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# Access to Health Care in Human Rights Law and the Case of the United States

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## **Abstract**

I diritti umani rappresentano uno dei modi in cui la comunità internazionale ha reagito agli orrori della Seconda Guerra Mondiale, tuttavia, la loro realizzazione è tutt'altro che semplice. Il diritto umano alla salute rappresenta in un certo modo tutta la complessità che emerge quando si cerca di passare dall'idea che si ha dei diritti umani, alla loro attuazione nel mondo reale. Questo diritto è definito e tutelato da numerosi strumenti del diritto internazionale, che permettono di dare una sua definizione, purtroppo, però, tutte le definizioni e le spiegazioni fornite da questi documenti, seppur teoricamente esaustive nel dare un quadro complessivo di ciò che il diritto alla salute è, non sono efficaci nel fornire delle informazioni specifiche per quello che riguarda l'implementazione di tali definizioni. La salute umana è il risultato dell'intersecarsi di molteplici aspetti della vita di una persona, quindi anche il diritto alla salute riporta tutte queste sfaccettature; questa complessità, se dal punto di vista teorico contribuisce a una definizione puntuale ed esaustiva di questo diritto, nella pratica rende molto difficile il giudizio relativo ai comportamenti degli Stati volti alla sua realizzazione. Data quindi la sua complessità, questo lavoro cerca di prendere in considerazione solo uno degli aspetti del diritto alla salute, che è il diritto a un accesso equo alla sanità.

Un altro aspetto che rende difficile la determinazione di quanto uno Stato stia o meno rispettando il diritto umano alla salute deriva dal fatto che, per poter fare in modo che tale diritto sia valido per tutti gli Stati del mondo, una delle sue disposizioni chiave riguarda la realizzazione progressiva in relazione alle risorse disponibili. Una norma diversa non sarebbe realizzabile, ovviamente, ma stabilire quali siano le risorse a disposizione di uno Stato è un argomento altrettanto ostico. Certo è, comunque, che questa componente del diritto umano alla salute implica che i Paesi ad alto reddito compiano uno sforzo maggiore per quello che riguarda l'attribuzione di risorse alle politiche volte alla realizzazione di questo diritto, rispetto ai Paesi a basso reddito. Questa disposizione, quindi, assume una connotazione ambivalente in quanto, da un lato, è uno degli elementi che stabiliscono una correlazione tra l'idea astratta del diritto alla salute e la sua realizzazione pratica; dall'altro invece, la vaghezza del concetto di disponibilità di risorse può essere utilizzata per impedire la piena implementazione delle disposizioni necessarie alla realizzazione del diritto in questione.

La questione dello stanziamento delle risorse da parte dei differenti Stati, congiuntamente alla mancanza di indicazioni specifiche riguardanti la tipologia di sistemi sanitari, pubblici o privati,

che uno Stato dovrebbe implementare per realizzare un sistema capace di garantire un accesso equo alla sanità, ha contribuito alla nascita di una varietà di sistemi sanitari. La sanità nei Paesi ad alto reddito, anche se assume forme diverse di finanziamento e distribuzione, è comunque garantita a livello nazionale; eccezione importante a questa tendenza è costituita dagli Stati Uniti. Il sistema sanitario statunitense è, infatti, prevalentemente privato, si basa su assicurazioni private tendenzialmente collegate al posto di lavoro, e offre una vasta gamma di piani assicurativi che coprono diversi servizi e hanno prezzi differenti, il ruolo del Governo nel garantire l'accesso ai sistemi sanitari è quasi esclusivamente limitato al finanziamento dei programmi pubblici che forniscono copertura assicurativa alle fasce più vulnerabili della popolazione, come anziani, disabili e poveri, tra questi programmi quelli di maggiore spicco sono Medicare e Medicaid. La situazione, se si prova ad analizzare il sistema statunitense attraverso i principi del diritto umano alla salute, denota diverse criticità, in quanto un sistema privato che segue le regole di mercato difficilmente può riuscire a fornire un accesso alla sanità equo e non discriminatorio. In questo contesto è molto interessante, però, approfondire le intersezioni tra il mondo del diritto umano alla salute e la sanità americana per poter rilevare i punti di incontro che già esistono, le criticità di entrambi e per poter prospettare un modo in cui questi due mondi apparentemente lontani possano interagire e portare all'instaurazione negli Stati Uniti di un sistema sanitario che rispetti i principi del diritto umano alla salute.

Fino a ora gli Stati Uniti si sono dimostrati piuttosto restii a ratificare trattati e convenzioni internazionali riguardanti i diritti economici, sociali e culturali, ciò non toglie che, pur non avendo ratificato dei documenti fondamentali per il riconoscimento del diritto umano alla salute, come l'ICESCR, si siano impegnati nel rispetto di questo diritto tramite la Convenzione per l'eliminazione delle discriminazioni razziali e sottoscrivendo la Costituzione dell'Organizzazione Mondiale della Sanità. Per questo motivo non risulta privo di fondamento un discorso che cerchi di valutare, tramite i principi del diritto umano alla salute, la struttura del sistema sanitario statunitense e la più recente riforma che ha cercato di apportare ad esso dei cambiamenti importanti, anche se non strutturali, per poter affrontare il problema dei milioni di Americani che non hanno l'assicurazione sanitaria e a cui, quindi, viene negato l'accesso ai servizi sanitari, che è il Patient Protection and Affordable Care Act. Questo approccio contribuisce a evidenziare le criticità di entrambi i sistemi: da un lato la vaghezza e la complessità delle disposizioni riguardanti il diritto umano alla salute, anche dovute al fatto che comprenda una serie di diritti che sono fondamentali per il concetto di salute, ma che sono anche diritti umani a sé stante, possono contribuire a relegare questo diritto così importante in secondo piano, in quanto è estremamente difficile stabilire le

eventuali violazioni, violazioni alle quali, inoltre, al di fuori del campo d'azione della Corte Europea dei Diritti Umani, non corrispondono sanzioni. Dall'altro lato la sanità statunitense emerge come un sistema che ha come obiettivo primario il profitto e quindi perde di vista lo scopo fondamentale di ogni sistema sanitario che è quello di curare le persone in base alle loro necessità. Inoltre dall'analisi della sanità americana emergono le contraddizioni proprie della società statunitense che oscilla tra individualismo e meritocrazia da un lato e il principio di uguaglianza che si attua nell'avere uguali possibilità di partecipazione alla vita pubblica e sociale del Paese dall'altro; quando questi principi vengono applicati alla sanità i loro significati vengono fortemente messi in discussione in quanto, da un lato, raramente si può affermare che la salute sia esclusivamente un merito personale e, dall'altro, un minimo livello di salute è necessario a qualsiasi attività si voglia portare avanti, inclusa la partecipazione alla vita sociale e pubblica del Paese. Questo lavoro non si pone, ovviamente, l'obiettivo di trovare una soluzione al problema delle discriminazioni riguardanti l'accesso ai sistemi sanitari negli Stati Uniti, ma cerca di evidenziare quanto l'assenza di un discorso basato sul diritto umano alla salute nelle riforme sanitarie sia evidente e abbia influito sulla struttura e sulla complessità del sistema.

La scelta dell'argomento nasce da un interesse personale per il diritto a un accesso equo alla sanità e dalla profonda convinzione che questo principio debba essere alla base delle politiche sociali degli Stati, in particolar modo di quei Paesi che hanno delle risorse tali da potersi permettere la realizzazione di un sistema sanitario accessibile a tutti, in tutte le connotazioni che il termine accessibile implica, equo e non discriminatorio, che riesca a tutelare in maniera eguale tutti, a prescindere dalla condizione socio-economica e dalle condizioni di salute, garantendo maggior sostegno proprio alle fasce più svantaggiate della popolazione, in modo tale che le condizioni di salute non vadano a compromettere una situazione già precaria; anche perché il momento in cui una persona si trova a dover accedere a un servizio sanitario è molto spesso un momento difficile e dal forte impatto emotivo, è quindi fondamentale che questa necessità non sia accompagnata da preoccupazioni economiche, soprattutto perché tendenzialmente le cure più costose sono proprio quelle a cui si ricorre senza avere possibilità alternative. Inoltre, garantire che le persone possano avere accesso alle cure quando ne hanno bisogno ha anche un impatto economico diverso dal mero costo di quelle cure, in quanto molto spesso degli esami diagnostici e delle cure corrette al momento opportuno permettono a chi li riceve di continuare a condurre una vita attiva e produttiva.

## Introduction

*“Of all the forms of inequality, injustice in health care is the most shocking and inhumane.”<sup>1</sup>*

The right to health has been introduced in the discourse of human rights through the Universal Declaration of Human Rights (UDHR) and the World Health Organization (WHO) Constitution. Throughout the years other international law documents have contributed to the framing of its scope and to the characterization of States obligations related to this right. However, this right remains an extremely complex one, because it includes a variety of different rights that have an important role in its realization, but that are also human rights for themselves. On the one hand, this encroachment of rights is unavoidable because human rights are so strictly interrelated that it is difficult to determine precisely their boundaries; on the other hand, this situation may weaken the possibility of a real implementation of the right to health. A minimum level of health is necessary to be able to enjoy other human rights: “One may not have all the human rights without first being *alright*”<sup>2</sup>. Among other provisions of the right to health, there is the right to equal access to health care, which is neither the main component of the right to health, not the only determinant of health; however, in guaranteeing a decent level of health, an important role is played by medicine and health care, and addressing inequalities and discrimination in health care is an action complementary to the concentration on non-medical determinants of health<sup>3</sup>. Therefore, an important part of the right to health involves the principle of equal access to health care. Health care is an instrument that have the primary scope of improving people’s health<sup>4</sup>; consequently, health care systems must be available to everyone on the basis of their needs, irrespective of their income, ethnic origin, gender, and age<sup>5</sup>. A health care system that respects the provisions of the right to equal access to health care (whose one basic characteristic is the elimination of all forms of

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<sup>1</sup> Cit. by Martin Luther King

<sup>2</sup> Upendra Baxi (2010). The Place of the Human Right to Health and Contemporary Approaches to Global Justice: Some Impertinent Interrogations. In “Global Health and Human Rights”. *Routledge, New York*. Edited by Harrington, J. and Stuttaford, M., p.13

<sup>3</sup> Ichiro Kawachi (2005). Why the United States Is Not Number One in Health. In “Healthy, Wealthy, and Fair. Health Care and the Good Society.” *Oxford University Press*. Edited by Morone, J. A.; Jacobs, L. R., p. 27

<sup>4</sup> Sarah Smith, et Al.(2005). Health Care Evaluation. *Open University Press.*, 8

<sup>5</sup> Gunilla Backman, et Al. (2008). Health Systems and the Right to Health: an Assessment of 194 Countries. *Lancet*. DOI:10.1016/S0140- 6736(08)61781-X., et Al., p.2051



discrimination<sup>6</sup>.) would provide at least a basic and adequate level of health care services available to the entire population; in an affluent society, the standard of services guaranteed to everyone should be more generous and comprehensive<sup>7</sup>. An efficient health care system, able to address people's health care necessities is a key element of an equitable and healthy society<sup>8</sup>.

The right to health is generally recognized by the international community, even though not all countries have ratified the treaties and covenants that establish it. Moreover, being a part of economic, social and cultural rights, its justiciability may appear controversial, and there still are some problems in the acceptance of the right to health as a matter of international customary law<sup>9</sup>.

High-income countries have overall accepted the right to health, ratified the treaties and covenant that recognize it, and somehow incorporated this right in their national legislation. A great exception is made by the United States. The U.S. Constitution does not recognize a right to health, and the U.S. has been reluctant to ratify international human rights instruments recognizing the right to health. Moreover, the structure of U.S. health care system is a peculiar one among OECD countries. It relies basically on a system of private insurance, mainly employment-based, in which the Government has limited powers. The Federal and States Governments have a role in the implementation of programs for vulnerable population: elderly, disabled, and the poor. Social and economic status play a fundamental role in determining the health condition of people: those most vulnerable from a socio-economic point of view are usually also the ones living in worse health conditions, and this is an extremely relevant notion in addressing a system based on private insurance like the one of the U.S.<sup>10</sup>.

Due to the importance of the access to health care in determining people's health, and the peculiarity of the U.S. health care system when compared to systems of the other high-income countries, this thesis presents an analysis of the international human rights framework that defines and delineates the principles and the provisions of the right to equal access to health care, and try to examine the U.S. system, and the recent changes brought to it by the Patient Protection and Affordable Care Act, through a right to health lens. Since the U.S. is not part to any regional treaty

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<sup>6</sup> Audrey R. Chapman (1994). Chapman, A. R. (1994). A Human Rights Approach to Health Care Reform. In *Health Care Reform: A Human Rights Approach*. Georgetown University Press. Edited by A. R. Chapman. pp.149-50

<sup>7</sup> Idem.

<sup>8</sup> Gunilla Backman, et Al. (2008). *Supra* note (5)., p.2047

<sup>9</sup> Eleanor D. Kinney. (2001). The International Human Right to Health: What Does This Mean for our Nation and World?. *Indiana Law review*, Vol. 34:1457., p. 1466

<sup>10</sup> Lu Ann Aday (2001). At Risk in America. The Health and Health Care Needs of Vulnerable Populations in the United States. Jossey-Bass Publishers, San Francisco., p.90

or covenant that recognizes the right to health, it has seemed appropriate to limit the analysis to the UN framework.

