and intersecting forms of discrimination. This increases the risks for deaf people to receive incomplete healthcare, especially for age-sensitive and gender-responsive needs[10]. For instance, persons with disabilities in the EU - especially women and girls - are still widely impacted by gender inequalities when accessing healthcare on reproductive rights, including a lack of access to screening for cancer, and forced sterilisation. Evidence of this has been provided in a recent study on the access to healthcare of deaf women in Spain: 41% of women do not feel adequately attended to on women related health issues (such as menopause, period pain, breast lumps, etc.) due to the inability of healthcare professionals to understand the national sign language[11]. Furthermore, a stigmatised approach is often applied to persons with disabilities concerning specific measures for sexual and reproductive healthcare needs, indeed, "*people with disabilities are often incorrectly considered not to be sexually active and may not receive education and care within this field*".[12]

4. ***Freedom of expression and opinion and access to information***

Additionally, Article 21(b) UN CRPD on Freedom of Expression and Opinion, and Access to Information, which obliges States Parties to facilitate the use of sign languages, including through the medium of professional and accredited national languages interpreters or translators, in official interactions with deaf people[13]. This means that States Parties to the Convention have the legal obligation to provide public information, including regarding healthcare, to deaf people through their national sign languages, including in times of crises. The Covid-19 pandemic provided an excellent illustration whereby the European Union and its Member States had to provide lifesaving Covid-19 related information during press conferences with the provision of professional national sign language interpreters.

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[10] The World Health Organisation, *WHO Global Report on the health equity of persons with disabilities*, 02/12/2022, page 115, URL: https://www.who.int/publications/i/item/9789240063600

[11] Fundación ONCE, "Encuesta Sobre Salud Integral y Mujeres Sordas", 2021

[12] Shakespeare, Bright, & Kuper, *"Access to health for persons with disabilities",* OHCHR, 2018, URL: https://www.ohchr.org/Documents/Issues/Disability/StandardHealth/BackgroundDoc_EGM_Righttohealth.docx

[13] World Federation of the Deaf, *Statement on the right of deaf people to equal treatment in the context of the Global Covid-19 pandemic*, 21/01/2022, page 2, URL: https://wfdeaf.org/news/resources/statement-on-the-right-of-deaf-people-to-equal-treatment-in-the-context-of-the-global-covid-19-pandemic-english-version-2/

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In addition, article 21(e) recognises that States Parties to the Convention must recognise and promote the use of sign languages. This means that, as the EU is a State Party to the Convention, it must recognises its 31 EU national sign languages through a legal instrument. To date, the 27 EU Member States have recognised their national sign languages through national legal instruments. It hasn't been achieved at the Regional level through the EU yet.

5. ***Involvement of persons with disabilities through their representative organisations***

Article 4.3 UN CRPD obliges States Parties to closely and meaningfully consult with Organisations of Persons with Disabilities (OPDs) for any legislation, policies or programmes concerning them. This legal obligation is further expanded in the General Comment 7 of the UN Committee on the Rights of Persons with Disabilities (CRPD Committee – insert link). To be in line with the Principle of the Disability Movement "nothing about us without us", all consultations must take place regularly, from the outset of the initiative to its conclusion and must be meaningful; the perspective of persons with disabilities but be taken into account; and these consultations must be made accessible. In the present situation, it means that national governments, health agencies, and healthcare facilities must consult with National Associations of the Deaf whereby these meetings must be accessible through the provision of professional and accredited national sign language interpreters.

2) European Legal Framework

The European legal basis to any initiative related to public health can be found in Article 168 of the ***Treaty on the Functioning of the European Union*** (TFEU). Public health is a competence shared between the European Union and its Member States. While Member States define and deliver their national health services and medical care, the EU seeks to complement national policies by means of its Global Health Strategy[14].

