# Round table I. Access to information, health care and banking services for persons with disabilities

## Ad hoc Committee on the Rights of People with Disabilities (CAHDPH), 6<sup>th</sup> Plenary Session Strasbourg, 28 September 2017

Access to health care for persons with disabilities

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### Good morning.

I would like to thank the Chairman of the Ad Hoc Committee on the Rights of People with Disabilities and the distinguished members of the Committee for this opportunity to share some reflections on "Access to health care for persons with disabilities."

I also would like to thank the Head of the Rights of Persons with Disabilities Unit for her kind invitation to participate in this round table.

Before getting into the issue of my presentation, let me highlight only some features of accessibility as articulated in the Convention on the Rights of Persons with Disabilities (the CRPD).

In the UN website dedicated to the Convention you can read: "Accessibility is about giving equal access to everyone. Without being able to access the facilities and services found in the community, persons with disabilities will never be fully included."<sup>1</sup>

This description captures the most important aspect of accessibility, which in the disability-specific instruments such as the UN Standard Rules on the Equalization of Opportunity for Persons with Disabilities (1993),<sup>2</sup> has always been considered as a key factor for social inclusion and full participation of disabled people in all aspects of life.<sup>3</sup>

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<sup>&</sup>lt;sup>1</sup> http://www.un.org/esa/socdev/enable/disacc.htm (accessed 20 August 2017).

<sup>&</sup>lt;sup>2</sup> Adopted by the UN General Assembly with resolution 48/96, annex, of 20 December 1993. The Standard Rules identify "accessibility" of the physical environment and of information and communication as two "target areas" to ensure equalization of opportunities (Rule 5. Accessibility). They also consider accessibility as a means and a goal of disability-inclusive development and recommend access to rehabilitation services for disabled people.

<sup>&</sup>lt;sup>3</sup> See also the World Programme of Action Concerning Disabled Persons adopted by the United Nations General Assembly, thirty-seventh session, Resolution 37/52 of 3 December 1982. See, *Yearbook of the UN*, 1982, pp. 980-984.

This feature has been further enhanced in the CRPD. In the Preamble, States Parties have recognized the importance of accessibility in many fields, **including health**, in enabling persons with disabilities to fully enjoy all human rights and fundamental freedoms (para. v). Accessibility is then one of the underlying core principles of the Convention listed in Article 3,<sup>4</sup> is included among the general obligations under Article 4,<sup>5</sup> and is regulated in Article 9, which provides a comprehensive provision on accessibility.

However, it should be noted that accessibility plays a key role throughout the Convention. References can be found in several provisions,<sup>6</sup> **including Article 25 on the right to health**, confirming that accessibility complements every human right set forth in the CRPD.<sup>7</sup>

The Convention neither in Article 9 nor elsewhere provides a definition of accessibility, but Article 9 addresses accessibility in all its complexity, encompassing the physical environment, transportation, ICT, and services. In addition, it considers accessibility as a precondition for persons with disabilities to live independently, participate fully and equally in society, and have unrestricted enjoyment of all their human rights and fundamental freedoms on an equal basis with others.<sup>8</sup>

It should be noted that accessibility is not new in the framework of international human rights law. Article 9 of the Convention is rooted in existing core human rights treaties containing provisions on the right to access to places and services, including **health care services**.<sup>9</sup>

The World Programme considered accessibility an essential means to further its goals of "full participation" and "equalization of opportunities", including in the field of health services.

<sup>&</sup>lt;sup>4</sup> Thailand originally suggested this principle, which was later also supported by Japan (see Schulze, p. 31).

<sup>&</sup>lt;sup>5</sup> States Parties are required to provide accessible information to persons with disabilities about mobility aids, devices and assistive technologies, including new technologies, as well as other forms of assistance, support services and facilities (Article 4, para. 1, letter h). In addition, States have the duty to undertake or promote research and development of universally designed goods, services, equipment and facilities, as defined in article 2 of the Convention, which should require the minimum possible adaptation and the least cost to meet the specific needs of a person with disabilities, to promote their availability and use, and to promote universal design in the development of standards and guidelines.

<sup>&</sup>lt;sup>6</sup> See Article 13 for access to justice, Article 19 with regard to living independently and being included in the community, Article 21 for access to information and communication services, Article 24 with regard to inclusive education, Article 27 on the accessibility of work environment, Article 28 concerning access to social protection, Article 29 for the participation in political and social life, Article 30 on access to cultural life, recreation, leisure and sport, Article 31 with regard to the accessibility of data and statistics, Article 32 on the accessibility of international cooperation programs and of scientific and technical knowledge, and Article 49 concerning the accessible format of the Convention.

<sup>&</sup>lt;sup>7</sup> Accessibility is included in the articles of general application (i.e. Articles 1-9), which are intended to be applied generally to the rest of the Convention (see, among others, Janet E. Lord, cit., p. 13).

<sup>&</sup>lt;sup>8</sup> General comment No. 2 (2014) Article 9: Accessibility, CRPD/C/GC/2, 22 May 2014, para. 14.

<sup>&</sup>lt;sup>9</sup> See Article 25 (c) of the International Covenant on Civil and Political Rights on the right to equal access to public service, and Article 5 (f) of the International Convention on the Elimination of All Forms of Racial Discrimination (CERD) on the right of access to any place or service intended for public use. The Convention on the Elimination of All Forms of Discrimination against Women (CEDAW) likewise refers to accessibility in a variety of contexts, *including health care* (Articles 10, 12, 14), while the Convention on the Right of the Child recognizes the right of mentally or physically disabled child *to have access* to education, training, *health care services*, rehabilitation services and others (Article 23, para. 3).

According to the CRPD Committee, these provisions have contributed to affirm the **right to access as a right per se** and to incorporate this right into international human rights law.<sup>10</sup> In the framework of the CRPD, therefore, "accessibility should be viewed as a disability-specific reaffirmation of the social aspect of the right of access" and the "the right to access for persons with disabilities must be ensured through strict implementation of accessibility standards."<sup>11</sup>

Academic experts have also highlighted the close link between accessibility and the principles of equality and non-discrimination.<sup>12</sup> The CRPD Committee in the General Comment No. 2 (2014) has clarified that the "d<u>enial of access should be considered to constitute a discriminatory act, regardless of whether the perpetrator is a public or private entity"</u> and that "Accessibility should be provided to all persons with disabilities, regardless of the type of impairment, and without distinction of any kind."<sup>13</sup>

The Committee has also stressed that States' obligation to provide accessibility is an essential part of the duty to respect, protect and fulfil equality rights and is closely linked with the obligation to provide reasonable accommodation, as defined in Article 2 of the CRPD.<sup>14</sup> In this regard, it is important to underline that while accessibility refers to groups, reasonable accommodation refers to individuals.<sup>15</sup> So, reasonable accommodation can be used as a means of ensuring accessibility for an individual with a disability a particular situation.