The first chapter presents an analysis of the international human rights instruments that have introduced and defined the right to health and the right to equal access to health care. Since the focus of this thesis is particularly on access to health care, only the provisions concerning this part of the broader right to health are taken into consideration. Specifically, the chapter is divided into two subparts: the first one dedicated to two of the three international documents that constitute the Bill of Rights, namely the UDHR and the International Convention on Economic, Social and Cultural Rights (ICESCR)<sup>11</sup>. Moreover, the General Comment 14, which represents the authoritative interpretation of the provisions of the Covenant, is used to address the crucial points of the right to equal access to health care, namely the principle of accessibility and availability, equality and non-discrimination, the minimum core and progressive realization, and the specific obligations on the States. The second part of the first chapter is dedicated to the WHO role and influence on the right, from its Constitution, to the way it addressed the human rights discourse in its history, and the development of the concept of universal health coverage. The last part of the first chapter is also dedicated to the Convention on the Elimination of Racial Discrimination (CERD) that assumes a relevant role in this thesis since it is one of the few international documents that involve the right to health to have been ratified by the U.S.

The second chapter addresses the problem of the justiciability of the right to health. It is difficult to define whether or not this right is justiciable, mainly because of the lack of an international court, which can take binding decisions, before which to bring a violation of the right to health (the only court that permits this procedure is the European Court of Human Rights that, however, has not competences for countries that are not part to the Council of Europe); and also because it is part of the economic, social and cultural rights that are still broadly considered positive rights, even though the difference among positive and negative right does not depend on the category they belong to, but on the degree of action required by the State to fully realize them, and this is connected to the nature of every single right and not to the category it belongs to<sup>12</sup>. In addressing the topic of justiciability, the reporting practice under the ICESCR is analyzed, and also the optional protocol to this convention. Moreover, particular attention is given to the concept of overlapping rights and to the notion of integrated approach that derives from it.

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<sup>11</sup> Jennifer Anna Sellin (2014). Access to Medicines: the Interface between Patents and Human Rights. Does One Size Fit All? *Intersentia.*, p.10

<sup>12</sup> *Ibid.*, p.71

The third chapter introduces the U.S. health care system. In analyzing the system, the focus is given characteristics that determine the access to health care, and to the attempts to change this system based on private insurance. The way in which the two main public programs (Medicare and Medicaid) address the problem of access to health care for specific categories of the U.S. population is examined. The second part of the chapter is dedicated to the ACA and to the changes that it has brought (and has tried to bring) to the determination of health care coverage in the U.S. system. The reform is analyzed from a right to health perspective and only the parts of the law that could have made a difference in the recognition of this right by the U.S. are taken into consideration. A part of the chapter also analyzes the impact that the ACA has on women rights.

The last chapter tries to correlate the American system and human rights provisions in order to address the problem of equality in access to health care in the U.S. First of all, the chapter highlights the main features of the health care system that may constitute an obstacle to the realization of the right to health in the U.S., then one of the key question of the discourse is whether or not it is possible to speak about the American system from a human rights perspective and if this approach is justifiable through the international human rights instruments that the U.S. has recognized and to which they have bind themselves.

## Chapter I - The UN Framework of the Right to Equal Access to Healthcare

Table of contents: 1. The Universal Declaration of Human Rights - 1.1 The Right to Health in the International Covenant on Economic, Social and Cultural Rights - 1.2 General Comment 14 and the main Key Points of the Right to Health - 1.2.1 Availability and Accessibility - 1.2.2. Equality and Non-Discrimination - States Obligations: the Minimum Core of the Right to Health and the Concept of Progressive Realization - 1.2.3. States Obligations: to Respect, to Protect, to Fulfill - 1.3 The Special Rapporteur on the Right of Everyone to the Enjoyment of the Highest Attainable Standard of Physical and Mental Health - 1.4 The Right to Health in specific UN Conventions: UN Convention on the Elimination of Racial Discrimination - 1.5 The Right to Health in specific UN Conventions: UN Convention on the Elimination of all Forms of Discrimination against Women - 2. The World Health Organization Framework - 2.1. The World Health Organization Constitution - 2.2 A historical Development of the World Health Organization Contribution to Human Rights - 2.3 The International Conference on Primary Health Care (Alma-Ata) - 2.4 Universal Health Coverage

The World Health Organization (WHO) Constitution and the Universal Declaration of Human Rights (UDHR) are considered, in international human rights law, two milestones of the recognition of the right to health. The former has given the definition of health as “state of complete physical, mental and social well-being and not merely the absence of disease or infirmity”<sup>13</sup>; the latter, through the provisions of its Article 25, has been an inspiration for the binding legal norms that have followed<sup>14</sup>. In both these documents, and other human rights documents that have developed the concept of the right to health, this right is seen as a prerequisite to the enjoyment of other human rights; the scope of this right is not to guarantee good health to everyone, which is not an accomplishable goal, but to guarantee that everyone can enjoy his or her highest attainable standard of health, in order to have the possibility to conduct a decent life<sup>15</sup>.

### 1.The Universal Declaration of Human Rights

The Universal Declaration of Human Rights was adopted by the United Nations General Assembly in December 1948<sup>16</sup>. The document received a general consensus among UN members; this agreement could probably derive also from the fact that being a declaration, the document is not legally binding upon States<sup>17</sup>. However, the Declaration gained substantial importance in

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<sup>13</sup> WHO Constitution (1946). Preamble

<sup>14</sup> Paul O’Connell (2010). “The human right to health in an age of market hegemony”. In *Global Health and Human Rights. Legal and philosophical perspectives*. Routledge, New York., pp.190-1

<sup>15</sup> Upendra Baxi (2010). *Supra note (2)*., p.13

<sup>16</sup> George Annas (2005). “Human Rights and Health. The Universal Declaration of Human Rights at 50”. In *Perspectives on Health and Human Rights*. Routledge, New York., p. 64

<sup>17</sup> Jennifer Anna Sellin (2014). *Supra note (11)*., p.69

international human rights law, since it has been seen as the direct interpretation of the references to human rights written in the UN Charter<sup>18</sup>. The Declaration includes civil and political rights, as well as economic, social and cultural (ESC) rights, but, due to the Cold War polarization, these rights were then split into two different Covenants: the International Covenant on Civil and Political Rights (ICCPR), and the International Covenant on Economic, Social, and Cultural Rights (ICESCR), with the United States focusing on the former, and Soviet Union on the latter<sup>19</sup>. Due to these disagreements among States, it took approximately 20 years (from 1949 to 1966) to draft the two Covenants, and other ten years were necessary for them to come into force<sup>20</sup>. These polarization has its justification in the fact that it is common assumption, even if questionable, that civil and political rights are more connected to negative obligations for the State, whereas ESC rights are generally related to positive State actions<sup>21</sup>.

The final text of the Declaration provides neither a specific article dedicated to health nor a definition of health<sup>22</sup>; anyway, the provisions state in various articles have a correlation with the right to health, which includes the right to equal access to healthcare. Starting the analysis by Article 22, which is quite broad, some references to health emerge, since it affirms that “Everyone [...] is entitled to realization, through national effort and international co-operation and in accordance with the organization and resources of each State, of the economic, social and cultural rights indispensable for his dignity and the free development of his personality”<sup>23</sup>; the article mentions both States resources and the correlation between economic, social and cultural rights and the realization of one’s dignity, which are key elements in the understanding of the right to health, as will be shown later in the analysis. Article 27 poses the attention on the right of everyone to “participate in the cultural life of the community, to enjoy the arts and to share in scientific advancement and its benefits”<sup>24</sup>, even if it lacks to provide an evident and specific reference to the right to health, a condition of general well-being, and health, is a precondition of our ability to “function in the real world”<sup>25</sup>, and so a condition necessary to the realization of the provisions of

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<sup>18</sup> Idem.

<sup>19</sup> Sofia Gruskin, Daniel Tarantola (2005). “Health and Human Rights”. In *Perspectives on Health and Human Rights*. Routledge, New York., p.7

<sup>20</sup> Brigit Toebe (1999). The Right to Health as a Human Right in International Law. *Intersentia.*, p.40

<sup>21</sup> Ibid., p.71

<sup>22</sup> Ibid., p. 40

<sup>23</sup> Universal Declaration of Human Rights (1948). Art.22

<sup>24</sup> Ibid., Art.27

<sup>25</sup> Sudhir Anand (2004). “The Concern for Equity in Health”. In *Public Health, Ethics, and Equity*. Oxford University Press., pp.17-8

this article. Anyway, it is in Article 25 that a more clear reference to health and social determinants of health is made, since it asserts 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>26</sup>. This article anticipates what would be elaborated in more details in the ICESCR, in its General Comment No.14, and in other international and regional treaties.

### **1.1. The Right to Health in the International Covenant on Economic, Social and Cultural Rights**

The International Covenant on Economic, Social and Cultural Rights, together with the UDHR and the ICCPR, constitutes the International Bill of Rights that represents the foundation of the international normative system for human rights<sup>27</sup>. The Covenant provides, with Article 12, which disposes of: “the right of everyone to the enjoyment of the highest attainable standard of physical and mental health”<sup>28</sup>, the most authoritative expression of the right to health in international law<sup>29</sup>. The approach of ICESCR differs from the one of the UDHR because it gives to this right importance on its own, and it does not treat it together with general provisions of adequate standard of living<sup>30</sup>; it also highlights the fact that States Parties to the Covenant have to implement certain provisions in order to effectively realize the right<sup>31</sup>. In this matter, Article 12 clearly affirms that the steps taken by States have to be those necessary to prevent, treat and control epidemic, endemic, occupational and other diseases, and to create the conditions to assure to everyone, in the event of sickness, medical service and medical attention<sup>32</sup>, therefore, even if it is not directly mentioned, there is a reference to the provision of healthcare.

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<sup>26</sup> UDHR (1948). *Supra note (23)*. Art.27

<sup>27</sup> Maite San Giorgi (2012). The Human Right to Equal Access to Health Care. *Intersentia.*, p.11

<sup>28</sup> International Covenant on Economic, Social and Cultural Rights (1966), Art.12

<sup>29</sup> Maite San Giorgi (2012). *Supra note (32)*, p.11

<sup>30</sup> Stephen Marks (2013). “The Emergence and Scope of the Right to Health”. In *Advancing the Human Right to Health*. Oxford University Press., p.7

<sup>31</sup> *Ibid.*, p.7

<sup>32</sup> ICESCR (1966). *Supra note (28)*. Art.12

Although the Covenant recognizes the right to health, critics have been made concerning the scope of the right and the role of States Parties, due to the vagueness of its provisions<sup>33</sup>, the standpoint of these critics is that it is difficult to determine the specific obligations provided by the Covenant, which could be considered as a first step to understand the concept of the right to health and its implications, but not as a sufficient source of provisions and guidelines<sup>34</sup>. However, as will be analyzed later in the chapter, States are subject to progressive realization<sup>35</sup> and to the implementation of a minimum core<sup>36</sup>; therefore, the Covenant may be vague, but it is incorrect to say that it does not provide specific obligations upon States. It must be said that during the sessions that brought to the definition of the final draft, there was a considerable debate on whether to include or not the WHO definition of health in the Covenant, which could have partly avoided the vagueness of the term 'health'<sup>37</sup>; in the end, it was decided not to include it mainly because even the WHO definition of health was considered vague and without a real meaning<sup>38</sup>. The Covenant recognizes the right to health, but the real scope remained of difficult understanding; thus the Committee decided to issue a General Comment on the topic, in order to specifically address the mean of the right to health and the obligations that derive from it<sup>39</sup>; it is the General Comment 14, which is analyzed in the next subchapter.

## **1.2. General Comment 14 and the main Key Points of the Right to Health**

Given the significance of the General Comment 14 on the understanding of the meaning of the right to health, and since it highlights many points that are fundamental to the implementation of this right<sup>40</sup>, the main provisions of the General Comment are used, in this thesis, as a guideline to better understand the scope of the right to health; therefore in this subchapter just a general analysis is made, with a focus on access to healthcare, while the following ones will focus on some of the

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<sup>33</sup> Rachel Hammonds, et Al. (2012). Under the (Legal) radar Screen: Global Health Initiatives and International Human Rights Obligations. *BMC International Health and Human Rights*, 12:31., p.4

<sup>34</sup> Virginia Leary (1994). The Right to Health in International Human Rights Law. *Health and Human Rights*, Vol.1, No.1. p.41

<sup>35</sup> ICESCR (1966). *Supra note (28)*., Art.2

<sup>36</sup> CESCR General Comment No. 14: The Right to the Highest Attainable Standard of Health (Art. 12) (2000)

<sup>37</sup> Brigit Toebes. *Supra note (20)*, p. 51

<sup>38</sup> *Ibid.*, p.51

<sup>39</sup> Maite San Giorgi. *Supra note (27)*, p.12

<sup>40</sup> It has such a great importance because, even though the provisions of the Comment may seem vague and broad, it does not just affirm what States have to do (e.g., provide goods, services, and facilities), but it also states how they have to do it (e.g., without discrimination).

main aspects of the right, which are: accessibility; equality and non-discrimination; progressive realization and core obligation; States obligations: to respect, to protect, to fulfill.

General comments are not binding in the context of international law, neither are they formally binding for States Parties to the ICESCR<sup>41</sup>. However, since they represent the authoritative interpretation of the provisions included in the Covenant, they are not only relevant for the interpretation of the Covenant, and consequently of the right, but they should also be taken into account while interpreting it<sup>42</sup>. Speaking of General Comment 14, it has the role of clarifying the normative provisions expressed in Article 12 of the ICESCR, setting guidelines concerning the obligations of States<sup>43</sup>.