This provision must be read in conjunction with Article 10 (non-discrimination)[15], Article 114 (single market)[16] and Article 153 (social policy)[17] of the same Treaty. The purposes of European public health policies are to protect and improve the health of EU citizens; supporting the modernisation and digitalisation of health systems and infrastructure; improving the resilience of Europe's health

[14] European Commission, *EU4Health Programme*, URL: https://health.ec.europa.eu/funding/eu4health-programme-2021-2027-vision-healthier-european-union_en#:~:text=EU4Health%20works%20together%20with%20other,%E2%80%A2%E2%80%A2%20for%20health%20research

[15] The Treaty of the Functioning of the European Union, *Article 10*, 25/03/1957, page 7, URL: https://eur-lex.europa.eu/LexUriServ/LexUriServ.do?uri=CELEX:12012E/TXT:en:PDF

[16] Treaty on the Functioning of the European Union, Article 114, October 2012, https://eur-lex.europa.eu/LexUriServ/LexUriServ.do?uri=CELEX:12012E/TXT:en:PDF

[17] Treaty on the Functioning of the European Union, Article 153, October 2012, https://eur-lex.europa.eu/LexUriServ/LexUriServ.do?uri=CELEX:12012E/TXT:en:PDF

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systems; and equipping EU countries to better prevent and address future pandemics[18]. The overall objective is to reach the freedom of movement of people and goods in the internal market by removing barriers to accessing healthcare.

Furthermore, Article 35 of the **EU Charter for Fundamental Rights** recognises the rights of EU citizens to access to preventive health care and to benefit from medical treatments in any EU member state*"*[19].

In terms of healthcare emergencies, there has been a lack of access to emergency services for deaf people in the EU. The EU emergency number 112 did not provide accessible features for deaf people such as SMS or video. However, in December 2022, the European Commission adopted a delegated regulation (non-legislative) supplementing the existing **Directive 2018/1972**[20], which includes a direct reference to persons with disabilities. It calls on Member States to establish "*requirements to ensure common understanding of equivalent access for users with disabilities."*[21] This amendment aims to ensure that emergency communications for persons with disabilities (alternative solutions to calls, e.g. real time text, SMS, etc.) become as effective in accessing emergency services to that of emergency voice calls. However, it remains to be seen whether this will be implemented successfully and consistently across Member States. For instance, Romania has the 113-emergency number which utilises SMS. Yet, most deaf people are not proficient in Romanian written language. They write Romanian following the Romanian Sign Language grammar which makes it difficult for emergency responders to understand the situation, causing a negative impact on the first response services for deaf people. In this way, the possibility to contact emergency responders in Romanian Sign Language should be put in place. Further, in Finland, the emergency service 112 number is only accessible in Finnish Sign Language from 8:00 to 16:00, leaving deaf people behind in situations of emergencies outside the opening hours. This is an example of a half measure, whereas deaf people have the right, under the UN CRPD, to have access to emergency services at all hours.

Equal access to healthcare for deaf people in the EU remains a significant issue. By ratifying the UN CRPD, the European Union took the responsibility before international law to safeguard the equal access of persons with disabilities in all areas of society, including the access of deaf people in healthcare. Despite this legal obligation, the EU does not have a comprehensive anti-discrimination legislation protecting persons with disabilities in accessing healthcare. An attempted legislative aimed to bridge that gap in 2008 through an anti-discrimination directive. This directive has been blocked by

[18] Christian Kurrer, "Public Health", *Fact Sheets on the European Union*, December 2022, https://www.europarl.europa.eu/factsheets/en/sheet/49/public-health

[19] The European Union Charter of Fundamental Rights, *Article 35 – Healthcare*, URL: https://fra.europa.eu/en/eu-charter/article/35-health-care

[20] Commission Delegated Regulation (EU) 2023/444 of 16 December 2022 supplementing Directive (EU) 2018/1972 of the European Parliament and of the Council with measures to ensure effective access to emergency services through emergency communications to the single European emergency number '112', URL: https://eur-lex.europa.eu/legal-content/EN/ALL/?uri=uriserv:OJ.L_.2023.065.01.0001.01.ENG

[21] European Commission, 112: EU Emergency Number, URL: https://digital-strategy.ec.europa.eu/en/policies/112

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the Council since 2008[22]. The absence of an EU legally binding framework on non-discrimination leaves the responsibility of tackling the issue of discrimination of persons with disabilities in healthcare access to the political will of EU Member States. The lack of harmonised legislation protecting persons with disabilities, including deaf people, is causing difference of treatment within Member States and creating further barriers to the freedom of movement of persons with disabilities within the EU, in addition to breaching the UN CRPD. What's more, Member States may lack the resources and awareness to ensure inclusive policies on healthcare access for persons with disabilities, including deaf people[23].