In relation to accessibility obligations, the Committee has further clarified that "States parties are not allowed to use austerity measures as an excuse to avoid ensuring gradual accessibility for persons with disabilities. **The obligation to implement accessibility is** *unconditional*, that is the entity obliged to provide accessibility may not excuse the omission to do so by referring to the burden of providing access for persons with disabilities."<sup>16</sup>

<sup>&</sup>lt;sup>10</sup> See General Comment No. 2 (2014), CRPD/C/GC/2, 22 May 2014, paragraphs 2-4. See also CESCR, General Comment No. 5 on persons with disabilities, in which it is affirmed "The right to physical and mental health also implies the right to have access to, and to benefit from, those medical and social services - including orthopaedic devices - which enable persons with disabilities to become independent, prevent further disabilities and support their social integration.32 Similarly, such persons should be provided with rehabilitation services which would enable them "to reach and sustain their optimum level of independence and functioning" (para. 34), E/1995/22, 9 December 1994.

<sup>&</sup>lt;sup>11</sup> Ibid., para. 4 and para. 14.

<sup>&</sup>lt;sup>12</sup> See F. Seatzu, Article 9 (Accessibiliy), in the Convention on the Rights of Persons with Disabilities. A Commentary, edited by V. Della Fina, R. Cera, G. Palmisano, Springer, 2017.

<sup>&</sup>lt;sup>13</sup> See General Comment No. 2 (2014), CRPD/C/GC/2, 22 May 2014, para. 13.

<sup>&</sup>lt;sup>14</sup> "Reasonable accommodation" means necessary and appropriate modification and adjustments not imposing a disproportionate or undue burden, where needed in a particular case, to ensure to persons with disabilities the enjoyment or exercise on an equal basis with others of all human rights and fundamental freedoms" (Article 2).

<sup>&</sup>lt;sup>15</sup> In this respect, the CRPD Committee has pointed out that "the duty to provide accessibility is an *ex ante* duty. States parties therefore have the obligation to provide accessibility before receiving an individual request to enter or use a place or service [...] The duty to provide reasonable accommodation is an *ex nunc* duty, which means that it is enforceable from the moment an individual with an impairment needs it in a given situation in order to enjoy her or his rights on an equal basis in a particular context." See General Comment No. 2 (2014), CRPD/C/GC/2, 22 May 2014, paragraphs 25 and 26. <sup>16</sup> Ibid, para. 25. Undue burden is defined by national legislation, in general means a burden that is unreasonable in the circumstances having regard to, inter alia, the cost and nature of the adjustments, the size and structure of the business,

Broadly speaking, these are the main features of accessibility that need to be taken into account also in the field of health care.

It should be also recalled that disability-specific regional instruments adopted in the wake of the CRPD refer to accessibility in the same terms of the Convention. This is especially true for the "European Disability Strategy 2010-2020"<sup>17</sup> and for the "Council of Europe Strategy on the Rights of Persons with Disabilities 2017-2023" - entitled "Human Rights: A Reality for All"- that includes accessibility among its five priority areas and expressly refers to Article 9 of the CRPD (para. 55).<sup>18</sup>

### Access to health care for people with disabilities: a) the international normative framework

Turning to the subject of access to health care for people with disabilities, it should be first noted that neither the CRPD nor the other core international human rights treaties contain a definition of the term "health care."<sup>19</sup> However, both in the literature and practice on the right to health, three levels of health care are usually distinguished, namely: **primary**,<sup>20</sup> **secondary**,<sup>21</sup> and **tertiary health care**.<sup>22</sup>

the scope of its operations, the number of employees, the make-up of the workforce, and the existence of external or state funding for the purpose of carrying out adjustments.

<sup>&</sup>lt;sup>17</sup> Accessibility is one of the eight areas of action of the Strategy. Under the Strategy 2010-2020, the EU undertakes to support and supplement national activities for implementing accessibility, removing existing barriers, and improving the availability and choice of assistive technologies. In 2008, the Commission proposed the "European Accessibility Act" to develop specific standards improving the proper functioning of the internal market in relation to accessible products and services (http://ec.europa.eu/smart-

regulation/impact/planned\_ia/docs/2012\_just\_025\_european\_accessibiliy\_act\_en.pdf. Accessed March 4, 2015). As of September 2017, the Act was not yet adopted.

<sup>&</sup>lt;sup>18</sup> The Strategy points out that accessibility is a broad concept that encompasses accessibility of products and services, is connected to all the provisions of the CRPD and therefore needs to be seen from the perspective of equality and non-discrimination, covering both the public and private sector. On this basis, the Strategy considers "accessibility an enabler for persons with disabilities in all areas of life" (para. 56). Even outside Europe, accessibility plays a key role in most of the disability-specific regional instruments and is considered a tool to allow the full participation, equality and empowerment of people with disabilities. In this regard, it is worth recalling the Arab Decade of Disabled Persons 2003-2012, the Program of Action for the Decade of the Americas for the Rights and Dignity of Persons with Disabilities 2006-2016 (Accessibility, together with health, was among the 9 fields of actions to guide Member States towards more inclusive societies) and the second African Decade of Persons with Disabilities 2010-2019.

<sup>&</sup>lt;sup>19</sup> The Explanatory Report to the Convention on Human Rights and Biomedicine, for the scope of Article 3 (on equal access to health care), specifies that "Health care" means "the services offering diagnostic, preventive, therapeutic and rehabilitative interventions, designed to maintain or improve a person's state of health or alleviate a person's suffering. This care must be of a fitting standard in the light of scientific progress and be subject to a continuous quality assessment." See the Explanatory Report to the Convention on Human Rights and Biomedicine, para. 23. https://rm.coe.int/16800ccde5. Accessed 2 September 2017.

<sup>&</sup>lt;sup>20</sup> "Primary health care is essential health care based on practical, scientifically sound and socially acceptable methods and technology made universally accessible to individuals and families in the community through their full participation and at a cost that the community and country can afford to maintain at every stage of their development in the spirit of self-reliance and self-determination. It forms an integral part both of the country's health system, of which it is the central function and main focus, and of the overall social and economic development of the community" (see Declaration of Alma-Ata on Primary Health Care, September 1978).

<sup>&</sup>lt;sup>21</sup> It is provided usually in hospitals, and typically deals with relatively common minor or serious illnesses that cannot be managed at community level, using specialty-trained health professionals and doctors, special equipment and sometimes inpatient care at comparatively higher cost.

<sup>&</sup>lt;sup>22</sup> It is provided in relatively few centres, typically deals with small numbers of minor or serious illnesses requiring specialty-trained health professionals and doctors and special equipment, and is often relatively expensive is provided in

These levels vary depending on the severity of the illness and the degree of specialization of the required medical treatment and equipment, which affect of course the costs of the health services. At domestic level, forms of primary, secondary and tertiary health care frequently overlap and interact; therefore, in relation to the normative framework in this field we consider all the three levels to be included in health care.<sup>23</sup>

Access to health care for persons with disabilities is considered an integral component of the right to health, as enunciated in the UN Standard Rules (**Rule 2. Medical care**) and in **Article 25 of the CRPD**.<sup>24</sup> Persons with disabilities are indeed more exposed to comorbidities associated with their disability, resulting in greater need for health care.