Paragraph 1 of the General Comment highlights the fact that health is a fundamental human right that is indispensable for the enjoyment and the exercise of other human rights<sup>44</sup>, and then it also reaffirms the statement of Article 12 of the Covenant asserting that “Every human being is entitled to the enjoyment of the highest attainable standard of health conducive to living a life in dignity”<sup>45</sup>, introducing the link between the enjoyment of a certain standard of health, and the possibility to live a decent life, which was missing in the ICESCR provision. Paragraph 3 enunciates the close relation occurring between the right to health and other human rights, stating that this right is not only related to them, but also dependent upon the realization of other human rights, such as the right to life, to non-discrimination and to equality<sup>46</sup>. Paragraph 8 focuses on one of the most misleading interpretations of the right to health, clearly affirming that “the right to health is not to be understood as a right to be healthy”<sup>47</sup>, this notion is of fundamental importance because it recognizes that none, neither States, can assure good health, given the existence, for example, of genetic factors and individual predispositions; therefore, the right to health must be interpreted as a right to the enjoyment of various facilities, services, conditions and goods that bring to the enjoyment of the highest attainable standard of health<sup>48</sup>.

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<sup>41</sup> Jennifer Anna Sellin. *Supra* note (11), p. 82

<sup>42</sup> *Ibid.*, p.82

<sup>43</sup> Paul O’Connell (2010). *Supra* note (14)., pp. 191-2

<sup>44</sup> CESCR General Comment No. 14 (2000). *Supra* note (36)., para.1

<sup>45</sup> *Idem*

<sup>46</sup> *Ibid.*, para 3

<sup>47</sup> *Ibid.*, para 8

<sup>48</sup> *Ibid.*, para 9



Even though the Comment does not provide a single way of realization of the right to health, recognizing that the measures of implementation may vary from State to State<sup>49</sup>, it emphasizes the role played by equal access to health care in the realization of the right to health<sup>50</sup>. In doing so, the attention is focused on the fact that States have an obligation to avoid any kind of discrimination regarding health care and also have to provide those without adequate means with health care facilities and health insurance<sup>51</sup>. It is important to note that General Comment 14 repeatedly reaffirms that the primary responsibility for the implementation of the right to health is of the States<sup>52</sup>.

### **1.2.1. Availability and Accessibility**

Two of the essential elements of the right to health<sup>53</sup>, as stated in the General Comment 14, which are also of fundamental importance for the realization of the more specific right to equal access to health care, are availability and accessibility. Concerning availability, the Comment clearly affirms that “Functioning public health and health care facilities, goods and services, as well as programmes, have to be available in sufficient quantity within the State party”<sup>54</sup>; in addressing the matter of availability, it is reaffirmed that nature of goods, services and facilities is not given, but it depends on various factors concerning each State party, anyway the Comment also clarifies that availability concerns also the underlying determinants of health, such as safe and potable water and hospitals<sup>55</sup>.

Speaking of accessibility, the focus is on two essential elements: non-discrimination and the role of the State, in fact, it does not only state that “health facilities, goods and services have to be accessible to everyone without discrimination”<sup>56</sup>, but emphasizes also that their accessibility have to be “within the jurisdiction of the State party”<sup>57</sup>. In explaining accessibility, the General Comment also highlights different aspects of the concept, such as physical accessibility and economic

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<sup>49</sup> Ibid., para 53

<sup>50</sup> Ibid., para19

<sup>51</sup> Idem

<sup>52</sup> Rachel Hammonds, et Al. (2012). *Supra* note (33), p. 6

<sup>53</sup> CESCR General Comment No. 14 (2000). *Supra* note (36), para 12

<sup>54</sup> Idem

<sup>55</sup> Ibid., para12 (a)

<sup>56</sup> Ibid., para12 (b)

<sup>57</sup> Idem

accessibility; the matter of economic accessibility (or affordability) is a core concept when speaking about health care, since health facilities, goods and services have to be affordable for all, and any payments, including those for health care services, must be based on the principle of equity, whether they are publicly or privately provided, so that they can be affordable for all, even for the most disadvantaged and vulnerable groups<sup>58</sup>, which represent the category that can be socially, economically or physically disadvantaged, such as the poor, ethnic minorities and persons with disabilities. For these groups the right to health asks for special attention in national health systems, also, when necessary with targeted health interventions<sup>59</sup>. So considering financial accessibility with respect to health care, it emerges that health care has to be affordable for everyone and that, moreover, affordability forms an integral part of the broader concept of accessibility to health care, this is why the cost of health care cannot be a burden to people who need to access it, since the enjoyment of health care has to depend on need and not on the ability to pay<sup>60</sup>.

### 1.2.2. Equality and Non-Discrimination

Even though equality and non-discrimination are not the same things, the relation between these two concepts is so tight that, here, they are analyzed together, also because discrimination generally strengthens inequalities and contributes to the denial of equal opportunities<sup>61</sup>. It is relevant to mention that the WHO provided a definition of inequities in health, describing them as unnecessary and avoidable differences, which are also considered unjust and unfair, in different fields that play a role in health, such as the economic one, and that affects a certain population group or subgroup<sup>62</sup>. Non-discrimination is one of the cornerstones of human rights<sup>63</sup>, and, generally, international laws prohibit any kind of discrimination<sup>64</sup> against people, based on factors such as race, sex, religion, and, sometimes, international law specifically refers also to

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<sup>58</sup> Idem

<sup>59</sup> Anand Grover, et Al. (2013). "The Consequences of Failure". In *Advancing the Human Right to Health*. Oxford University Press., p.429

<sup>60</sup> Maite San Giorgi. *Supra* note (27), p. 57

<sup>61</sup> Sofia Gruskin, Daniel Tarantola. (2005). *Supra* note (19)., p. 8

<sup>62</sup> Gorik Ooms (2014). "From International Health to Global Health: How to Foster a Better Dialogue between Empirical and Normative Disciplines". *BMC International Health and Human Rights*, 14:36., p.3

<sup>63</sup> Paul Hunt, Gunilla Backman (2008). "Health Systems and the Right to the Highest Attainable Standard of Health", *Health and Human Rights: An International Journal*, Vol. 10, No.1, p.43

<sup>64</sup> In the words of San Giorgi "Discrimination refers to an unjustified difference in treatment. This is unequal treatment based on prohibited grounds or based on a distinction for which no justification can be found" p. 67

discriminations based on disability or health status<sup>65</sup>. Non-discrimination is also, quite obviously, one of the key elements of the right to health; General Comment 14 affirms it in paragraph 3, where it states that the right to health depends on the realization, among others, of the right to non-discrimination<sup>66</sup>; furthermore, in paragraph 18 it clearly mentions the fact that, under the Covenant, any discrimination in access to health care, or to other underlying determinants of health, is proscribed<sup>67</sup>. In enumerating the different grounds on which discrimination is prohibited, such as race, sex, physical or mental disability, and health status, the paragraph emphasizes the fact that are considered discrimination, in this matter, not only the ones which has the direct intention of nullifying the equal realization of the right to health among people, but also those that create as an effect a discrimination in enjoying the right<sup>68</sup>, this demonstrates that both *de jure* and *de facto* discriminations are prohibited under the General Comment 14.

As already mentioned, health is what permits to people to enjoy other rights, and, more generally to function in the real world<sup>69</sup>, if we interpret health in this way, it appears clear that inequalities in health represent a denial of people opportunity to have a decent life<sup>70</sup>; however, speaking about equality and equity in the context of health, regards the achievement of the equal distribution of health-related services (including healthcare), and not of health in itself<sup>71</sup>, because it would be impossible. Equal access to health care constitutes one the clearest representation of the concept of equality in health. It consists of both formal and substantive equality of access; substantive equality also implies equity, since if a particular measure results in a form of unequal access to health care (being it direct or indirect), and this unequal accessibility cannot be justified, it constitutes a form of discrimination<sup>72</sup>. An expression of substantive equality can be vertical equity, which implies treating people who are unequal in society in different ways<sup>73</sup>. This approach could be seen as an interpretation of the concept of equality of the right to health since it tries to overcome the social and clinical different situations faced by people.

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<sup>65</sup> Richard Elliott, et Al. (2009, November). "HIV, Disability and Discrimination: Making the Links in International and Domestic Human Rights Law". *Journal of the International AIDS Society*, 12:29., p.8

<sup>66</sup> CESCR General Comment No. 14 (2000). *Supra* note (36), para 3

<sup>67</sup> *Ibid.*, para 18

<sup>68</sup> *Ibid.*, para 18

<sup>69</sup> Sudhir Anand. *Supra* note (25), p.18

<sup>70</sup> *Ibid.*, p.18

<sup>71</sup> Colleen Flood (2000). "International Health Care Reform. A legal, economic and political analysis." *Rutledge, London*. p.29

<sup>72</sup> Maite San Giorgi. *Supra* note (27), pp.74-5

<sup>73</sup> Alun Joseph, David Philips (1984). "Accessibility & Utilization Geographical Perspectives on Health Care Delivery". *Harper & Row, London.*, p.182

According to paragraph 12 of the General Comment 14, non-discrimination is a crucial aspect of accessibility<sup>74</sup>, and it is probably the first dimension of it<sup>75</sup>, therefore an analysis of how discrimination can emerge in access to health care is necessary. Concerning health care, discriminatory policies may assume different two forms, according to the fact that the decision concerns, generally, who to give health, or what group of health care services to provide in the field of a national health care system<sup>76</sup>. In the first case, the discrimination would not be based on the health status of the person, but on other grounds, such as income, sex, and ethnic background; in the second case, an analysis of the final cumulative benefit for the population would occur<sup>77</sup>. So a discriminatory decision of the first type would exclude from a treatment a particular category of the population (such as the poor, or women, or ethnic minorities), instead, one of the second type can be seen not as a discrimination, but as a way of distributing the available resources<sup>78</sup>. However, in most developed countries, where a private system coexist with the public one, this can bring, since it excludes, for example, the treatments for a particular illness from the ones provided by the healthcare system, to a *de facto* discrimination on the base of income, since only the ones who can bear the cost of private provisions of health care, would be able to afford the necessary means to face the illness: this concept is strongly related to the one previously expressed about substantive equality. The problem with this interpretation is that given that international documents do not give precise provisions concerning the resource that a State should invest in the realization of the right to health<sup>79</sup>, it is difficult to detect discriminations deriving from the second type of policies mentioned before; moreover, these could also not being identified as forms of discrimination, since a State can claim that it does not have the sufficient resources to treat specific illnesses<sup>80</sup>. This matter will be further analyzed in the chapter concerning the justiciability and the enforceability of the right to health, anyway, personally, the starting point of this kind of discriminations (lack of resources) it, seem pointless in developed countries.

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<sup>74</sup> CESCR General Comment No. 14 (2000). *Supra* note (36)., Ph.12

<sup>75</sup> Stephen Marks. *Supra* note (30), p.10

<sup>76</sup> Reidar Lie (2014, October). "Health, Human Rights and Mobilization of Resources for Health". *BMC International Health and Human Rights*, 4:4., p.6

<sup>77</sup> *Idem*

<sup>78</sup> *Idem*

<sup>79</sup> *Ibid.*, p. 3

<sup>80</sup> *Idem*

### **1.2.3. States Obligations: the Minimum Core of the Right to Health and the Concept of Progressive Realization**

The scope of the right to health refers to all the elements given by the treaties concerning the topic; these elements can be divided into two parts: on the one hand, the ones that regard health care, on the other hand, the ones that relate to underlying preconditions of health<sup>81</sup>. This division is functional to the object of this thesis, and therefore just the part relevant to the analysis of equal access to health care will be examined. In international treaties (and in ICESCR and General Comment 14 more specifically), there is no provision in regard to the nature (public or private) of health care systems<sup>82</sup>; some authors, as reported by Toebes, have argued that in order to achieve equality in access, a strong central health authority is necessary<sup>83</sup>, however, there is not any documents imposing to States a particular kind of health care system<sup>84</sup>; what is essential is that States are responsible for the implementation of the right, therefore even when services are provided privately, the responsibility is of the State<sup>85</sup>. In fact, States do not just have to take measures aimed at the enjoyment of the right and at the provision and promotion of access to health care and refrain from violating the right directly, they also have to prevent third parties from infringing the right<sup>86</sup>. Furthermore, even if States decide not to directly provide health care to their population, under the right to health they have to adequately finance health through measures regarding resource allocation and budget prioritization, in order to guarantee the principle of accessibility, especially to marginalized and vulnerable population<sup>87</sup>. The attention devoted by the right to health to disadvantaged population is motivated by the fact that, first of all, many health systems fail at really addressing the needs of these groups, consequently, this lack of access to health services, such as preventive and primary health care, contributes to the exacerbation of their health problems, increasing, among other risks, their possibilities to contract communicable diseases<sup>88</sup>, and exacerbating their marginalization.