3) International and European policy frameworks

This section will present the existing relevant policies and strategies covering the right of deaf people to the highest attainable standard of health. These policies complement the above-mentioned legal framework. They include the recently released World Health Organization's (WHO) Framework for Action to achieve the highest attainable standard of health for persons with disabilities[24] (based on resolution WHA74.8[25]); the WHO's Global Report on health equity for persons with disabilities[26]; the 2030 Agenda for Sustainable Development[27]; the European Global Health Strategy[28]; the European

[22] Proposal for a Council Directive on implementing the principle of equal treatment between persons irrespective of religion or belief, disability, age or sexual orientation {SEC(2008) 2180} {SEC(2008) 2181} COM/2008/0426 final - CNS 2008/0140, URL: https://eur-lex.europa.eu/legal-content/en/ALL/?uri=CELEX%3A52008PC0426

[23] Waddington Lisa, "*Prohibition of Disability Discrimination with regard to Healthcare in the European Union",* May 2021, URL: https://cris.maastrichtuniversity.nl/en/publications/prohibition-of-disability-discrimination-with-regard-to-healthcar

[24] The World Health Organisation, The WHO European framework for action to achieve the highest attainable standard of health for persons with disabilities 2022–2030, September 2022, Tel Aviv, Israel, URL: https://apps.who.int/iris/bitstream/handle/10665/360966/72wd07e-Disabilities-220523.pdf?sequence=2&isAllowed=y

[25] 74th World Health Assembly, Agenda Item 26.4 on Resolution WHA74.8 on the Highest Attainable Standards of Health for Persons with Disabilities, 31/05/2021, URL: https://apps.who.int/gb/ebwha/pdf_files/WHA74/A74_R8-en.pdf

[26] The World Health Organisation, WHO Global Report on the health equity of persons with disabilities - Case study: sign language training in Kenya, 02/12/2022, URL: https://www.who.int/publications/i/item/9789240063600

[27] United Nations, The Sustainable Development Agenda, *Sustainable Development Goals*, URL: https://sdgs.un.org/goals

[28] European Commission, *EU Global Health Strategy to improve global health security and deliver better health for all*, November 2022, URL: https://ec.europa.eu/commission/presscorner/detail/en/ip_22_7153

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Disability Strategy 2021 - 2030[29]; and the European Pillar of Social Rights[30] with its corresponding Action Plan.[31]

The **WHO resolution WHA74.8 on the highest attainable standard of health for persons with disabilities** emphasises that - "*accessible health facilities, accessible health-related information and disability specific health services and solutions are essential for persons with disabilities to benefit equally from health education, promotion, prevention, treatment and rehabilitation; and stressing further that technological solutions could be an effective means to enhance accessibility"*[32]*.* The resolution also stresses the need for *disability-sensitive, quality, basic and continued education and training of health professionals to ensure they can provide safe, quality, accessible and inclusive health services.*[33] To fulfil this resolution in the EU, the WHO published, in August 2022, a European Framework for Action to achieve the highest attainable standard of health for persons with disabilities 2022-2030. This Framework for Action provides concrete actions to pave the way for achieving disability-inclusive healthcare in the EU.

As a result of this resolution and its corresponding Framework for Action, the **WHO Global report on health equity for persons with disabilities was published** in December 2022. It provides a comprehensive guideline to provide equity for persons with disabilities in accessing healthcare by implementing Article 25 UN CRPD on health. The report calls its Member States, which includes all EU countries, to take actions to advance health equity for persons with disabilities, including deaf people. "*The lack of interpretation services for one-on-one consultations and wider public health information campaigns affects the deaf community uniquely."*[34]. In its recommendations, the report highlights a case study from Kenya on the obligation for training of healthcare providers - "*Today, basic sign language is a required competency for all health-care workers in Kenya, with a training module embedded into health-care training at colleges and universities."*[35] In total, the report offers 40