It is known that historically disability has been considered itself a health issue to be treated only through a medical approach. With the shift away from the "medical model" of disability (which interpreted disability as a "health problem") towards a "social" or "human rights-based model", a more holistic perspective on disability and a more accurate understanding of its role as a health determinant have been adopted.<sup>25</sup> The human rights-based approach to disability upholds the right of disabled persons to enjoy all human rights on an equal basis with others, including equal access to health care. The CRPD Committee has in fact recommended States Parties to "apply a human rights-based approach to disability in the provision of health services to persons with disabilities."<sup>26</sup>

The disability community has worked hard to move disability out of the medical framework and to redefine disabilities as functional limitations, occurring as a natural part of human diversity and requiring an adjustment of the social, physical and legal environments to accommodate them. By focusing on the barriers to participation of people with disabilities in society and the effects of these barriers on access to health, it has become clear that disabled people may enjoy their human right to health mainly through access to health care without discrimination on the basis of disability.<sup>27</sup>

relatively few centres, typically deals with small numbers of minor or serious illnesses requiring specialty-trained health professionals and doctors and special equipment, and is often relatively expensive.

<sup>&</sup>lt;sup>23</sup> See CESCR, General Comment No. 14, 'The right to the highest attainable standard of health' (Art. 12) (Twentysecond session, 2000), para. 13, footnote no. 9

<sup>&</sup>lt;sup>24</sup> See also Article 6 of the UN Declaration on the Rights of Disabled Persons of 1975, GA Res. 3447 (XXX), which states that "Disabled persons have the right to medical, psychological and functional treatment..."; the UN Standard Rules affirm that persons with disabilities have the right to "provision of the same level of medical care within the same system as other persons." See also the World Programme of Action concerning Disabled Persons, paragraphs 95-107.

<sup>&</sup>lt;sup>25</sup> Under the International Classification of Functioning, Disability and Health (known as ICF) - adopted by the WHO in 2001- the notions of "health" and "disability" have acquired a new meaning as this classification acknowledges that every person can experience a decrement in health and thereby experience disability. This latter is not viewed as an individual's intrinsic feature but as an interaction between the features of the person and the characteristics of the overall context in which the person lives. http://www.who.int/classifications/icf/en/.

<sup>&</sup>lt;sup>26</sup> Concluding observations on the initial report of Cyprus, CRPD/C/CYP/CO/1, 8 May 2017, para. 52.

<sup>&</sup>lt;sup>27</sup> Frieden L (2005) *The Right to Health: Fundamental Concepts and the American Disability Experience*. National Council on Disability, https://www.ncd.gov/rawmedia\_repository/5cef6559\_d74d\_43e3\_99fc\_de935f36d9b6.pdf: Accessed 2 September 2017.

Discrimination in the context of access to healthcare can take a number of forms. A report published by the EU Agency for Fundamental Rights (FRA) has grouped discrimination in health care into six categories, which are the following: delay of treatment; refusal of treatment; lack of dignity and stereotyping; malpractice and poor quality of care; lack of informed consent; and harassment.<sup>28</sup>

Moreover, the World Health Organization (WHO) has identified a range of barriers that people with disabilities encounter when they attempt to access health care, which include the following: a) prohibitive costs of health services and transportation;<sup>29</sup> b) limited availability of services; c) physical barriers related to design of health facilities, medical equipment or transport;<sup>30</sup> d) inadequate skills and knowledge of health workers;<sup>31</sup> e) informational barriers and communication difficulties, including inadequate information for disabled persons about their right to access health care services.<sup>32</sup> With a view to eliminating these barriers, in 2013 the WHO adopted **the Global Disability Action Plan 2014-2021** whose first goal is to remove barriers and improve access to health care

programmes and services to meet the rights of persons with disabilities as set out in Articles 9 and 25 of the CRPD.<sup>33</sup>

This Plan brings accessibility to the heart of the provision of health care to disabled persons in conformity with the General Comment No. 2 (2014) of the CRPD Committee. In the General Comment the Committee has pointed out that health care would remain unattainable for disabled persons without the physical accessibility of the premises where those services are provided and without accessible transportation to travel to the places where the services are provided. In addition, all information and communication pertaining to the provision of health care should be accessible through sign language, Braille, accessible electronic formats, alternative script, and augmentative and alternative modes, means and formats of communication. The Committee has also emphasized that it

<sup>&</sup>lt;sup>28</sup> European Union Agency for Fundamental Rights (FRA), *Inequalities and multiple discrimination in access to and quality of healthcare*, 2013, p. 63.

<sup>&</sup>lt;sup>29</sup> Affordability of health services and transportation are two main reasons why people with disabilities do not receive needed health care in low-income countries (32-33% of non-disabled people are unable to afford health care compared to 51-53% of people with disabilities).

<sup>&</sup>lt;sup>30</sup> Uneven access to buildings (hospitals, health centres), inaccessible medical equipment (for example, women with mobility difficulties are often unable to access breast and cervical cancer screening because examination tables are not height-adjustable), poor signage, narrow doorways, internal steps, inadequate bathroom facilities, and inaccessible parking areas create barriers to health care facilities.

<sup>&</sup>lt;sup>31</sup> People with disabilities are more than twice as likely to report finding health care provider skills inadequate to meet their needs, four times more likely to report being treated badly and nearly three times more likely to report being denied care.

<sup>&</sup>lt;sup>32</sup> http://www.who.int/mediacentre/factsheets/fs352/en/. WHO Global Disability Action Plan 2014-2012, para. 28.

<sup>&</sup>lt;sup>33</sup> The Plan identifies a set of actions for Objective 1 and proposes inputs for Member States, the Secretariat and international and national partners (see WHO Global Disability Action Plan 2014-2012, pp. 10-13, http://www.who.int/disabilities/actionplan/en/).

is especially important to take into account the gender dimension of accessibility when providing health care, particularly reproductive health care for women and girls with disabilities.<sup>34</sup>

The relevance of accessibility in guaranteeing the right to health was especially underlined by the UN Committee on Economic, Social and Cultural Rights (CESCR) in the General Comment No. 14 adopted in 2000.<sup>35</sup> In identifying the <u>four interrelated and essential elements</u> of the right to health, which are **availability**,<sup>36</sup> **accessibility**, **acceptability**,<sup>37</sup> and **quality**,<sup>38</sup> the UN Committee has outlined that accessibility has <u>four overlapping dimensions</u>. These are:

1. *non-discrimination*: health facilities, goods and services must be accessible to all, especially the most vulnerable or marginalized sections of the population, in law and in fact, without discrimination on any of the prohibited grounds, including disability.

2. *physical accessibility*: health facilities, goods and services must be within safe physical reach for all sections of the population, especially vulnerable or marginalized groups, including disabled people. Accessibility further includes adequate access to buildings for persons with disabilities.

3. *economic accessibility or affordability*: health facilities, goods and services must be affordable for all. Payment for health-care services has to be based on the principle of equity, ensuring that these services, whether privately or publicly provided, are affordable for all, including socially disadvantaged groups.

4. *information accessibility:* accessibility includes the right to seek, receive and impart information and ideas concerning health issues. However, accessibility of information should not impair the right to have personal health data treated with confidentiality (this right is protected under Article 22 of the CRPD).