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<sup>81</sup> Brigit Toebes. *Supra* note (20), p.245

<sup>82</sup> *Ibid.*, p.248

<sup>83</sup> *Ibid.*, p.249

<sup>84</sup> *Ibid.*, p.248

<sup>85</sup> *Ibid.*, p.249

<sup>86</sup> Thérèse Murphy (2004). "Health and Human Rights". In *Public Health, Ethics, and Equity*. Oxford University Press., p.43

<sup>87</sup> Anand Grover, et Al. (2013). *Supra* note (59), pp.428-9

<sup>88</sup> *Ibid.*, pp.429-30

What is asked to States is to take steps aimed at the implementation and the realization of the right; therefore the obligations of States can be seen as ‘obligations of conduct’, which bring to the achievement of a result (the accomplishment of the highest attainable standard of health)<sup>89</sup>. In order to pursue the objective, States are not obliged to incorporate the right to health in national constitutions, since legislative measures are not seen as the only way to achieve the purpose<sup>90</sup>; this is clearly connected to the notion, mentioned before, that States are not obliged to implement a particular kind of health care system in order to comply with human rights provisions. Furthermore, even though the recognition of the right to health in national legislations may attest a stronger will of the State to realize the right to health, it is not a compulsory step to be taken (a more in-depth analysis of this subject will be provided in the chapter dealing with the justiciability and enforceability of the right to health). One of the main problems connected to the minimum core, is that it does not specify which kind of health services and goods are part of it; this lack of precision really penalizes the ambition of the core content, since it is difficult to claim for its realization and to distinguish situations of inaction from those of effective resource scarcity<sup>91</sup> (even if minimum core implementation does not have to depend on resource availability, it is undeniable that for certain developing countries it is impossible to realize it without international assistance, which is not always provided).

The development and the implementation of the right to health have to be met in a context of progressive realization. This means that States do not have to immediately realize it, which would be impossible, due in particular to resources availability<sup>92</sup>, but they have to act in a positive way that aims at the complete implementation of the human rights provision. However, the Committee also creates a core minimum set of obligations that cannot be applied in a progressive perspective<sup>93</sup>, this is to highlight the fact that States have to take concrete actions intended to the realization of the right<sup>94</sup>. According to this core minimum, States have to, among other actions, ensure that access to health facilities, goods and services is non-discriminatory, in particular for disadvantage and vulnerable population; that essential drugs are provided; that equality in the distribution of health goods, services and facilities is assured; and that a national public health

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<sup>89</sup> John Tobin (2012). *The Right to Health in International Law*. Oxford University Press, p.178

<sup>90</sup> *Ibid.*, p.179

<sup>91</sup> Lisa Forman, et. Al. (2013). “What could a Strengthened Right to Health Bring to the Post-2015 health Development Agenda?: Interrogating the Role of the Minimum Core Concept in Advancing Essential Global Health Needs”. *BMC International Health and Human Rights*, 13:48., p. 2

<sup>92</sup> CESCR General Comment No. 14. (2000). *Supra* note (36)., para. 30-31

<sup>93</sup> Stephen Marks (2013). *Supra* note (30), p.10

<sup>94</sup> Thérèse Murphy (2004). *Supra* note (86), p.44

strategy, which addresses the health concerns of the whole population, is implemented, also in this last provision, the importance of giving particular attention to the vulnerable population is stressed<sup>95</sup>.

The progressive realization of the right asked to States should start from the implementation of the minimum content. Since just achieving the realization of the core content is not enough to the accomplishment of the right to health, the minimum content should act as "an 'expanding floor' and not as a 'fixed ceiling'"<sup>96</sup>, it is correct to say that the progressive realization of the right is strictly related to available resources of States, however, the maximum of them as to be used<sup>97</sup> in order to implement the progressive realization that as the full realization of the right as first scope. Even though the risk of having the minimum core perceived as a 'ceiling' exists, and some States may attempt to use realization of the core content as a demonstration of the implementation of the right, the concept of progressive realization plays an essential role in the discourse of economic, social and cultural rights, in general, and in the one concerning the right to equal access to health care in particular, since it represents the recognition of the fact that these rights cannot, even when there is a strong will, be realized immediately or in a short period of time, due to the fact that they depend on the availability of resources<sup>98</sup>. Even if necessary, progressive realization linked to the availability of resources gives rise to the necessity to evaluate the appropriateness of States measures<sup>99</sup>, which is one of the main problems in the matter of justiciability of the right to health.

### **1.2.3. States Obligations: to Respect, to Protect, to Fulfill**

In paragraph 33, General Comment 14 identifies three levels of States obligations: the obligations to respect, to protect, and to fulfill (the latter including the obligations to facilitate, to provide, and to promote)<sup>100</sup>. The comment dedicates a considerable amount of spaces to each one of these obligations, dedicating them the paragraphs from 33 to 37. Briefly, these three types of obligations, impose to States different kinds of actions, both negative and positive: States have to avoid direct or indirect interferences with the realization of the highest attainable standard of health; they also have to prevent third parties from intruding in the enjoyment of the right, and they have to

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<sup>95</sup> Stephen Marks (2013). *Supra* note (30), p.10

<sup>96</sup> Maite San Giorgi (2012). *Supra* note (27), p.17

<sup>97</sup> *Ibid.*, p.32

<sup>98</sup> *Ibid.*, p.33

<sup>99</sup> Reidar Lie (2014, October). *Supra* note (76), p.5

<sup>100</sup> CESCR General Comment No. 14 (2000). *Supra* note (36)., para.33

adopt adequate measures aimed at a full implementation of the right to health<sup>101</sup>. The three levels of obligations will be further analyzed, focusing on the provisions concerning equal access to health care.

According to the obligation to respect, States have to abstain from both denying and limiting equal access to all persons to health services of preventive, curative, and palliative nature<sup>102</sup>; quite obviously, States have to adhere to this obligation according to the principles of equality and non-discrimination. Therefore, in implementing the right to health, equal access have to be guaranteed also to categories such as prisoners, detainees, minorities, illegal immigrants, and asylum-seekers<sup>103</sup>, without any forms of prohibited discrimination.

In explaining the scope of the obligations to protect, General Comment 14 in its paragraph 35, clearly states that “Obligations to *protect* include, inter alia, the duties of States to adopt legislation or to take other measures ensuring equal access to health care and health-related services provided by third parties”<sup>104</sup>. Therefore this obligation emphasizes the responsibility role of States that have to guarantee that even when they do not directly provide health care and health-related services, they still respect the principles of availability and accessibility<sup>105</sup>; this is of fundamental importance when addressing the right to equal access to health care since States have to guarantee to their population the possibility of accessing health care without discrimination and on an equal basis<sup>106</sup>. The State, therefore, even when is not the provider of health care, play the role of protector of human rights<sup>107</sup>. In the field of the obligation to protect, also fall the obligation, for the State, to protect the population against unreasonable essential medicines’ prices and against certain health insurance that tends to exclude particular categories of patients, such as elderly or women in the reproductive age<sup>108</sup>.

Paragraphs 36 and 37 of the Comment are dedicated to the obligation to fulfill, according to which, States are encouraged to recognize the right to health in their national legal system, preferably through legislative measures<sup>109</sup>, however, as already noted, this encouragement does not

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<sup>101</sup> *Idem*

<sup>102</sup> *Ibid.*, para 34

<sup>103</sup> *Idem*

<sup>104</sup> *Ibid.*, para 35

<sup>105</sup> *Ibid.*, para 35

<sup>106</sup> Maite San Giorgi (2012). *Supra* note (27), p.61

<sup>107</sup> *Ibid.*, p. 46

<sup>108</sup> *Ibid.*, p. 47

<sup>109</sup> CESCR General Comment No. 14 (2000). *Supra* note (36)., para 36



constitute an obligation. What States must ensure, according to the obligation to fulfill, is to provide health care and to guarantee equal access for everyone<sup>110</sup>. In addressing the measures to be implemented and how to do it, the Comment does not provide a preference concerning the nature of health care, in fact it affirms that “Further obligations include the provision of a public, private or mixed health insurance system”, however, emphasis is posed on the fact that, irrespective of the nature of the system, it has to be affordable for all<sup>111</sup>. According to the obligation to fulfill, States also have to take adequate measures aimed at enabling and assisting people to enjoy the right, especially in the case in which these people are unable, for reasons beyond their control, to realize the right themselves; moreover, States have to take actions with the purpose of creating, maintaining, and restoring the health of the population<sup>112</sup>. This obligation represents the positive obligation of States with respect to the realization of the right to health since States have a duty to ensure that health care is accessible to the whole of its population<sup>113</sup>; even if health care is privately provided, States have to guarantee that vulnerable and marginalized population have access to health care, also by directly providing the service<sup>114</sup> (other obligations of States in the case of private health care systems fall under the obligation to protect).

### **1.3. The Special Rapporteur on the Right of Everyone to the Enjoyment of the Highest Attainable Standard of Physical and Mental Health**

In order to have a complete perspective of the international human rights law framework of the right to equal access to health care, the figure of the Special Rapporteur on the right of everyone to the enjoyment of the highest attainable standard of physical and mental health<sup>115</sup> (from now on ‘Special Rapporteur’), established in 2002 by the UN Commission on Human Rights needs to be mentioned. From the ‘90s the Commission started to establish these ‘special procedure’ to topics of economic, social and cultural rights, before it had just established such procedures for matters of civil and political rights<sup>116</sup>. This procedure was supported by some developing countries, while most

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<sup>110</sup> Idem

<sup>111</sup> Idem

<sup>112</sup> Ibid., para 37

<sup>113</sup> Maite San Giorgi (2012). *Supra* note (27), pp. 47-8

<sup>114</sup> Ibid., p.48

<sup>115</sup> Paul Hunt, Sheldon Leader (2010). "Developing and applying the right to the highest attainable standard of health. The role of the UN Special Rapporteur (2002–2008)". In *Global Health and Human Rights Legal and philosophical perspectives.*, Routledge New York., p.28

<sup>116</sup> Ibid., pp.28-9

developed countries were circumspect about it and the U.S.A. and Australia actually voted against it when the resolution came before the UN Economic and Social Council<sup>117</sup>. The Special Rapporteur is an independent figure, he or she is not a member of the UN Secretariat, that report directly to the General Assembly and Human Rights Council<sup>118</sup>. The first Special Rapporteur was Paul Hunt who submitted an average of 30 reports during a period of 6 years (2002-2008). Since General Comment 14 represents a central step in the evolution of the understanding of the right to health, it significantly contributed to shaping the Special Rapporteur's work; taking the general analysis provided by the Comment as a starting point, the reports of the Special Rapporteur aimed at framing the right to health in a more specific and accessible manner<sup>119</sup>.

Among the reports of various Special Rapporteurs, the "Report of the Special Rapporteur on the Right of Everyone to the Enjoyment of the Highest Attainable Standard of Physical and Mental Health" by Paul Hunt is of particular interest to the topic of this thesis. In fact, he emphasizes the importance of a strong health system as an essential element of a healthy and equitable society, posing it, as a core institution, on the same level of a democratic political system and of a fair justice system<sup>120</sup>. More precisely, he recognizes that inequities in health status are a problem that affects all countries in the world, not only developing countries, he refers to this situation as a human crisis caused by the failure of health systems<sup>121</sup>; furthermore, he states that "at the heart of the right to the highest attainable standard of health lies an effective and integrated health system, encompassing health care and the underlying determinants of health, which is responsive to national and local priorities, and accessible to all. Without such a health system, the right to the highest attainable standard of health can never be realized"<sup>122</sup>, recognizing the central importance of healthcare in the realization of the right as a whole.

Another principle highlighted by Hunt in his report is the fundamental role played by equality and non-discrimination, which being among the most fundamental elements of human rights, are incredibly relevant also to the right to health<sup>123</sup>; States have to ensure that health systems are accessible to everyone without discrimination, including minorities, vulnerable and disadvantaged population; moreover, States have also to be responsive to particular health needs of

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<sup>117</sup> Idem

<sup>118</sup> Ibid., p.29

<sup>119</sup> Ibid., p.30

<sup>120</sup> Paul Hunt. Report of the Special Rapporteur on the Right to Everyone to the Enjoyment of the Highest Attainable Standard of Physical and Mental Health. para12

<sup>121</sup> Ibid., para13

<sup>122</sup> Ibid., para 15

<sup>123</sup> Ibid., para 24

the population or of a group of it, such as the ones of disabled, elderly, children, and women<sup>124</sup>. Irrespective of the measures taken by States, in his report Hunt reaffirms that equal access to health care has to be based on need<sup>125</sup>, and not on other conditions, such as the ability to pay.

#### **1.4. The Right to Health in specific UN Conventions: UN Convention on the Elimination of Racial Discrimination**

There are a number of declarations and conventions regarding minorities or specific groups that include references to the right to health and equal access to healthcare. Among those, it is necessary to briefly analyze the Convention on the Elimination of Racial Discrimination (CERD), since it is the only one convention that includes the right to health that has been ratified by the United States, which health care system will be examined in the second part of the thesis. The U.S. has also signed, but not ratified the ICESCR, this means that they are not legally bound to the Covenant, but, anyway, they cannot act in contrast with the purpose and object of the treaty<sup>126</sup>, instead they have ratified the Constitution of the World Health Organization (WHO).

Article 5 of the CERD affirms that “States Parties undertake to prohibit and to eliminate racial discrimination in all its forms and to guarantee the right of everyone, without distinction as to race, color, or national or ethnic origin, to equality before the law”<sup>127</sup>; this commitment of States Parties has to be notably directed to the enjoyment of a particular group of rights. Economic, social and cultural rights are included in these rights, and, speaking of them, an explicit reference to the right to health and health care is made in Article 5 (e)(IV), where public health and medical care are enlisted<sup>128</sup>. A reference to the right to health can also be detected in Article 5 (e)(VI), where the right to equal participation of cultural activities is mentioned<sup>129</sup>; since health is a precondition of people’s social life and of their active participation also in cultural activities, it could be said that, even if not directly, this right could also be read from right to health perspective.