[29] European Commission, *EU Strategy for the Rights of Persons with Disabilities 2021-2030*, URL: https://ec.europa.eu/info/law/better-regulation/have-your-say/initiatives/12603-Strategie-en-faveur-des-droits-des-personnes-handicapees-pour-la-periode-2021-2030_fr

[30] European Commission, *The European Pillar of Social Rights*, URL: https://commission.europa.eu/strategy-and-policy/priorities-2019-2024/economy-works-people/jobs-growth-and-investment/european-pillar-social-rights/european-pillar-social-rights-20-principles_en

[31] European Commission, The European Pillar of Social Rights Action Plan, URL: https://op.europa.eu/webpub/empl/european-pillar-of-social-rights/en/

[32] 74th World Health Assembly, Agenda Item 26.4 on Resolution WHA74.8 on the Highest Attainable Standards of Health for Persons with Disabilities, 31/05/2021, page 3, URL: https://apps.who.int/gb/ebwha/pdf_files/WHA74/A74_R8-en.pdf

[33] 74th World Health Assembly, *Agenda Item 26.4 on Resolution WHA74.8 on the Highest Attainable Standards of Health for Persons with Disabilities*, 31/05/2021, page 3, URL: https://apps.who.int/gb/ebwha/pdf_files/WHA74/A74_R8-en.pdf

[34] The World Health Organisation, *WHO Global Report on the health equity of persons with disabilities*, 02/12/2022, page 115, URL: https://www.who.int/publications/i/item/9789240063600

[35] The World Health Organisation, WHO Global Report on the health equity of persons with disabilities - Case study: sign language training in Kenya, 02/12/2022, page 219, URL: https://www.who.int/publications/i/item/9789240063600

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targeted and comprehensive actions that countries can adopt to strengthen their health systems and reduce inequities for persons with disabilities.

Furthermore, the **UN 2030 Agenda for Sustainable Development,** in its goal 3, aims to achieve the goal of universal health coverage.[36]

With regards to the EU's policy commitments aiming to support the implementation of its commitments under the UN CRPD, particularly article 25 on health, it launched its **EU Global Health Strategy** in 2022 to tackle health inequalities on a wide scale[37].

The **EU Strategy for the Rights of Persons with Disabilities 2021-2030** includes a commitment to assess and ensure cross-border, high-quality healthcare for persons with disabilities, in line with the UN CRPD. The same commitment is stated in Principle 16 on healthcare of the **European Pillar of Social Rights**.[38] In support of this, the EU Pillar of Social Rights Action Plan includes a section titled "Promoting Health and Ensuring Care" which outlines several actions that the EU Commission has committed to undertake, for instance to *propose new tools to better measure barriers and gaps in access to healthcare.*[39] Further, in this section of the Action Plan, the Commission encourages Member States to take action in certain ways, for example for Member States to *invest in health and care workforce, improving their working conditions and access to training.*[40]

IV. Access to the highest attainable standard of health for deaf people in the EU

According to the International and European legal and policy frameworks, deaf people have the fundamental human right to access the highest attainable standard of health, without discrimination on the basis of their disabilities, equally with their hearing counterparts. The highest attainable standard of health for deaf people is achieved through sign language inclusive health environments where deaf people can access healthcare in their national sign language. The access to health in the national sign language can be achieved both through the provision of professional national sign language interpreters or through medical practitioners fluent in the national sign language. Furthermore, the 112-emergency service must be accessible to all deaf people at all times, including in times of crises, in the European Union in their national sign languages and requiring no additional costs.

Additionally, all public health information and communication must always be accessible to deaf people through their national sign language at all times - including in times of crises. This access in

[36] United Nations, *UN Sustainable Development Goals*, URL: https://sdgs.un.org/goals
[37] European Commission, *EU Global Health Strategy to improve global health security and deliver better health for all*, November 2022, URL: https://ec.europa.eu/commission/presscorner/detail/en/ip_22_7153
[38] European Commission, *The European Pillar of Social Rights*, *Principle 16 – Health Care*, URL: https://commission.europa.eu/strategy-and-policy/priorities-2019-2024/economy-works-people/jobs-growth-and-investment/european-pillar-social-rights/european-pillar-social-rights-20-principles_en
[39] European Commission, The European Pillar of Social Rights Action Plan, URL: https://op.europa.eu/webpub/empl/european-pillar-of-social-rights/en/
[40] Ibid.