These elements, that make express reference to disabled people, may apply *mutatis mutandis* to the right to health under Article 25 of the CRPD.<sup>39</sup>

<sup>&</sup>lt;sup>34</sup> GC No. 2(2014), CRPD/C/GC/2, para. 40. During negotiations on draft Article 21 some delegations proposed the deletion of the words "including sexual and reproductive health services" but there was broad support for retaining it. The Ad Hoc Committee noted that this phrase was not intended to alter or prejudice the general policies of governments in regard to family planning or related matters, to the extent that these were permitted by national legislation of general application. The phrase was a statement on the right to be free from non-discrimination, and its effect was that persons with disabilities would need to be treated on an equal basis with others in this area (See sixth session). However, some States Parties issued interpretative declarations concerning the meaning of the term, see I. Pavone, *Article 25 (Health)*, in the *Convention on the Rights of Persons with Disabilities. A Commentary*, edited by V. Della Fina, R. Cera, G. Palmisano, Springer, 2017

<sup>&</sup>lt;sup>35</sup> CESCR, General Comment No. 14, 'The right to the highest attainable standard of health' (Art. 12) (Twenty-second session, 2000), U.N. Doc. E/C.12/2000/4 (2000).

<sup>&</sup>lt;sup>36</sup> Public health care facilities, goods and services, as well as programs, have to be available in sufficient quantity within the State Party.

<sup>&</sup>lt;sup>37</sup> All health facilities, goods and services must be respectful of medical ethics and culturally appropriate as well as sensitive to gender and life-cycle requirements.

<sup>&</sup>lt;sup>38</sup> Health facilities, goods and services must be scientifically and medically appropriate and of good quality.

<sup>&</sup>lt;sup>39</sup> The right to health as a fundamental human right has been recognized for the first time at the international level in the World Health Organization (WHO) Constitution of 1946 which established that "The enjoyment of the highest attainable

It is worth recalling that they are also at the heart of the "Universal health coverage", which is one of the targets of Sustainable Development Goal no. 3 focused on health,<sup>40</sup> whose realization has been recommended by the CRPD Committee in several Concluding observations.<sup>41</sup>

Accessibility requirements complement Article 25 of the CRPD that establishes specific obligations on access to health care with the aim of guaranteeing to disabled persons the "enjoyment of the highest attainable standard of health without discrimination on the basis of disability."<sup>42</sup>

Under Article 25, non-discrimination and equality are critical components of the right to health. This provision, read in conjunction with Articles 3, 4 and 5 of the Convention, further strengthens the protection of disabled people against all forms of discrimination based on disability, requiring that not only the public health sector but also private providers of health services and facilities comply with the non-discrimination obligations under the Convention.<sup>43</sup>

With the specific aim of guaranteeing the right to health without discrimination based on disability,

Article 25 provides that States Parties take all appropriate measures to **ensure access for persons with disabilities to health services** that are gender-sensitive,<sup>44</sup> including health-related rehabilitation.<sup>45</sup>

The provision lists a set of measures aimed at ensuring that persons with disabilities have access to and benefit from those medical and social services they need specifically because of their disabilities. These measures concern early identification and intervention, services designed to

standard of health is one of the fundamental rights of every human being without distinction of race, religion, political belief, economic or social condition" (Preamble). Subsequently this right was enshrined in Article 25, para. 1, of the Universal Declaration of Human Rights of 1948, which states that "Everyone has the right to a standard of living adequate for the health and well-being of himself and of his family, including food, clothing, housing and medical care and necessary social services, and the right to security in the event of unemployment, sickness, disability, widowhood, old age or other lack of livelihood in circumstances beyond his control."

<sup>&</sup>lt;sup>40</sup> In the 2030 Agenda for Sustainable Development, UN Member States have committed themselves to "achieve universal health coverage and access to quality health care," and to "ensuring universal access to sexual and reproductive health-care services, including for family planning, information and education" (para. 26). UN General Assembly Resolution 70/1 "Transforming our world: the 2030 Agenda for Sustainable Development" adopted on 25 September 2015. See also the Report of the UN Special Rapporteur on the right of everyone to the enjoyment of the highest attainable standard of physical and mental health, UN Doc. A/71/304, 5 August 2016.

<sup>&</sup>lt;sup>41</sup> See, among the others, the Concluding observations on the initial report of Cyprus, CRPD/C/CYP/CO/1, 8 May 2017, para. 52.

 $<sup>^{42}</sup>$  The notion of "the highest attainable standard of health" has been clarified by the Committee on Economic, Social and Cultural Rights (CESCR) in the General Comment No. 14 (2014) on Article 12 of the Covenant. The Committee made clear that "it takes into account both the individual's biological and socio-economic preconditions and a State's available resources. Good health cannot be ensured by a State, nor can States provide protection against every possible cause of human ill health. Consequently, the right to health must be understood as a *right to the enjoyment of a variety of facilities*, *goods, services and conditions* necessary for the realization of the highest attainable standard of health" (para. 9).

<sup>&</sup>lt;sup>43</sup> See CESCR, General Comment No. 14: The Right to the Highest Attainable Standard of Health (Art. 12), para. 26; CESCR General Comment No. 5: Persons with Disabilities, para. 34.

<sup>&</sup>lt;sup>44</sup> See Article 6 of the CRPD devoted to "Women with disabilities" who are subject to multiple discrimination.

<sup>&</sup>lt;sup>45</sup> Rehabilitation is regulated in Article 26 of the CRPD, see I. Pavone, *Article 26 [Habilitation and Rehabilitation]* in V. Della Fina et al. (eds.), *The United Nations Convention on the Rights of Persons with Disabilities*, DOI 10.1007/978-3-319-43790-3\_30.

minimize and prevent further disabilities, and rehabilitation services, which enable disabled people to become independent and support their social integration.

Similarly, under Article 25 States must provide health services and centres as close as possible to people's own communities, including in rural areas. Furthermore, the application of nondiscrimination principle requires that disabled persons be provided with "the same range, quality and standard of free or affordable health care and programmes as provided to other persons", including in the area of sexual and reproductive health<sup>46</sup> and population-based public health programmes. Health professionals must as well provide care of the same quality to persons with disabilities as to others, including on the basis of free and informed consent, by, *inter alia*, raising awareness of the human rights, dignity, autonomy and needs of disabled people through training and ethical standards (both in public and private health care). Even health or life insurance must be provided without discrimination, where it is permitted by national law.<sup>47</sup>

The CRPD Committee has clarified the contents of Article 25 in several Concluding observations, recommending States Parties take measures to ensure that disabled women have access to accessible medical services and facilities,<sup>48</sup> "to adopt measures to ensure that health-care services, including all mental-health-care services, are based on the informed consent of the person concerned,"<sup>49</sup> and to repeal "laws permitting involuntary treatment and confinement, including upon the authorization of third party decision-makers such as family members or guardians."<sup>50</sup>

In the General Comment No. 1 (2014), the CRPD Committee has further clarified that States parties have an obligation to require all health and medical professionals (including psychiatric professionals) to obtain the free and informed consent of disabled persons prior to any treatment.<sup>51</sup>

<sup>&</sup>lt;sup>46</sup> In 2003, the UN Commission on Human Rights established that: "sexual and reproductive health are integral elements of the right of everyone to the enjoyment of the highest attainable standard of physical and mental health" (Commission on Human Rights Resolution 2003/28). This position was reaffirmed in 2004 (Commission on Human Rights Resolution 2004/27).