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<sup>124</sup> Ibid., para 43

<sup>125</sup> Idem

<sup>126</sup> Carol Castleberry (2015). A Human Right to Health: Is There One and, If So, What Does It Mean. *10 Intercultural Hum. Rts. L. Rev.* 189, 232., p.192

<sup>127</sup> U.N. Convention on the Elimination of Racial Discrimination (1963) Art.5

<sup>128</sup> Ibid., Art.5 (e)(iv)

<sup>129</sup> Ibid., Art.5 (e)(vi)

## **1.5 The Right to Health in specific UN Conventions: UN Convention on the Elimination of all Forms of Discrimination against Women**

Among UN Conventions targeted at specific groups, it is important to mention the Convention on the Elimination of all Forms of Discrimination against Women (CEDAW), mainly because the U.S. has signed it, even though still not ratified, and because women's rights are one of the topic of the ACA. Part III of the Convention is the one dedicated to ESC rights. Article 12 of this part specifically addresses women's rights with respect to health care: the focus of Article 12 is the elimination of discrimination against women with respect to access to health care, which has to be equal for both women and men; this article specifically address the matter of access to reproductive care<sup>130</sup>. The second paragraph of this article provides further explanations with respect to reproductive care, and states that States have to guarantee to women appropriate services throughout all the period related to pregnancy, including in its provision not only the pregnancy in itself, but also confinement and post-natal care<sup>131</sup>. Moreover, the Convention specifies that these services have to be provided without charges when necessary, and also the fact that States have to guarantee adequate nutrition to women during pregnancy and post-natal period<sup>132</sup>.

The provisions of this Convention related to access to health care are fundamental in understanding the meaning of guaranteeing equal access, because, through the example of women, they emphasize the fact that in order to assure equality in access to health care, each group has to be provided with different services; if someone is excluded by the system because of a specific need (such as services related to pregnancy) it is hard to define that system as an equal one. This notion, taken in its general meaning and not only on its reference to women's necessities, also assumes a specific importance in analyzing the U.S. health care structure. The fact that biological differences cannot justify inequalities in health care is clearly explained in the CEDAW General Recommendation No. 24 issued in 1999<sup>133</sup>. In addressing the matter of access to health care for women, States have to take into consideration also other forms of discrimination that women may be subject to, since they can affect women's health or result in their impossibility to access health

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<sup>130</sup> Convention on the Elimination of All Forms of Discrimination against Women (1979), Art.12 para 1

<sup>131</sup> Ibid., Art. 12 para 2

<sup>132</sup> Idem.

<sup>133</sup> CEDAW General Recommendation No.24. (1999). Para 12 (a)

care services; for example domestic violence and gender-based violence can have an impact on women's health, but can also result in difficulty in seeking for certain health care services<sup>134</sup>.

## 2. The World Health Organization Framework

### 2.1. The World Health Organization Constitution

The World Health Organization (WHO) Constitution was adopted by the International Health Conference in 1946, and it entered into force in April 1948<sup>135</sup>; with the adoption of the Universal Declaration of Human Rights (UDHR) still ongoing, the Constitution of the WHO represents the first international treaty to recognize the right to health, and to enunciating it through the concept of the right to the highest attainable standard of health<sup>136</sup>; moreover it also constituted an inspiration for the development of the right to health in other international documents<sup>137</sup>. One of the peculiarities of this document is that it defines health<sup>138</sup>, definition that is not included neither in the UDHR, nor in the ICESCR, as already noted; this definition is in the preamble to the Constitution and it describes health as a “state of complete physical, mental and social well-being and not merely the absence of disease or infirmity”, however vague, this definition is fundamental to the understanding of the meaning of the right to health, since it recognizes the fact that having a right to health is different from having a right to be healthy<sup>139</sup>: the first one, though complex, can be achievable, the second one cannot be achieved, due to factors that depend neither on human beings nor on States or society (e.g., genetic mutations). The Constitution goes on highlighting the fact that the highest attainable standard of health is a fundamental right of every human being, without any discrimination; another focus of this preamble is the fact that Governments do play an important role in the realization of the right to health, since they have the responsibility for the health of their people<sup>140</sup>. Besides the provision of a definition of health and of the right to health, a considerable amount of the Preamble focuses on the obligations of States. In fact, it affirms that “Governments

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<sup>134</sup> Ibid. various paragraphs.

<sup>135</sup> WHO Constitution (1946). *Supra note (13)*. Preamble

<sup>136</sup> Benjamin Meier (2017, June). Human Rights in the World Health Organization: Views of the Director-General Candidates. *Health and Human Rights Journal, Vol. 19, No.1.*, p.5

<sup>137</sup> Maite San Giorgi (2012). *Supra note (27)*,p.10

<sup>138</sup> Helena Nygren-Krung (2013). “The Right to Health: from Concept to Practice”. In *Advancing the Human Right to Health. Oxford University Press.*, p.39

<sup>139</sup> John Tobin (2012). *Supra note (89)*,p.67

<sup>140</sup> WHO Constitution (1946). *Supra note (13)* Preamble

have a responsibility for the health of their peoples which can be fulfilled only by the provision of adequate health and social measures”<sup>141</sup>; even if this statement does not clarify which measures have to be implemented<sup>142</sup>, it clearly mention the responsibility of States in the realization of the right. However, neither in the Preamble, nor in the Articles of the Constitution, a clear statement enunciating which are the responsibilities of States is provided, therefore even if there seems to be a general consensus among WHO Member-States concerning the universality of access, there is less clarity about to what access should be ensured, and who is in charge of guaranteeing it<sup>143</sup>, the WHO Constitution is not of any help in this matter. In the conclusion of the Preamble, the Constitution explicitly affirms that contracting Parties agree with the Constitution and with the establishment of the WHO as a specialized agency, in the context of Article 57 of the Charter of the United Nations<sup>144</sup>.

The language used in the Constitution is of considerable relevance. First of all, the definition of health determined in the document is an essential step toward the recognition that the health discourse does not have to be just biomedical- or pathology-based, but it can go further in the direction of the domain of general well-being, with the acknowledgment of the value of health as a fundamental determinant of human life<sup>145</sup>. This is also witnessed by the fact that the notions expressed in the Preamble emphasize the attention also posed on the instrumentalist dimension of health. This interest emerges in the final version of the Preamble, where the concept of the highest attainable standard of health is accompanied by the idea that health is relevant also to the attainment of peace and security<sup>146</sup>; thus the right to health was believed to be either normative and instrumental, since it imposes obligations on States both on acting in order to achieve the full realization of the right to health of individuals and to co-operate in order to satisfy strategic and community interests<sup>147</sup>. Though far-sighted, the definition of health given in the Preamble causes various problems of interpretation, since it is difficult to understand and determine the means of certain words, such as ‘attainable’<sup>148</sup>; unfortunately, this kind of vaguenesses constitute a relevant problem in the definition, and consequently in the implementation, of the right to health in

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<sup>141</sup> Idem

<sup>142</sup> Rachel Hammonds, et Al. (2012). *Supra* note (33),p.4

<sup>143</sup> Helena Nygren-Krung (2013). *Supra* note (138), p.46

<sup>144</sup> WHO Constitution (1946). *Supra* note (13). Preamble

<sup>145</sup> Sofia Gruskin, Daniel Tarantola (2005). *Supra* note (19), p.22

<sup>146</sup> John Tobin (2012). *Supra* note (89), p.29

<sup>147</sup> Ibid., p.29

<sup>148</sup> Joia Mukherjee (2013). “Financing Governments: towards Achieving the Right to Health”. In *Advancing the Human Right to Health*. Oxford University Press., p.411

international law. Also, the boundary of the meaning of the word 'health' is problematic. Provided that this definition was (and still is) necessary, and that other international documents do not furnish any kind of it, creating even more uncertainty in the interpretation of the right, the WHO definition of health is often considered too broad to also have any meaning<sup>149</sup>.

## **2.2. A historical Development of the World Health Organization Contribution to Human Rights**

During the first years of its life, the WHO consistently contributed to the recognition and improvement of the right to health, as analyzed in the previous subchapter. Under its guidance, the discourse about health shifted from a concept of mere absence of disease to the one of a development of a standard of living adequate for health, including, therefore, both medical care and the underlying determinants of health<sup>150</sup>. During this period, the WHO works consistently with a human rights perspective of the right to health, its role was relevant also in the starting elaboration of the ICESCR<sup>151</sup>. However, after this first period during which the WHO seemed to focus on the human rights perspective of the right to health, after a change in leadership at the Organization, in 1953, the WHO stopped playing an active role in the drafting of the Covenant<sup>152</sup>. In this period, the approach of the Organization started to be a more biomedical one, so the interest of the WHO was no more primarily on national health systems and underlying determinants of health, but it was a more medicalized one, which brought the Organization to focus on a disease-specific approach to health<sup>153</sup>; this brought to the absence of WHO comments on the final draft of the ICESCR, enabling the weakening of health protection in the Covenant, since it gave the possibility to States to reopen debates about the inclusion of a definition of health and the idea of social well-being<sup>154</sup>, which are in the WHO Constitution but had not be reported or further analyzed in the ICESCR. Furthermore, the Organization also refused to advocate for the ratification of the Covenant among its Member States, after the Director of the U.N. Division of Human Rights, Mr. Schreiber, asked for the

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<sup>149</sup> Stephen Marks (2005) "Human Rights in Development the Significance for Health". In *Perspectives on Health and Human Rights*. Rutledge New York., p.92

<sup>150</sup> Benjamin Meier (2010). "The World Health Organization, the Evolution of Human Rights, and the Failure to Achieve Health for All". In *Global Health and Human Rights Legal and philosophical perspectives*. Routledge, New York., pp.166-7

<sup>151</sup> Ibid., p. 168

<sup>152</sup> Stephen Marks (2013). *Supra* note (30), p.7

<sup>153</sup> Benjamin Meier (2010). *Supra* note (150), p.172

<sup>154</sup> Ibid., p.173

Organization assistance<sup>155</sup>. This kind of inactivity of the WHO in the matter of human rights continued for several years, and, even though these were years of general expansion of the welfare state in developed countries, this did not happen within a human rights perspective<sup>156</sup>.

In the '70s, due mainly to the health risks caused by heart disease, cancer, labor migration and exploitation, environmental harms, drug addiction, and overpopulation, the public health discourse came back to emphasizing the importance of socio-economic determinants of health. This contributed to a return of the WHO to the human rights approach<sup>157</sup>. One of the first actions of the Organization in this respect, was the definition of the 'Health For All' strategy to primary health care at the World Health Assembly in 1977, which aimed at the attainment for the population of the whole world of a level of health that would enable them to live a socially and economically productive life by the year 2000<sup>158</sup>. In this context, the Organization reaffirmed the responsibilities of States in the achievement of the goal of the strategy<sup>159</sup>. With its return to the human rights discourse, the WHO also sponsored the Declaration of Alma-Ata, on primary health care; various resolutions and reports, such as the 2005 WHA Resolution and the 2010 World Health Report in the context of universal health coverage (UHC): these will be further analyzed in the next subchapters; and issued the Fact Sheet No.31 that gives some further details on the interpretation of the right to health. Explaining what the right to health is, the Fact Sheet defines that this right guarantees, among other entitlements, a system of health protection that provides equal opportunities for all to the enjoyment of the right<sup>160</sup>, anyway, also in this document, the entitlements of the right remain quite vague. It also dedicates some attention to the definition of what the right to health is not, emphasizing the fact that it is not a right to be healthy<sup>161</sup>, and clearly stating that it is not a "programmatic goal to be attained in the long term"<sup>162</sup>, however, also here the entity of the measures that States have to enact in order to achieve at least the realization of those obligations that must be immediately implemented is not explained, and therefore it stays quite blurred. What is

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<sup>155</sup> Benjamin Meier (2010). *Supra* note (150), pp.30-1

<sup>156</sup> John Tobin (2012). *Supra* note (89), p.32

<sup>157</sup> Benjamin Meier (2010). *Supra* note (150), p. 175

<sup>158</sup> *Ibid.*, pp.176-7

<sup>159</sup> *Ibid.*, p.177

<sup>160</sup> Office of the United Nations High Commissioner for Human Rights. (2008) "*The Right to Health, Fact Sheet No. 31*", p.3

<sup>161</sup> *Ibid.*, p.5

<sup>162</sup> *Ibid.*, p.5



of interest is that it affirms that States have a primary obligation to protect and promote human rights, since they are guaranteed by international customary law<sup>163</sup>.

### **2.3 The International Conference on Primary Health Care (Alma-Ata)**

In the framework of the ‘Health For All’ strategy, the Declaration on Primary Health Care of the International Conference on Primary Health Care (also known as Declaration of Alma-Ata), of 1978, would provide a consensus at international level for national primary healthcare systems, which is consistent with the WHO’s vision of health and human rights; it recognized to primary health care a leading role in the addressing of the underlying determinants of health, in compliance with the right to health<sup>164</sup>. Article 1 of the Declaration reaffirms the some of the core principles of the WHO Constitution Preamble, such as the fact that health is a state of physical, mental and social well-being, and that it is a fundamental human right, but it takes a further step, stating that “the attainment of the highest possible level of health is a most important world-wide social goal whose realization requires the action of many other social and economic sectors in addition to the health sector.”<sup>165</sup>; to this Article refers the Special Rapporteur Paul Hunt when in his report he recognizes the importance of the fact that the Declaration considers together the different domains of the right to health: medicine, public health, and human rights<sup>166</sup>. For this reason, even though the Declaration is not binding, it is often recognized as one of the most important moment in the human right to health discourse, since it extended the notion of the right and, in particular, because it poses it in the context of social and economic determinants of health<sup>167</sup>.