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the national sign language must imply no additional costs for deaf people. Furthermore, medical practitioners have a tailored approach when consulting deaf people, taking into account their specific cultural and linguistic identity and requirements.

V. Promoting inclusive healthcare environments through the national sign language

Article 4.2 UN CRPD highlights that its implementation should be undertaken progressively. The ultimate objective of the Convention is to provide a European society fully accessible to deaf people through national sign languages. In the health sector, this means that health care practitioners must be fluent in the national sign language to be able to directly interact with deaf people in their preferred language. Yet, while the implementation of full accessibility is taking time, measures of reasonable accommodations must be provided temporarily.

Consequently, professional national sign language interpreters must be provided whilst health care practitioners are not fully fluent in their national sign languages. In the meantime, basic national sign language can be taught to the practitioners to communicate with deaf patients. The basic knowledge of the national sign language is sufficient for communication of relative importance, such as booking an appointment, indicating the name of the doctor or the consultation room etc. However, when crucial information about health must be communicated, fluent use of the national sign language is required either through professional national sign language interpreters or through practitioners fluent in the national sign languages.

VI. Policy Recommendations

Within this section, EUD aims to provide concrete recommendations to tackle the challenges faced by deaf people when accessing healthcare in the EU. The present recommendations also aim bridge the gap between existing policies and legislation at both the international and EU levels and the current situation deaf people are facing today. Such recommendations also aim to guide the European Union and its Member States in achieving the human right of deaf people to the highest attainable standard of health.

This section intends to deliver guidance to decision makers and to ensure their implementation in the promotion of deaf people's right of access to healthcare. Regarding the areas of improvement in terms of the access to healthcare for deaf people, EUD identified 5 areas including inclusive national sign language healthcare environment; equality and non-discrimination; affordability; deaf-inclusive healthcare policies; and data collection.

A. Inclusive national sign language healthcare environment where deaf people can impart healthcare information and interact with healthcare practitioners in their national sign language should become mainstreamed to achieve the highest attainable standard of health for deaf people. Having healthcare professionals fluent in the national sign languages constitutes accessibility for deaf people. Therefore, the hiring of deaf medical professionals is the ultimate course of action to fulfil this. However, until such situation is achieved, sign language interpreters must be used as reasonable

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accommodation. In order to achieve this, the healthcare sector must undergo a deaf-awareness learning process. This means that the training of healthcare professionals of national sign languages and on deaf awareness must be developed by national healthcare sectors in close cooperation with National Associations of the Deaf-and mainstreamed across the EU. Similarly, complete accessibility of emergency services means that such services need to be provided in national sign language at all times.

In view of these aspects, EUD recommends that EU Member States:

- **Design national sign language training for healthcare practitioners with a focus on medical lexicon and terminology;**
- **Bring awareness to medical practitioners on the communication requirements of deaf people as well as their linguistic and cultural identity;**
- **Train professional national sign language interpreters to interpret in medical settings;**
- **Include national sign language courses within medical and paramedical schools at universities.**
- **Ensure the provision of virtual remote interpretation (VRI) services when interpreters are not able to be physically present during an appointment.**
- **Implement accessible 112 emergency services in the national sign language available 24/7.**

B. Equality and non-discrimination – The refusal of using national sign languages and the denial of funding professional national sign language interpreters in healthcare environment constitutes, respectively, a denial of accessibility and a denial of reasonable accommodation. Both situations constitute a discrimination on the basis of disability. This principle of non-discrimination must be protected by comprehensive legal frameworks at the national and EU levels.