<sup>&</sup>lt;sup>47</sup> Under Article 25, States are also required to "prevent discriminatory denial of health care or health services or food or fluids on the basis of disability." This could be of particular concern, for instance, in the case of a disabled person whom is denied an organ for transplantation due to his/her condition of disability. It also regards end of life issues, such as the right to refuse a medical treatment in severe health conditions, such as those affecting a person in permanent vegetative state (PVS).

<sup>&</sup>lt;sup>48</sup> See, among the others, the Concluding observations on the initial report of the Republic of Moldova, CRPD/C/MDA/CO/1, 18 May 2017, para. 46.

<sup>&</sup>lt;sup>49</sup> Concluding Observations on Spain, CRPD/C/ESP/CO/1, 19 October 2011, para. 36.

<sup>&</sup>lt;sup>50</sup> Concluding observations on the initial report of China, CRPD/C/CHN/CO/1, 15 October 2012, para. 23.

<sup>&</sup>lt;sup>51</sup> The Committee has in particular stressed that in conjunction with the right to legal capacity guaranteed by Article 12, States parties have an obligation not to permit substitute decision-makers to provide consent on behalf of people with disabilities and all health and medical personnel should ensure appropriate consultation that directly engages the person with disabilities (para. 41). See para. 41. Australia and Norway made interpretative declarations on Article 25 when they ratified the CRPD. The Australian declaration states "Australia [...] declares its understanding that the Convention allows for compulsory assistance or treatment of persons, including measures taken for the treatment of mental disability, where such treatment is necessary, as a last resort and subject to safeguards." The Norwegian declaration affirms that "Norway declares its understanding that the Convention allows for compulsory care or treatment of persons, including measures to

In addition, in the Views adopted in the case *Mr. X v. Argentina* concerning a disabled person with severe health problems detained in prison, the Committee has clarified that the State party is under an obligation to adopt appropriate measures to ensure that "**persons with disabilities who have been deprived of their liberty have access to medical and rehabilitation treatments so that they may enjoy the highest attainable standard of health without discrimination**" (para. 9).<sup>52</sup>

## b) The Council of Europe normative framework

After having outlined the international normative framework on access to health care for disabled people, we will explore the protection of this right at regional level with particular regard to the human rights instruments of the Council of Europe and the case law of the European Court of Human Rights (the Court).

The European Convention on Human Rights protects a number of civil and political rights, but it does not protect the right to health and access to health care. Despite this shortcoming, issues concerning the protection of these rights have been raised before the Court mainly in relation to Article 2 (right to life), Article 3 (prohibition of torture, inhuman or degrading treatment or punishment) and Article 8 (right to respect for private and family life).

Given the short time available to me, I will mention only some relevant case law.

With reference to the **jurisprudence on Article 2**, the Court ruled that this provision encompasses positive obligations on States to provide medical facilities and services. In particular, in some case law the Court held that under Article 2 the State might be under an obligation to provide health care measures where there is evidence of a causal link between the applicants' death and the shortcomings in the medical care system.<sup>53</sup> For example, in the case *Panaitescu v. Romania*<sup>54</sup> concerning a cancersick person who died during the proceeding before the Court, this latter held that the State failed to prevent the applicant's life from being put at risk by not providing him the appropriate health-care as ordered by the national courts, in breach of Article 2 of the Convention.<sup>55</sup>

treat mental illnesses, when circumstances render treatment of this kind necessary as a last resort, and the treatment is subject to legal safeguards."

<sup>&</sup>lt;sup>52</sup> Views adopted by the Committee at its eleventh session Communication No. 8/2012 (31 March–11April 2014), CRPD/C/11/D/8/2012, 18 June 2014.

<sup>&</sup>lt;sup>53</sup> See Pentiacova and 48 Others v Moldova (2005) 40 E.H.R.R. SE23; Nitecki v Poland App no 65653/01 (ECtHR Decision, 21 March 2002); Cyprus v Turkey (2002) 35 E.H.R.R. 30 [219].

<sup>&</sup>lt;sup>54</sup> Panaitescu v. Romania, Appl. No 30909/06, 10 April 2012.

<sup>&</sup>lt;sup>55</sup> See also the case *Center of Legal Resources on behalf of Valentin Câmpeanu v. Romania* of 17 July 2014, the Grand Chamber found that there had been a violation of Article 2 (right to life) of the Convention, in both its substantive and its procedural aspects. The application was lodged by a non-governmental organization (NGO), on behalf of Valentin Câmpeanu, abandoned at birth and placed in an orphanage. He had been diagnosed as a young child as being HIV-positive and as suffering from a severe mental disability. He died in 2004 at the age of 18 in a psychiatric hospital.

Also, in the case *Mehmet Sentürk and Bekir Sentürk v Turkey* the Court found a violation of Article 2 for a failure to provide basic health care which led to death.<sup>56</sup>

The case law of the Court that have **found a violation of Article 3** of the Convention concern mainly the conditions of detention of disabled people in relation to access to health care.<sup>57</sup> Where persons with disabilities are detained, the Court ruled that national authorities must take care to provide conditions that meet any special needs resulting from the disability, and ensure that health care in detention facilities, including prison and psychiatric hospitals, is prompt and appropriate in light of their impairment,<sup>58</sup> and that **health care facilities in prisons must be accessible**.<sup>59</sup>

There are several cases in this regard, I will just mention the case *Arutyunyan v. Russia*.<sup>60</sup> In this case, the Court held that there had been a violation of Article 3 (prohibition of inhuman or degrading treatment) of the Convention, finding that the domestic authorities had failed to treat the applicant in a safe and appropriate manner consistent with his disability and had **denied him effective access to the medical facilities.** 

## the medical facilities.

Finally, the right to health care has been invoked in **relation to Article 8**, which addresses the right to private and family life. In general, the Court largely relied on the State's margin of appreciation leaving States to arrange their health care system in accordance with the available resources, such cases include *Sentges v Netherlands* and *Passannate v Italy* that the Court rejected as manifestly ill-founded.<sup>61</sup>

In other cases, the Court found a violation of Article 8 of the Convention for specific aspects related to health care such the lack of access to personal medical records, <sup>62</sup> as in the case *K.H. and Others v.* 

ECtHR (Fifth Section), Judgment (Merits and Just Satisfaction) of 30July 2009; Price v. the United Kingdom,

<sup>&</sup>lt;sup>56</sup> Mehmet Sentürk and Bekir Sentürk v Turkey App No 13423/09 (ECtHR, 09 April 2013). The case concerned the death of a pregnant woman (Mrs Sentürk) following a series of misjudgements by medical staff at different hospitals and the subsequent failure to provide her with emergency medical treatment. The Court held that the deceased had been the victim of blatant shortcomings on the part of the hospital authorities and had been *denied the possibility of access to appropriate emergency treatment*. The Court reiterated that failure by a State to comply with its duty to protect a person's physical well-being amounted to a breach of the substantive aspect of Article 2 of the Convention. Therefore, it found the State to be in violation of Article 2 for not providing emergency medical treatment to a patient that eventually led to death.