Article 5 of the Declaration affirms that e level of health that permits to people all over the world to enjoy a socially and economically productive life has to be achieved by the year 2000. Even though the WHO tried to return to the human rights discourse, its absence of about 25 years, and more specifically the lack of its presence in the fundamental moment for the right to health of the transition from the UDHR to the ICESCR, has proved fatal to the realization of the goal of primary healthcare included in the Declaration<sup>168</sup>.

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<sup>163</sup> Ibid., p.22

<sup>164</sup> Benjamin Meier (2010). *Supra* note (150), p.177

<sup>165</sup> International Conference on Primary Health Care, Alma-Ata, Art.1

<sup>166</sup> Paul Hunt. *Supra* note (120), para 25

<sup>167</sup> Carol Castleberry (2015). *Supra* note (126), pp.208-9

<sup>168</sup> Benjamin Meier (2010). *Supra* note (150), p.163

## 2.4. Universal Health Coverage

In the history of global health, the improvements of public health (e.g. sanitation), and the reduction of communicable diseases are seen, respectively, as the first and the second transition; universal health coverage may represent the third transition in global health<sup>169</sup>. Universal coverage has been identified as a priority for every health system<sup>170</sup>; under the guidance of the WHO, the realization of this goal has been seen as directly related to the improvement of prepaid health care financing systems that permit equality in access to quality health care<sup>171</sup>.

The universal health coverage discourse is challenging to address also because there is no treaty about this topic<sup>172</sup>, anyway it is one of the core concept of the action of the WHO since its return to the human rights perspective. The 2005 WHA Resolution on “Sustainable Health Financing, Universal Coverage and Social Health Insurance” is a good starting point to approach the topic; moreover, it has been accepted by the World Health Assembly, where almost all countries are represented, and every country has the right to vote (one per State); therefore it could be considered at the same level of a declaration by the United Nations<sup>173</sup>. The resolution exhorts States to adhere to certain provisions, among them, States are asked “to ensure that health-financing systems include a method for prepayment of financial contributions for health care, with a view to sharing risk among the population and avoiding catastrophic health care expenditure and impoverishment of individuals as a result of seeking care”<sup>174</sup>; moreover, States are also required to guarantee equitable distribution of health care structures, which have to provide everyone, in an equal manner, access to good-quality health services<sup>175</sup>.

Another important document concerning universal health coverage is the 2010 WHO Health Report that describes UHC in three dimensions<sup>176</sup>: the first one addresses the amount of population covered under UHC, highlighting that neither high-income countries “that are commonly said to have achieved universal coverage actually cover 100% of the services available and for 100% of the

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<sup>169</sup> Audrey Chapman (2016). “Assessing the Universal Health Coverage Target in the Sustainable Development Goals from a Human Rights Perspective” p.1

<sup>170</sup> Gilbert A. Abihiro, Manuela De Allegri (2015). Universal Health Coverage from Multiple Perspectives: a Synthesis of Conceptual Literature and Global Debates. *BMC International Health and Human Rights*, 15:17., p.2

<sup>171</sup> Idem, p.2

<sup>172</sup> Gorik Ooms, et. Al. (2014). *Supra* note (62), p.2

<sup>173</sup> Idem

<sup>174</sup> 2005 World Health Assembly Resolution

<sup>175</sup> Idem.

<sup>176</sup> Gorik Ooms, et. Al. (2014). *Supra* note (62) p.5

cost - and with no waiting list<sup>177</sup>, I would personally argue that such a result is quite impossibly achievable; the second dimension deals with the financial contribution covered by States or by government-supported plans; the third one addresses the benefits that the realization of the UHC would bring<sup>178</sup>.

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<sup>177</sup> 2010 World Health Report, pp.15-6

<sup>178</sup> Gorik Ooms, et. Al. (2014). *Supra* note (62), p.5

## Chapter II - The Justiciability of the Right to Health

Table of contents: 1. Is the Right to Health justiciable? - 1.1 The Reporting Practice - 1.2 The Optional Protocol to the ICESCR - 2. The Concept of Overlapping Rights and the Integrated Approach

### 1. Is the Right to Health Justiciable?

Ever since their emergence, the justiciability of Economic, Social, and Cultural Rights has been matter of debate<sup>179</sup>. This emerges, partly, from the fact that these rights are considered to imply financial investments by States, but also from the fact that courts are often claimed not to have the competencies to address resource allocation since the content of these rights is considered quite vague<sup>180</sup>; furthermore, there is a limited amount of human rights bodies before which a violation of this type of rights can be brought<sup>181</sup>. Given the general condition of Economic, Social, and Cultural Rights, in order to correctly analyze the right to health, it is necessary to inspect the justiciability and enforceability of this right. The first standpoint to be clarified in addressing this matter is that the right to health does exist, even though it is not mentioned in various constitutions, and States have an obligation to progressively realize it<sup>182</sup>, in accordance to the international treaties and covenants, they have ratified, and to international customary law. Alongside, the fact that at the UN level there is not a specific compliance procedure able to make the right to health justiciable is relevant<sup>183</sup> since it contributes to the creation of a lack of consensus in regard to the justiciability of the right, which has brought to the idea that the existence of the right to health is only in the abstract, but its recognition does not bring to any kind of practical consequence<sup>184</sup>. It has also been argued that the real effect of the principle of progressive realization is to debilitate the meaning of the right to health, since as long as States efforts move progressively toward the realization of the right, no violations can be addressed as a violation<sup>185</sup>. I would here reaffirm the importance of the

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<sup>179</sup> Maite San Giorgi (2012). *Supra* note (27), p.198

<sup>180</sup> Oscar Cabrera, Ana Ayala (2013). "Advancing the Right to Health through Litigation". *In Advancing the Human Right to Health*. Oxford University Press. p.30

<sup>181</sup> Maite San Giorgi (2012). *Supra* note (27), pp.4-198

<sup>182</sup> José Zuniga, Imane Sidibé (2013). "Primum non Nocere and the Right to Health". *In Advancing the Human Right to Health*. Oxford University Press. p.337

<sup>183</sup> Brigit Toebes (1999). *Supra* note (20), p.181

<sup>184</sup> George Smith (2005, November). Human Rights and Bioethics: Formulating a Universal Right to Health, Health Care, or Health Protection. *Vanderbilt Journal of Transnational Law, Vol. 38, Iss. 5*. p.1317

<sup>185</sup> *Ibid.*, pp.1320-1

concept of progressive realization, which I have explained in the first chapter, this time with respect to the justiciability of the right since I consider the reality to be exactly the opposite of the one described by Smith. Progressive realization is, actually, what helps to transpose the right to health from the abstract dimension, to the reality one. It is undeniable that one of the key points to reach the realization of the right to health is the availability of resources; the possibility to progressively implementing the right is what gives States (especially developing ones) the possibility to start a path toward the realization of the right; moreover, it also avoids developed countries to stop moving forward. Equal access to health care strongly represents the importance of progressive realization, since it usually undermines an investment from States, and through the application of this principle, a downward level of realization of the right can be avoided. Of course, progressive realization needs an effective monitoring procedure, to prevent States to use it as an excuse to bypass compliance to the provisions of the right: however, what would really weaken the right to health and would relegate it in the theory is to pretend that progressive realization is wrong, and to claim for a fixed set of provisions in the matter of the right to health.

The justiciability of the human right to equal access to health care is complex<sup>186</sup>. Generally, the division of rights among civil and political, on the one side, and economic, social, and cultural, on the other side is based on the nature of the obligations they place on States; the first set of rights is believed to create ‘negative’ duties on States, which means that they do not have to interfere with the realization of the rights, the second set of rights that is considered ‘positive’ in nature, require interventions from States<sup>187</sup>. When the justiciability of Economic, Social, and Cultural rights is challenged, one of the main objections refers to the difference just mentioned<sup>188</sup>. Since in the previous chapter the obligations on States to respect, to protect, and to fulfill have been analyzed, here the justiciability of each one of these obligations will be inspected. The obligation to respect is considered ‘negative’ in nature since according to it, States have to avoid actions against the realization of the right, therefore there are almost no doubt concerning its justiciability<sup>189</sup>. The obligation to protect gives rise to more doubts concerning its justiciability, since it appears to be ‘positive’ in nature, and this may cause certain resistance about its enforceability, but it also includes the responsibility of States to prevent third parties to interfere with the realization of the

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<sup>186</sup> Maite San Giorgi (2012). *Supra* note (27), p.4

<sup>187</sup> Jennifer Anna Sellin (2014). *Supra* note (11), p.103

<sup>188</sup> *Ibid.*, p.104

<sup>189</sup> Brigit Toebes (1999). *Supra* note (20) p.339

right, which is seen as a more concrete and tangible obligation to implement<sup>190</sup>. The obligation to fulfill is the more problematic one since it is considered ‘positive’ in nature, and, moreover, is the one that is more influenced by the concept of progressive realization; anyway, under the obligation to fulfill fall also various concrete obligations, and also the core content of the right to health, which is not subject to progressive realization, but has to be implemented immediately<sup>191</sup>. This brief analysis contributes to demonstrate that the realization of the right to health also involves ‘negative’ obligations for States and action for which they do not have to invest resources<sup>192</sup>. The availability of resources is a key element in addressing the right to health and its justiciability. This is both because resources are limited, even though they are nowadays less limited than ever before<sup>193</sup>, and because they are not equally distributed either between and within Countries<sup>194</sup>. Anyway, although the role of resources is fundamental, in the perspective of this thesis their function is not deepen.

As mentioned in the first paragraph, to grant States some kind of freedom of action, aimed at considering their economic, social, and cultural situation in defining which strategies to apply, to comply with the right to health is necessary; at the same time, it is essential to implement a strategy, which can leading the path toward an effective realization of the right<sup>195</sup>. Sellin proposes three different approaches in this matter. The first one consists in the definition of universal outcome measures that would measure the implementation of the right, this system would include indications about the matters on which States have to concentrate their efforts, and would also assist States in the definition of concrete goals to implement; according to the second approach, when a State meets the universal outcome measure, indicated in a systematic reporting system, it would be assumed that implementation and compliance have occurred; this should mitigate the necessity of international bodies to investigate deeply into national affairs; the third approach provides that civil rights violation (such as discrimination) should be highlighted: according to the author, this three approaches would help the promotion of the notion of human right to health<sup>196</sup>. As will be analyzed in the next subchapter, a reporting procedure to evaluate the compliance of States to the right, and to

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<sup>190</sup> Ibid., p.340

<sup>191</sup> Brigit Toebe (1999). *Supra* note (20), p.341

<sup>192</sup> Jennifer Anna Sellin (2014). *Supra* note (11), p.104

<sup>193</sup> Paul Farmer, Nicole Gastineau (2005). “Rethinking Health and Human Rights. Time for a Paradigm Shift”. In perspectives on health and human rights. Routledge Taylor & Francis Group. New York.p.88

<sup>194</sup> Terry Carney (2006). “Culture, Community or Rights. Securing Health in a Post-Modern, Privatised World” *In Autonomy and Human Rights in Health Care. An International Perspective*. International Library of Ethics, Law, and the New Medicine, Vol. 36. Springer, Dordrecht, The Netherlands. p.155

<sup>195</sup> Eleanor D. Kinney (2001). *Supra* note (9), p.1471

<sup>196</sup> Jennifer Anna Sellin (2014). *Supra* note (11), pp.1471-3

advise States on what they have to focus on is already in place, however, unfortunately, relying so much on States reports does not have such a positive impact on the implementation of the right, probably also because the Committee cannot take binding decisions. Sellin also notes that what would make the difference is a legal mandate for a human right to health; this change could play an essential role in the promotion of public health and in the expansion of health coverage; moreover, this would encourage States to prioritize the implementation of health care programs<sup>197</sup>. Such a promotion would play a role also in the involvement of civil society, which could have a crucial role in the realization of the rights through its demand for the implementation of the right and also holding Governments accountable for the violations<sup>198</sup>. In the recent history of the right to health, the importance of the role of civil society has been seen, for example, with regard to the AIDS pandemic, when an international movement actually produced significant achievement in, among other things, the reduction of Antiretrovirals prices and their universal provision free of charge<sup>199</sup>. The case of AIDS witnesses the fact that there already is, at least on a moral basis, a recognition of the right to health among people, and this is also due to the fact that, actually, many national constitutions do recognize this right<sup>200</sup>.