In view of these aspects, EUD recommends that the EU and its Member States:

- **Adopt an anti-discrimination legal framework protecting deaf people from any discrimination on the basis of disability and the use of their national sign language, including in healthcare settings;**
- **The legislation must provide comprehensive definitions of discrimination on the basis of disability, reasonable accommodation and accessibility;**
- **Put in place reporting mechanisms in the national sign language when discrimination in healthcare arises;**
- **Establish accessible feedback mechanisms to ensure that people with disabilities, including deaf people, can provide their experience of certain healthcare services.**
- **The EU to adopt a regulation recognising the EU national sign languages as fully fledged EU languages and protecting its users in line with the Regulation 1958R0001 determining the languages of the European Union;**

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C. Affordability of healthcare should be an essential element of healthcare for deaf people. Full access to healthcare should not produce further cost for deaf people and, as such, should be covered by any health insurances within the EU or funded by EU Member States.

In view of these aspects, EUD recommends that EU Member States:

- **Foresee a concrete budget to fund professional national sign language interpreters in medical settings, in line with Article 9.2 UN CRPD;**
- **Harmonise their national insurance plan to cover the cost of accessibility of deaf people to access the highest attainable standard of health.**

D. Deaf-inclusive healthcare policies must be designed in close cooperation with National Associations of the Deaf to make sure all upcoming policies, legislation and programmes safeguard the human right of deaf people to the highest attainable standard of health.

In view of these aspects, EUD recommends that EU Members States:

- **Meaningfully engage with their National Associations of the Deaf when designing and implementing these policies, legislation or programmes in line with Article 4.3 UN CRPD;**
- **Provide the required reasonable accommodations to ensure such meeting are accessible;**
- **Ensure the meaningful involvement of their National Association of the Deaf from the outset to the conclusion of the policy design and implementation process.**

E. Data collection – To best design policies to reach national sign language inclusive healthcare environments it is crucial to have quality and reliable data on deaf people. Data disaggregated by disability and gender constitute an essential precondition for the elaboration of equitable and effective health policies. The use of the Washington Group set of questions is regarded to have harmonised data.

In view of these aspects, EUD recommends that EU Member States:

- **Implement data collection disaggregated by disability and gender in healthcare settings by using the Washington Group set of questions, in line with Article 31 UN CRPD;**
- **Involve NADs in the collection of data on healthcare through the elaboration of surveys and questionnaires addressed to the deaf community in the national sign language;**
- **Collect shared data on accessible services providers and healthcare systems for deaf people across the different Member States**

VII. Conclusion

By ratifying the UN CRPD, the EU and its Members States committed to safeguard the highest attainable standard of health for deaf people. This can only be achieved through a national sign

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language inclusive healthcare environment where deaf people can access all health care related information, communication and services in their national sign language. This objective is in line with the obligations of the UN Convention on the Rights of Persons with Disabilities, as well as the commitments of the EU Disability Rights Strategy, and the EU Pillar of Social Rights to achieve a Union of Equality.

However, the path to achieve this goal is long and the obstacles are numerous.

Although the EU has made several commitments to improving the access to healthcare for persons with disabilities through certain disability-based initiatives, the only health specific commitments are made under the EU Global Health Strategy. This is not only not legally binding but also it is not based on the healthcare access specifically of persons with disabilities. What's more, this approach addresses the healthcare access of deaf people only though a disability lens without any consideration for their linguistic and cultural identity. Information and communication in their national sign language is not only a means of accessibility for deaf people, but this also respects and promotes the use of their preferred languages - their national sign languages. National sign languages are not always perceived as fully fledged languages, that are on an equal footing to spoken languages, by the EU and its Member States.

In this way, binding legislation are required to achieve the right of deaf people to the highest attainable standard of health. Without such, the in-practice reality for deaf persons points to a lack of accessible, quality and affordable healthcare across the EU. Ensuring barrier-free access to healthcare for deaf persons requires a concerted effort from all stakeholders at EU and national level.

This paper highlighted the gap between existing policies and legislations safeguarding the right of deaf people to the highest attainable standard of health and its actual implementation. Quality and inclusive healthcare is yet to be a reality for deaf people in the EU. The EUD provided several recommendations to policymakers to bridge that gap in making national sign languages inclusive healthcare environments a reality for deaf people in the European Union. This will constitute the first necessary step towards achieving a Union of Equality.

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