<sup>&</sup>lt;sup>57</sup> The Court has embraced a wide notion of persons with disabilities, including not only physically or mentally impaired people, but also persons with serious illness, such as diabetes (see *Glor v Switzerland*, App no 13444/04, ECtHR, 30 April 2009. For all the cases reported see http://www.echr.coe.int/Documents/FS\_Disabled\_ENG.pdf. Accessed 2 September 2017.

<sup>&</sup>lt;sup>58</sup> See See İlhan v. Turkey [GC], no. 22277/93, § 87, ECHR 2000-VII; Pitalev v. Russia, Application no. 34393/03,

Application no. 33394/96 [2001] ECHR 458; *Naumenko v. Ukraine*, no. 42023/98, § 112, 10 February 2004; *Farbtuhs v. Latvia*, no. 4672/02, § 51, 2 December 2004.

<sup>&</sup>lt;sup>59</sup> See the cases *Grimailovs v. Latvia* App no 6087/03, judgment 25.6.2013; *Semikhvostov v. Russia* of 6 February 2014; *Helhal v. France* of 19 February 2015.

<sup>&</sup>lt;sup>60</sup> Arutyunyan v. Russia of 10 January 2012.

<sup>&</sup>lt;sup>61</sup> Sentges v Netherlands (2004) 7 C.C.L. Rep. 400.

<sup>&</sup>lt;sup>62</sup> See *Guerra and Others v. Italy*, 19 February 1998, § 60, Reports 1998-I; *McGinley and Egan v. the United Kingdom*, 9 June 1998, § 101, Reports of Judgments and Decisions 1998-III; *Roche v. the United Kingdom* [GC], no. 32555/96, para. 155, ECHR 2005-X.

*Slovakia*,<sup>63</sup> or the issue of informed consent for medical treatment, such as in the case of X. v. *Finland*.<sup>64</sup> However, the Court found that consent was not required in cases involving 'therapeutic necessity' for treatment,<sup>65</sup> or forced medication in a psychiatric hospital such as in the case *Schneiter* v. *Switzerland*.<sup>66</sup>

At the end of this overview of the practice of the Court, we may observe that in general on the issue of health care the Court has been very cautious leaving to States a wide margin of appreciation and in only a few cases, has it recognized this right under the Convention.

However, it should be recalled that within the Council of Europe the **right to health is protected under Article 11 (The right to protection of health)**<sup>67</sup> **of the European Social Charter** (Revised)<sup>68</sup> that supplements the European Convention in this matter as underlined by the European Committee of Social Rights (ECSR)<sup>69</sup> and also guarantees the right to access to health care.<sup>70</sup> In addition, mention

<sup>&</sup>lt;sup>63</sup> Application no. 32881/04.

<sup>&</sup>lt;sup>64</sup> ECtHR, X. v. *Finland*, 3 July 2012, Appl. No 34806/04. A violation of Article 5(1) (right to liberty and security) was also found in this case. See also See *Testa* v. *Croatia*, 12 July 2007, Appl. No 20877/04, in which the Court held that "failing to provide patients with adequate information harms the self-determination of the person concerned and could constitute a violation of Article 8."

<sup>&</sup>lt;sup>65</sup> Herczegfalvy v. Austria, No 10533/83 and ECtHR 7 October 2008, Bogumil v. Portugal No 35228/03.

<sup>&</sup>lt;sup>66</sup> ECtHR, *Schneiter* v. *Switzerland*, 31 March 2005, Appl. No 63062/00. The Court found that the applicant's complaint under Article 8 was ill-founded because the treatment had a legal basis and pursued the legitimate aim of protecting the rights and freedoms of others.

<sup>&</sup>lt;sup>67</sup> See also ESCR, 7 November 2004, *International Federation of Human Rights Leagues (FIDH)* v. *France*, No 14/2003 and ECSR, 2 December 2008, *European Roma Rights Centre* v. *Bulgaria*, No 46/2007. Article 11 is a 'non-core" right, but all the States that have accepted it are under the authority of the European Committee of Social Rights which monitors the compliance of national legislation with the obligations laid down in Article 11. Moreover, if these States have also ratified the CRPD, as is the case of Italy, they have a double legal obligation to give effect to the right to health, including the right to access to health care for persons with disabilities. As for 10 September 2017, among the member States of the Council of Europe only Ireland, Lichtenstein, and Monaco had not ratified the CRPD.

<sup>&</sup>lt;sup>68</sup> The Revised Charter of 1996 is gradually replacing the initial 1961 treaty. The widespread support for social rights is assured by the fact that 43 out of the 47 member States of the Council of Europe are parties to either the 1961 Charter or the Revised Charter. Only Liechtenstein, Monaco, San Marino and Switzerland have not ratified either of these treaties. http://www.coe.int/en/web/turin-european-social-charter/about-the-charter. Accessed 10 September 2017.

<sup>&</sup>lt;sup>69</sup> The ECSR has pointed out that "the right to protection of health guaranteed in Article 11 of the Charter complements Articles 2 and 3 of the European Convention on Human Rights - as interpreted by Court– by imposing a range of positive obligations designed to secure its effective exercise". See M. Marochini, *Council of Europe and the Right to Healthcare* - *Is the...Zb*. Prav. fak. Sveuč. Rij. (1991) v. 34, br. 2p. 750.

<sup>&</sup>lt;sup>70</sup> See "The right to health and the European Social Charter", Information document prepared by the secretariat of the ESC (March 2009). The Information document is based on the conclusions adopted by the European Committee of Social Rights (ECSR) through its Reporting system over the years and it might be said to represent a summary of the Committee's conclusions in the health care issues. Indeed, the ECSR interpreted and made observations regarding Article 11 not only in its conclusions but also through its decisions in the Collective Complaints procedure. Cf. M. Marochini, *Council of Europe and the Right to Healthcare*, cit., 729-760 (2013).

# should be made of the **Convention on Human Rights and Biomedicine that in Article 3<sup>71</sup> protects** the right to equitable access to health care.<sup>72</sup>

To date, the European Court of Human Rights has not invoked the right to equitable access as protected under the Convention on Biomedicine therefore we cannot assess the influence which this Convention might have on the inclusion of the right to health care under the European Convention.

#### c) Domestic laws: some best practice

Turning to the domestic implementation of the right of access to health care for persons with disabilities in Europe, the CRPD Committee in its Concluding Observations on the initial report of the Union noted the existence of barriers faced by those persons in accessing health care in different member States.<sup>73</sup> The presence of different levels of barriers in this field among the EU Member States was also documented in a Report published last year by the Expert Panel on Effective Ways of Investing in Health<sup>74</sup> which focuses, *inter alia*, on people with mental health problems.

Limiting the analysis to the normative framework, it is worth recalling that the CRPD Committee recommended States Parties adopt specific legislation prohibiting discrimination on the grounds of disability in the health sector in order to conform with Convention obligations.<sup>75</sup> As already mentioned, the principle of non-discrimination is the cornerstone of Article 25 of the CRPD and is one of the four dimensions of accessibility as applied to the right to health.