Moreover, if the right to health is seen in conjunction with the non-discrimination principle, it is quite natural to affirm that the right is justiciable. In respect to equal access to health, this consideration is of relevance since, as mentioned in the previous chapter, equality in access to health has to result in reality, so to have legislation that provides equality in this matter is not enough<sup>201</sup>. After this analysis, it can be said that the notion that the right to health is not justiciable is not plausible<sup>202</sup>, especially in accordance with the principle of interdependency and indivisibility of human rights<sup>203</sup>, which gives rise to the integrated approach that will be analyzed later in the chapter. However, to be effective, human rights have to be enforceable, and States have to adhere to their international obligations<sup>204</sup>; the right to health has an impact on the policies of States since it introduces a set of norms and responsibilities that have to be respected; therefore these obligations have to be monitored and, furthermore, an effective, transparent and accessible accountability

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<sup>197</sup> Jennifer Anna Sellin (2014). *Supra* note (11) p.1474

<sup>198</sup> Joia Mukherjee (2015). *Supra* note (148), pp.411-2

<sup>199</sup> *Ibid.*, p.416

<sup>200</sup> Stephen Marks (2013). *Supra* note (30), p.20

<sup>201</sup> Brigit Toebes (1999). *Supra* note (20), p.340

<sup>202</sup> Jennifer Anna Sellin (2014). *Supra* note (11), p.107

<sup>203</sup> *Ibid.*, p.107

<sup>204</sup> *Ibid.*, p.116

mechanism is needed<sup>205</sup>. Without the existence of such a mechanism, the right to health cannot be applied, and it exists only in theory<sup>206</sup>. With respect to the right to the highest attainable standard of health, it can be said that there are various forms of monitoring and accountability systems, but the majority of them are at national levels, such as national human rights institutions, patients' committees, and judicial proceedings<sup>207</sup>; but a fundamental problem concerning the implementation of the right is that, with the exclusion of the European Court of Human Rights<sup>208</sup>, which is a regional body, there is no legal mechanism for the enforcement of the right to health outside of national jurisprudence<sup>209</sup>. This irrespective of the fact that the recognition of the right is more widespread on an international basis than on a national one, but this can be due also to the absence of an international body that can take binding decisions concerning the realization of the right to health, which creates a weaker accountability for the right on the international level<sup>210</sup>. Nonetheless, national courts can play a fundamental role in moving the justiciability of the right to health forward by, among other actions, be open to claims concerning matters of immediate enforceability of the minimum core, and guaranteeing the underlying determinants of health through their recognition under the right to health, or, more generally, the right to life<sup>211</sup>, however, in order to act in this perspective, a clear interpretation of the provisions of the right to health is necessary.

## 1.1. The Reporting Practice

The Committee on Economic, Social and Cultural Rights (the Committee) has been the monitor body of the ICESCR since 1987, it acts under the authority of the ECOSOC, which is the body in charge of the reporting procedure; the Committee is not established by the Covenant; therefore it is not a 'treaty body'<sup>212</sup>. The Committee meets annually in Geneva for a period of up to

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<sup>205</sup> Paul Hunt, Sheldon Leader (2010). *Supra* note (115), p.36

<sup>206</sup> *Ibid.*, p.37

<sup>207</sup> *Idem*

<sup>208</sup> Maite San Giorgi (2012). *Supra* note (27), p.199

<sup>209</sup> Ronald Labonté, Michelle Gagnon (2013). Understanding how and why Health is Integrated into Foreign policy - a Case Study of *health is Global, a UK Government Strategy 2008 - 2013*. *Globalization and Health*, 9:24. p.13

<sup>210</sup> Gunilla Backman, et. Al. (December, 2008). *Supra* note (5), p.2059

<sup>211</sup> Eric Friedman, Lawrence Gostin (2013). "Pillars for Progress on the Right to Health". *In Advancing the Human Right to Health*. Oxford University Press. p.76

<sup>212</sup> Brigit Toebes (1999). *Supra* note (20), p.90



three weeks<sup>213</sup>, in, generally, public sessions<sup>214</sup>. Among other things, the Committee has to submit reports to the Council, on an annual basis, which include the concluding observations of the Committee on each State's report<sup>215</sup>. States have to submit to the Council reports dealing with the entire Covenant on a five-year basis; these reports are to be analyzed by the Committee<sup>216</sup>. One of the roles of the Committee is to prepare general comments on reports, based on articles and provisions of the Covenant, in order to assist States to fulfill their reporting obligations<sup>217</sup>; the Committee also provides an opinion on the level of realization of the rights of the Covenant in its 'Concluding Observations'<sup>218</sup>. In its General Comment No. 1, the Committee highlighted seven objectives that reports have to encounter, which are: to ensure that the review is comprehensive and that it deals in an exhaustive way with national procedures, legislation, and administrative rules; to guarantee a regular monitor of the situation; to assure that the process of policy-making takes into account the provisions of the Covenant; to facilitate public scrutiny; to evaluate the progress; to provide States a better understanding of the problems; to facilitate the sharing of information and cooperation among States Parties<sup>219</sup>.

Considering the impact of the reporting process on Article 12, it can be said that States, on a general basis, have not taken the reporting method seriously. They often tend not to submit reports and, when they issue them, these reports are incomplete, or they do not follow a consistent method in discussing States obligations provided by the Article in question; this somehow demonstrates that the guidelines on reporting, mentioned above and established by the Council through the Committee, have not great authority<sup>220</sup>. Moreover, it can take up to four years to the Committee to discuss and analyze a report, in this case, these reports, even if they have been accurately made, give information that are already outdated. Moreover, one of the problems of this reporting practice concerns the status of the Covenant in national law; the Committee has asked to States Parties to indicate whether or not the rights enlisted in the Covenant can be directly invoked before national

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<sup>213</sup> UN. Doc. E/C. 12/1990/4/Rev.1, *Rules of Procedure of the Committee*. rule 1

<sup>214</sup> *Ibid.* rule 28

<sup>215</sup> *Ibid.*, rule 57

<sup>216</sup> *Ibid.*, rule 58

<sup>217</sup> *Ibid.*, rule 65

<sup>218</sup> Maite San Giorgi (2012). *Supra* note (27), p.85

<sup>219</sup> Brigit Toebe (1999). *Supra* note (20), p.94

<sup>220</sup> *Ibid.*, p.98

courts<sup>221</sup>, in the opinion of the Committee, at least certain rights, such as the ones guaranteed by Article 8 and 13 of the Covenant should be capable of immediate and direct application in the context of national law; unfortunately, it seems that the right to health is not included<sup>222</sup>.

Focusing on the reporting practice on Article 12, among other requests, States are asked to include in the report: the presence of a national health policy; the percentage of Gross National Product (GNP) speeded on health; the differences in the standard of health services provided by the public and private sectors, in States where they coexist<sup>223</sup>. With respect to national health policies, States are also required to indicate whether or not their national health policy includes commitment to the WHO's Primary Health Care strategy, and they also have to comprehend the measures adopted in order to comply with that strategy in the report. Several countries have adhered to this reporting provision<sup>224</sup>. The matter of the percentage of GNP devoted to health is a difficult one to analyze. In this matter emerges a considerable problem of distinction between developing and developed countries since the percentage of expenditure may vary consistently between these two groups, not only due to availability of resources, but also because wealthier countries tend to invest in specialized health care services, which prices are continually rising, while poorer countries spend their resources on basic health services<sup>225</sup>, considering this fundamental difference, it does not appear of help to compare the percentages of different States; these data are, quite naturally, necessary, but they should probably be used just in relation to the country they refer to; if they are used to provide a general vision of the situation, they may be misleading. Moreover, first of all, it is not clear what should be included in national health expenditures, then the amount of spending is not necessarily proportionally related to the level of the health system, or to the health of the population<sup>226</sup>. In addressing the matter of resources devoted to health services, the Committee places emphasis also in analyzing whether lack of resources is the only reason behind non-

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<sup>221</sup> Relevant in this matter is the case of Belgium that in its initial report claims that the nature itself of the Covenant prevents the rights provided in it by being directly invoked before a Belgian court, since a national judge needs precise and binding provisions to be able to apply them. These characteristics, according to the Belgian report are not proper of the ICESCR provisions. (Toebes, p.101)

<sup>222</sup> Brigit Toebes (1999). *Supra* note (20), pp.100-1

<sup>223</sup> *Ibid.*, p.105

<sup>224</sup> *Ibid.*, p.106

<sup>225</sup> *Ibid.*, p. 105

<sup>226</sup> *Ibid.*, p.107

compliance<sup>227</sup>, and in comparing the amount of reserves dedicated to health to the ones dedicated, for example, to military expenditures. From this comparison emerges that, on a general basis, the Committee considers that when defense spending is high compared to, among others, health expenditure, this means that the State could have distributed resources in a different way: these two examples raise the problem of distinguishing between States capacity and States willingness<sup>228</sup>.

With regard to the provision of health care services, the Committee tries to evaluate from the reports the compliance with the concepts of availability, accessibility, and quality, which are at the core of Article 12 provisions<sup>229</sup>. Concerning availability, in order to understand the level of compliance with this principle, the Committee decided to evaluate certain indicators, such as aggregate number of hospital beds, and of the number of nurses and doctors per population<sup>230</sup>, however, these indicators are not sufficient to understand the level of availability of health services since they do not give evidence of where services are located and of who can actually access available services. Concerning accessibility, the attention of the Committee is focused on the problems connected to the compliance with this principle that have already been explained in the previous chapter.

After this analysis appears quite clear that the effectiveness of the reporting process under Article 12 ICESCR can be discussed. Firstly, it is difficult to appraise whether health legislation and national health policies are really aimed at the realization of the right to health, considering that they involve various aspects of the right; secondly, the use of statistics gives rise to many problems, due to the unreliability of these statistics that are often made available by specialized agency that take them from States, and, moreover, frequently, statistics are not complemented by necessary information about the facts reported in them; thirdly, disaggregated data concerning which groups have access to which services would be necessary in order to consistently evaluate the availability, accessibility, and effectiveness of health services<sup>231</sup>. Disaggregation of data would be profoundly relevant to the work of the Committee. Enabling the identification of the discrimination at the basis of different levels of availability and accessibility of health services, the use of disaggregated data

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<sup>227</sup> Toebes reported the case of Kenya that generated some concerns in the Committee, worried by the constant decline of governmental health expenditures. In this case, Kenya justified its conduct with the scarcity of available resources, but the Committee claimed that a relevant role was also played by the slow and complicate reform process that was both mismanaged and aimed at the maintenance of the political status quo (Toebes p.109)

<sup>228</sup> Brigit Toebes (1999). *Supra* note (20), p.110

<sup>229</sup> *Ibid.*, p.114

<sup>230</sup> *Ibid.*, p.141

<sup>231</sup> *Ibid.*, pp.143-4

can allow the Committee to advise each State on the specific targets its policies should implement, in order to bring an improvement in the realization of the right to health, and a decrease in the gap existing between those who can rely on better health-related services, and those who, for civil, economic, social, or cultural reasons, belong to more vulnerable or marginalized groups<sup>232</sup>. The use of disaggregated data is needed when the aim is to implement effective monitoring on the realization of human rights<sup>233</sup>.

In respect to the subject of this thesis, it is relevant to mention the reporting practice under ICCPR the body responsible for the supervision of the Covenant is the Human Rights Committee (HRC), which is a treaty body; the reporting procedure is the main measure of implementation of the ICCPR<sup>234</sup>. Even though the right to health does not fall directly under the supervision of ICCPR, it is important to mention it, because within ICCPR reporting procedure, various health-related issues have been debated<sup>235</sup>. Usually, health-related issues are addressed in relation to Article 6 and 7 of ICCPR, which concern the right to life and the prohibition of torture and inhuman and degrading treatments<sup>236</sup>; also Article 26 has been taken into consideration since it deals with non-discrimination<sup>237</sup>. This topic will be further analyzed in the subchapter about the integrated approach.

## 1.2. The Optional Protocol to the ICESCR

Speaking about the justiciability of the right to health under ICESCR, it is essential to mention the fact that one of the scopes of human rights is to give people to possibility to have rights against the State under international law<sup>238</sup>; in this perspective, a brief analysis of the Optional Protocol to the ICESCR (OP ICESCR) is relevant. In its preamble, the Protocol highlights the fact that the implementation of the provisions included in it is recommended in the perspective of the realization of the requirements of the Covenant<sup>239</sup>. The focus of the OP is that it accepts communications from individuals or groups of individuals, concerning the violation of every right

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<sup>232</sup> Sofia Gruskin, Daniel Tarantola (2005). *Supra* note (19), p.39

<sup>233</sup> Audrey Chapman (2016). *Supra* note (169), p.4

<sup>234</sup> Brigit Toebes (1999). *Supra* note (20), p.160

<sup>235</sup> *Ibid.*, p.160

<sup>236</sup> *Ibid.*, p.160

<sup>237</sup> Maite San Giorgi (2012). *Supra* note (27), p. 181

<sup>238</sup> George Smith (2005, November). *Supra* note (184), p.1303

<sup>239</sup> Optional Protocol to the International Covenant on Economic, Social and Cultural Rights. 2008., Preamble

included in the Covenant<sup>240</sup>; becoming part of the Protocol, a State recognizes the competence of the Committee to consider and deal with these communications, quite obviously, the Committee can accept only communications related to States that are part of the Protocol<sup>241</sup>. In this matter it is relevant to highlight the scarce recognition that the Protocol have gained until now (the Protocol opened for ratifications in 2009, at the moment, 23 States have ratified it, 26 have signed it, 149 have taken no actions on the subject (among them the U.S.)<sup>242</sup>; this means that the OP has entered into force<sup>243</sup>, but, at the same time, it raises questions concerning its actual impact on the implementation of the right.