<sup>&</sup>lt;sup>71</sup> Council of Europe, Convention for the Protection of Human Rights and of the Human Being with regard to the Application of Biology and Medicine (Convention on Human Rights and Biomedicine) (CETS n. 164), adopted in Oviedo on 4 April 1997 (entered into force on 1 December 1999). Article 3 states "Parties, taking into account health needs and available resources, shall take appropriate measures with a view to providing, within their jurisdiction, equitable access to health care of appropriate quality." It is also relevant Article 5 of the Convention that provides that any intervention in the health sector can be carried out only if (and after) 'the person concerned has given free and informed consent to it.' Article 26 of the Convention, as well as Article 6, deals with the protection of persons not able to consent, Article 7 concerns the protection of persons who have mental disorders and Article 8 is about the emergency situations and defines the instances in which the exercise of the rights contained in the Convention and hence the need for consent may be limited.

<sup>&</sup>lt;sup>72</sup> The Explanatory Report to the Convention has clarified that the aim of this provision "is to ensure equitable access to health care in accordance with the person's medical needs. .... In this context, "equitable" means first and foremost the *absence of unjustified discrimination* "(paragraphs 24-25). Furthermore, the Parties are required to take appropriate steps to achieve this aim as far as the available resources permit (para. 26). https://rm.coe.int/16800ccde5.

<sup>&</sup>lt;sup>73</sup> CRPD/C/EU/CO/1, para. 62.

<sup>74</sup> "Access See to health services in the European Union." https://ec.europa.eu/health/expert\_panel/sites/expertpanel/files/015\_access\_healthservices\_en.pdf. Accessed 30 August 2017. The Panel was set up the European Commission to provide advice on effective ways of investing in health. The Report points out that it is not clear what actions governments in different Member States have taken to address social exclusion or how much priority has been given to targeted mental health promotion and strategies to improve access to appropriate health services. However, it highlights the existence of some good practices in the organization of services that go in the direction of the integration and co-ordination of services across the health and social care sectors that ensures good coordination between primary care and mental health services. Good practices have been identified in some Northern European countries, such as Finland, Norway, and outside Europe, the United States, see Wahlbeck K (2010). Moving towards integrated addiction treatment systems. Nordic Studies on Alcohol and Drugs 27: 699-702.

<sup>&</sup>lt;sup>75</sup> See, among the others, the Concluding observations on the initial report of Portugal, CRPD/C/PRT/CO/1, para. 50.

In this respect, it should be noted that although EU law does not specifically protect disabled people against discrimination in health care,<sup>76</sup> several member States have adopted laws that explicitly prohibit discrimination based on disability in access to health care,<sup>77</sup> as recommended by the CRPD Committee. Mention should be made in particular of the following: **Belgium**,<sup>78</sup> **Croatia**,<sup>79</sup>**Cyprus**,<sup>80</sup> **the Czech Republic**,<sup>81</sup> **Germany**,<sup>82</sup> **Hungary**,<sup>83</sup> **Luxembourg**,<sup>84</sup> **Portuga**l,<sup>85</sup> **Romania**,<sup>86</sup>

<sup>&</sup>lt;sup>76</sup> The EU law does not guarantee the right to access health care for disabled persons specifically since in the field of human health the Union has only the competence to carry out actions to support, coordinate or supplement the actions of the Member States (Articles 4, 6 and 168 of the Treaty on the Functioning of the European Union). Article 35 of the EU Charter of Fundamental Rights protects the right of access to health care. As for specific disability acts, the European Disability Strategy 2010-2020 identifies health as one of the eight areas for action. The Strategy recognizes that people with disabilities may have limited access to health services and they are entitled to equal access to healthcare, including preventive healthcare, and specific affordable quality health and rehabilitation services which take their needs into account, including gender-based needs. However, it affirms that it is mainly the task of the Member States, which are responsible for organising and delivering health services and medical care."

<sup>&</sup>lt;sup>77</sup> See Synthesis Report "Access to Healthcare by People with Disabilities in Europe – A Comparative Study of Legal Frameworks and Instruments" prepared by Professor Waddington in 2014 the basis of 25 country reports provided by ANED experts.

<sup>&</sup>lt;sup>78</sup> Act of 10 May 2007 on combating certain forms of discrimination (*Moniteur belge*, 30 May 2007), Article 4, para. 4, Article 5, para. 1.2. Prohibited conduct includes the refusal to make a reasonable accommodation for a person with a disability (Article 14). The three Communities in Belgium (Flanders, the French-speaking Community, and the German-speaking Community) also all have non-discrimination legislation covering the ground of disability and the area of health.

<sup>&</sup>lt;sup>79</sup> The Anti-discrimination Act prohibits discrimination on the grounds of disability (Article 1) and covers health care *Official Gazette* 85/08, 112/12. *Zakon o suzbijanju diskriminacije, Narodne novine* 85/08, 112/12, Article 8.

<sup>&</sup>lt;sup>80</sup> The Persons with Disabilities Law of 2000 (127(I)/2000) prohibits discrimination against people with disabilities in health services. The Anti-Racial and Certain Other Discrimination (Ombudsman) Law of 2004 (42(I)/2004) also prohibits discrimination on the ground of disability and covers access to healthcare Article 3(b)(c). Article 6(e).

<sup>&</sup>lt;sup>81</sup> The Law No 198/2009 Coll. on Equal Treatment and Legal Means of Protection against Discrimination prohibits discrimination on the grounds of disability and covers *inter alia* access to health as well as other services. In addition, the Law on Healthcare Services No 372/2011 Coll. provides for reasonable accommodation in the context of communication, but not in other respect.

<sup>&</sup>lt;sup>82</sup> The 2006 General Equal Treatment Act prohibits discrimination in regard to social protection (social benefits and social services) and health services. Moreover the Disability Equality Act requires German public institutions, including those providing healthcare, to ensure accessibility of built and designed environments and in communications between citizens and public authorities. The Act covers only public health services, private companies are excluded.

<sup>&</sup>lt;sup>83</sup> Act 125 of 2003 on Equal Treatment and the Promotion of Equal Opportunities (ETA) prohibits discrimination the grounds of disability in health care.

<sup>&</sup>lt;sup>84</sup> Law of 24 July 2014 on the rights and obligations of the patient and obligations of health care providers establishes that, except in emergencies, all patients will enjoy equal access to healthcare as required and states the duty to provide to disabled people information on accessibility of hospitals.

<sup>&</sup>lt;sup>85</sup> Law 46/2006 (Law that Prohibits and Punishes Discrimination based on Disability and Aggravated Health Risk), expressly prohibits discrimination in access to healthcare in public and private services.

<sup>&</sup>lt;sup>86</sup> Government Ordinance No 137/2000 prohibits discrimination *inter alia* on the grounds of disability and covers the health system. This law is complemented by the Law on People with Disabilities' Rights (Law No 448/2006) which provides for an obligation on health service providers to ensure a reasonable accommodation to individuals with disabilities, including through providing high tech assistance.

## Slovakia,<sup>87</sup> Slovenia,<sup>88</sup> Spain,<sup>89</sup> and the United Kingdom.<sup>90</sup>

These laws may be considered best practice and models to be followed by other member States, which do not have specific legislation in this field.

## d) Relevant domestic case law on the access to healthcare

Domestic courts have also ruled on the right to access to healthcare for persons with disabilities.<sup>91</sup> Due to time constraints, I will mention only two landmark decisions that have set some fundamental principles in this matter. The first is the decision of the **Supreme Court of Canada** in the case *Eldridge v British Columbia*.<sup>92</sup> The case concerned deaf individuals who had been denied sign language interpreters while attending hospital for medical treatment. The Court found that "the government has not made a "reasonable accommodation" of the appellants' disability" and ruled that "sign language" interpreters must be provided in the delivery of medical services where doing so is necessary to ensure effective communication. The other decision was delivered by the **Colombian Constitutional Court** in the case T-760/08 of 2008.<sup>93</sup> The Court examined multiple cases that

<sup>&</sup>lt;sup>87</sup> Act No 365/2004 Coll. on equal treatment in certain areas and protection against discrimination covers health care, the provision of goods and services (Article 3). In addition, Act No 576/2004 Coll. on healthcare and services related to

health care, as amended, prohibits discrimination on grounds of disability.

<sup>&</sup>lt;sup>88</sup> The Implementation of the Principle of Equal Treatment Act of 2007, the Equalisation of Opportunities for Persons with Disabilities Act (EOPDA) of 2010. The Patient's Rights Act of 2008.

<sup>&</sup>lt;sup>89</sup> The Act No. 51 of 2003 on Equality, Non-Discrimination and Universal Accessibility (LIONDAU) prohibits discrimination on the grounds of disability and establishes the obligation to ensure equal opportunities and universal access in areas such as goods and services provided to the public, including health services. In addition, the General Act on the Rights of Persons with Disabilities and their Social Inclusion of 2013 states that "People with disabilities have the right to protection of health, including the prevention of disease and the protection, promotion and recovery of health, without discrimination on grounds of disability or special attention to mental health and sexual and reproductive health" (Article 10). Furthermore, a number of provisions provide for accessibility of information and *medical records* (Act 41/2002 establishes the right of every patient to receive information on his/her health and to access to medical records. Act 14/1986 on General Health also states that every patient has the right to receive information about the health services they can access and the necessary requirements for use.

<sup>&</sup>lt;sup>90</sup> The Equality Act (2010) makes it unlawful to discriminate against disabled people in the provision of services, including health care services and establishes the duty of providers of health services to take reasonable steps to anticipate and remove accessibility barriers (see Section 20). In England and Wales the 2005 Mental Capacity Act sought to reduce difficulties concerning capacity to consent and best interests decisions for persons with intellectual disabilities.

<sup>&</sup>lt;sup>91</sup> See for US case law, Mark A. Hall, *The Role of Courts in Shaping Health Equity, JHPPL* Advance Publication, posted on June 29, 2017 http://jhppl.dukejournals.org/content/early/2017/06/26/03616878-3940432.full.pdf-.In South Africa, following the Constitutional reform of 1994 that introduced the right to health and the right to have access to health care services (including reproductive rights) into the Constitution, there have been several court cases which have thrown light on the concepts of "available resources" and "reasonable measures" in terms of section 27 (1) (b) of the Constitution, see respectively the cases *Soobramoney v Minister of Health, Kwa-Zulu Natal*, 1997 (12) BCLR 1696 (CC) and *Government of the Republic of South Africa and Others v Grootboom and Others* 2000 (11) BCLR.

<sup>&</sup>lt;sup>92</sup> Eldridge v British Columbia (AG) [1997] 3 S.C.R. 624.

<sup>&</sup>lt;sup>93</sup> The decision was delivered by the Court in its actions of *tutela* ('protection writ,' a flexible jurisdictional action designed to protect fundamental rights). The main question addressed to the Court was if the regulatory failures presented through the individual cases constituted a violation of the competent authorities' constitutional obligations to respect, protect, and fulfil the right to health and its effective enjoyment. To this question, the Court responded affirmatively, also in the light of international obligations in this field. The judgment has a complete annex describing the right to health under international law, the Court proceeds to set out the analytical categories through which the obligations arising from

invoked the protection of the right to health,<sup>94</sup> specifically access to needed health service guaranteed by law.<sup>95</sup>

In the decision, the Court recalled that the jurisprudence of the same Constitutional Court has identified a set of rules that guarantee **the right to access to quality, timely, and effective health services.** In the judgment, it is further stressed that the right to access to the required health services involves the **right to adequate means of transport,** and to the **continuity of health care service**, once it has started. The Constitutional Court also pointed out that the right to access to health care under the terms set out above also applies to the subjects of special constitutional protection, such as children and **people with disabilities.** 

This ruling is particularly relevant not only for the contents but also for its effects at national level. In fact, following the decision of the Constitutional Court, 22 individuals received a remedy for their particular violations of the right to health and the Ministry of health and other government agencies have introduced the structural changes ordered by the Court.

The above-mentioned judgments show how courts' decisions can contribute to the enjoyment of the right to access to health care at domestic level in line with the international obligations in this field and to make changes in the internal legal order to ensure this right.

May I conclude my presentation by underlining that the enjoyment of the right to access to health care by disabled people requires the proactive role of States, which are called upon to act on different levels. In line with the CRPD, at domestic level it is in fact necessary to conform all health care environments to accessibility requirements, including overcoming physical, communication and information barriers through structural modifications to facilities, using equipment with universal design features, and communicating information in appropriate formats.

the right to health have been characterized under the International Covenant on Economic, Social and Cultural rights (ICESCR), as detailed by General Comment No. 14 (2000) of the UN Committee on Economic, Social and Cultural Rights. The main question addressed to the Court was if the regulatory failures presented through the individual cases constituted a violation of the competent authorities' constitutional obligations to respect, protect, and fulfil the right to health and its effective enjoyment. To this question, the Court responded affirmatively, also in the light of international obligations in this field. The judgment has a complete annex describing the right to health under international law, the Court proceeds to set out the analytical categories through which the obligations arising from the right to health have been characterized under the International Covenant on Economic, Social and Cultural rights (ICESCR), as detailed by General Comment No. 14 (2000) of the UN Committee on Economic, Social and Cultural Rights.

<sup>&</sup>lt;sup>94</sup> The Constitutional Court held that the right to health is a fundamental constitutional right, whose protection encompasses "a <u>basic set of services</u>, contemplated by the Constitution, the law, and the obligatory health plans. The Court has also affirmed that everyone has the constitutional right to be guaranteed access to the *required* services, that is, those services that are indispensable to maintain one's health when one's life, personal integrity or dignity is seriously threatened.

<sup>&</sup>lt;sup>95</sup> Law 100 of 1993, promulgated in a context of structural readjustment common to at the beginning of the 1990s, created a managed care system based on market mechanisms, coupled with defined benefits schemes. The system offered subsidies for demand, in contrast to the old scheme that mainly provided subsidies to the supply side of the health market. The cases referred to diverse situations in which the access to the required health services was denied.

From this perspective, national legislation (especially national accessibility standards) designed to improve accessibility to health care services and facilities for disabled persons can contribute to the removal of the barriers preventing their equal access and in this way to the elimination of discrimination based on disability.

Thank you for your attention.