The Committee, in order to accept communications, has to ascertain that all available domestic remedies have been exhausted, the only exception to this rule is when the application of remedies results unreasonably prolonged<sup>244</sup>. Communications are also considered inadmissible under the Protocol when, among other conditions, the matter of the communication happened in a period prior to the entry into force of the Protocol for the State concerned (with the exception of those facts continued after the entry into force); or the same subject is under the analysis of another international procedure or settlement<sup>245</sup>. After that a communication has been considered admissible under the OP, if the Committee evaluates a grave and systemic violation of the Covenant by a State Party, it shall invite the State to cooperate in the analysis of the information and to submit considerations with regard to the information concerned in the communication<sup>246</sup>. With all the necessary material, the Committee starts an inquiry procedure that can include a visit in the territory of the State involved; after this examination, the Committee shall send to the State findings, comments, and recommendations<sup>247</sup>. Consequently, the Committee may invite the State to include all the measures implemented in respect with the violations highlighted in its report, the Committee may also invite the State to provide information concerning the measures adopted in response to the inquiry<sup>248</sup>.

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<sup>240</sup> Ibid., Art.2

<sup>241</sup> Ibid., Art.1

<sup>242</sup> <http://indicators.ohchr.org> access 11th May

<sup>243</sup> As disposed by Art.18, the Protocol has entered into force three months after the tenth ratification; for every States that ratify the Protocol after the deposit of the tenth ratification, it enters into force after three months from its ratification.

<sup>244</sup> OP ICESCR (2008). *Supra note (239)*., Art.3

<sup>245</sup> Ibid., Art.3(b)-(c)

<sup>246</sup> Ibid., Art. 11

<sup>247</sup> Idem

<sup>248</sup> Ibid., Art.12

## 2. The Concept of Overlapping Rights and the Integrated Approach

In order to make the right to health really justiciable, a definition of what the right precisely includes is necessary<sup>249</sup>. Although sometimes the right to health is considered one of the least contestable social rights from a normative point of view, what it specifically entails is challenging to certify<sup>250</sup>. Unfortunately, considering the universal level, it could be said that it is not only difficult to define a specific scope and core content of the right to health, but often impossible, this is partly due to the enormous differences occurring among the Countries of the world; what is possible is to broadly deduce which health-related services States should provide to implement the right<sup>251</sup>. In addressing this situation, a key element is indeed the concept of overlapping rights, which somehow may complicate the discourse concerning the justiciability of the right to health, but at the same time can be of help in this matter. The right to health is composed of various elements that overlap with one or more other human rights, this is the reason why it is extremely difficult to analyze the right to health by itself, at the same time, however, this condition of overlapping can be helpful with regard to the justiciability of the right: in fact, it is not only covered by provisions directly concerning the right to health<sup>252</sup>. So it can be said that a view of the right to health in isolation is misleading since, as just mentioned, it includes also rights covered by other human rights, but also because this condition creates a situation of dependence among human rights, where the enjoyment of one right deeply influences the enjoyment of other rights; one of the most shining examples of this condition are the right to equality and to non-discrimination<sup>253</sup>, which are at the core of human rights, and of extreme importance for the realization of the right to health, more specifically. Concerning the matter of the justiciability of the right to equal access to health care, this overlapping among human rights demonstrates how they are interdependent and this can serve as a mean toward the protection of the right to health since it can be guaranteed also, for example, under the autonomous civil and political right provision of non discrimination<sup>254</sup>. Analyzing the extent to which certain rights that are included in the right to health are also protected by other human rights,

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<sup>249</sup> George Smith (2005, November). *Supra* note (184), p.291

<sup>250</sup> Lindsey Kingston, et. Al. (2010). Debate: Limitations on Universality: the “Right to Health” and the Necessity of Legal Nationality. *BMC International Health and Human Rights*, 10:11. p.3

<sup>251</sup> Brigit Toebes (1999). *Supra* note (20), p.285

<sup>252</sup> Maite San Giorgi (2012). *Supra* note (27), p.18

<sup>253</sup> Marcia Rioux (2006). “The Right to Health. Human Rights Approaches to Health”. *In Staying Alive. Critical Perspectives on Health, Illness, and Health Care*. Canadian Scholars’ Press Inc., Toronto. p.93

<sup>254</sup> Maite San Giorgi (2012). *Supra* note (27), pp.118-9

Toebe found four areas of overlap, which are: life, physical integrity, education and information, and food, housing, and work. All these rights are protected by different provisions of civil and political rights<sup>255</sup>: this introduces the concept of the integrated approach to the protection of the right to health.

As already mentioned, often the main difference identified between civil and political rights and economic, social, and cultural rights is the fact that the obligations imposed by the former are considered ‘negative’ in nature, while the ones imposed by the latter ‘positive’; anyway this vision is becoming increasingly controversial. In the first chapter, the ‘negative’ obligations demanded by the right to health have been analyzed; ‘positive’ and ‘negative’ obligations have also been analyzed at the beginning of this chapter, with regard to the obligations to respect, to protect, and to fulfill; here it is relevant to mention the fact that the realization of civil and political rights also requires ‘positive’ actions of States. Courts have increasingly affirmed that civil and political rights do not only imply that States have to avoid violating a right, but also States action and intervention aimed at the implementation of the right is required<sup>256</sup>. This situation is relevant also because it demonstrates that arguing that economic, social, and cultural rights are not justiciable because they impose ‘positive’ obligations on States is pointless. In speaking about the interdependence of rights, it is necessary to distinguish between organic interdependence and related interdependence. These two concepts have been theorized by Scott, and San Giorgi analyzed them stating that the difference lays in the fact that the former one describes a situation in which a right represents a part of another right, and can, therefore, be incorporated in it; according to this theory, the core rights justifies the derivative right, therefore to protect the core right means protecting the derivative one<sup>257</sup>. Instead, according to related interdependence, the rights considered are in a relation of mutual dependence, but they are distinct, they are, anyway, treated as equally important and complementary<sup>258</sup>. The discourse about related interdependence is the one that raises the argument of application of a right of ICCPR to a right of the ICESCR, without taking into account whether the economic, social, and cultural right is part of the civil and political one<sup>259</sup>. Moreover, it testifies that the distinction between the two categories of rights is not so strict when it comes to justiciability; there have been cases where adjudicatory human rights bodies have analyzed matters of economic, social, and

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<sup>255</sup> Brigit Toebe (1999). *Supra* note (20), p.260

<sup>256</sup> *Ibid.*, p.232

<sup>257</sup> Maite San Giorgi (2012). *Supra* note (27), p.115

<sup>258</sup> *Ibid.*, pp.115-6

<sup>259</sup> *Ibid.*, p.116

cultural rights through civil and political rights<sup>260</sup>. This approach is called ‘integrated approach’: under this approach, civil and political rights can be instrumental for the adequate protection of economic, social, and cultural rights<sup>261</sup>.

The integrated approach is useful since it can guarantee that certain rights can be subject to adjudication by human rights bodies that can assure stronger protection for them: the Human Rights Committee (HRCee) has used the integrated approach in this sense under Article 26 ICCPR<sup>262</sup>. The idea of related interdependence can serve as a mean for the protection of the right to equal access to health care since the autonomous civil and political right to equal treatment, and non-discrimination can be applied to protect it<sup>263</sup>. Article 26 ICCPR states that “All persons are equal before the law and are entitled without any discrimination to the equal protection of the law”<sup>264</sup>, moreover, it clearly states that the law does not only have to prohibit any discrimination, but it also has to guarantee to everyone equal and effective protection against discriminations<sup>265</sup>. This provision is an autonomous one that means that it can also be applied to rights which are not included in the ICCPR<sup>266</sup>. Even though this provision may seem to give rise to the possibility to bring violations of economic, social, and cultural rights to the HRCee, the Committee itself has specified that unless the distinctions made are evidently discriminatory, the Committee has no competences in replacing the States in the evaluation of its socio-economic situation<sup>267</sup>. According to this statement of the HRCee it seems difficult that it will deal consistently with the right to equal access to health care, even though the integrated approach under Article 26 ICCPR still have a great potential in the matter of justiciability of economic, social, and cultural rights, due to its autonomous character<sup>268</sup>. Anyway, in the perspective of future cases dealing with unequal access to health care, it is relevant to briefly highlight certain characteristics of complaints at HRCee. First of all, the applicant has to be part of a defined group; then, the fact that the applicant belongs to a certain group serves the objective of defining if the ground of distinction falls under Article 26<sup>269</sup>.

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<sup>260</sup> Ibid., p.4

<sup>261</sup> Ibid., p.112

<sup>262</sup> Ibid., pp.112-3

<sup>263</sup> Ibid., pp.118-9

<sup>264</sup> International Covenant on Civil and Political Rights. (1966), Art.26

<sup>265</sup> Idem

<sup>266</sup> Maite San Giorgi (2012). *Supra* note (27), p.183

<sup>267</sup> Ibid., p.192

<sup>268</sup> Ibid., p.193

<sup>269</sup> As mentioned by San Giorgi, grounds of distinction under Article 26 are not strictly defined since under the denomination ‘other status’ can fall any kind of distinct category of people



## Chapter III - Health Care in the United States

Table of contents: 1. How does the System Work? - 1.1 A brief History of the Attempts to Create a National Health Care System in the United States - 1.2 Medicare - 1.3 Medicaid - 2. The Patient Protection and Affordable Care Act - 2.1 The main Provisions Related to the Right to Equal Access to Health Care - 2.2 The Relevance for Women Rights - 3. President Trump Interventions on the Patient Protection and Affordable Care Act

### 1. How does the System Work?

The United States has a peculiar health care system among OECD countries. In fact it is the only country among them that do not have some kind of national health care system<sup>270</sup> with the Government playing a fundamental role in it, neither is there a national Ministry of Health (or a similar figure) that manages the operation or the financing of the system or supervises the functioning of the structure within which the health care system operates<sup>271</sup>. This does not mean, as will be analyzed later in the chapter, that the Government is entirely absent in the health care discourse; the Department of Health and Human Services is the responsible, among other things, of the federal Social Security program, of the federal role in public assistance programs, which are managed by States; the department's responsibilities are usually fulfilled through allocation of money and delegation to public and private entities that deal with health services<sup>272</sup>. The federal approach of the department also appears at States level: in most States, the Health Department delegate the provision of mental illness treatments and Medicaid operations to other departments<sup>273</sup>. Certainly, certain aspects of the system are regulated by the Government; however, these interventions are usually reactive measure to the outcomes of financial problems<sup>274</sup>; this tendency emerges clearly from the analysis of the path of the reforms of the health care adopted by the U.S. Government throughout the years since the standpoint is usually related to the containment of costs, and not a rights-based approach. The Government role in the health care system will be further analyzed in the chapter, here just a brief introduction to the private involvement is given.

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<sup>270</sup> David M. Cutler (2002, February). Health Care and the Public Sector. *NBER Working Paper No. 8802*, p.9

<sup>271</sup> Steven Jonas, et Al. (2007). *An Introduction to the U.S. Health Care System*. Sixth edition. Springer Publishing Company. New York., p. 9

<sup>272</sup> *Ibid.*, p.13

<sup>273</sup> *Ibid.*, p.121

<sup>274</sup> *Idem.*

The system in the U.S. is fragmented and decentralized, the aim of the health care is not only providing health services to the population but also producing outcomes for providers and payers<sup>275</sup>. In the aftermath of the Second World War, the system, based on a fee-for-service practice, produced high incomes for American physicians; since the 1980s, it has created high profits from the direct provision of services<sup>276</sup>: the role of private for-profit enterprises in this sector is increasingly important since they are engaged in all the main aspects of health care, such as pharmaceutical production, health insurance, and hospitals<sup>277</sup>.

Lacking a national system, the payment system to the providers of health is extremely complicated<sup>278</sup>. The payment of health care has three actors in the U.S. system: patients, providers, third-party payers. Every amount of money paid directly by the patient is called “out-of-pocket”; third-party payers refer to anyone involved in the payment of the service that is not the patient or his or her relatives; patient’s employer, private insurance, managed-care organizations, charity organizations, and Governments (federal, state, local) are part of this category<sup>279</sup>. The division of the payment system is, therefore, simplified as private and public, with the private sector, which comprehends private health insurance and “out-of-pocket” payments, playing a primary role<sup>280</sup>. The main feature of the private insurance system in the U.S. is that people usually obtain it through their employer, in fact it is quite difficult to obtain private health insurance outside of employer-sponsored plans<sup>281</sup>; this is because health insurance are more affordable and available to groups rather than to individuals since they are more appealing for insurers that through groups can expand the risk pools (expanding the risk pools, balancing high and low risk individuals is essential to the financial sustainability of the insurance since the costs of the sick are covered by the lack of need of those who are well)<sup>282</sup> and have less danger connected to adverse selection, and employment is the easiest way to create groups<sup>283</sup>. Even though private health insurance are still provided through

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<sup>275</sup> Ibid., p.9

<sup>276</sup> Idem.

<sup>277</sup> Ibid., p.15

<sup>278</sup> Ibid., pp.129-30

<sup>279</sup> Ibid., p. 132

<sup>280</sup> Ibid., p.132

<sup>281</sup> Ibid., p. 133

<sup>282</sup> Howard P. Greenwald (2010). *Health Care in the United States. Organization, Management, and Policy. Jossey-Bass.*, p.182

<sup>283</sup> Timothy Stoltzfus Jost (2003). *Disentitlement? The Threats Facing Our Public Health-Care Programs and a Rights-Based Response.* Oxford University Press., pp.186-7

patient's employer, the entrance in the system of managed care has brought further complications into the system since before it patients received health care on the basis of a contract (usually unwritten) between them and the provider, through managed care patients have a written contract with the managed care organization (MCO) that establishes which care the patient has to receive, under which circumstances and by whom<sup>284</sup>; more recently MCOs started to offer larger panels of providers and to provide partial coverage for services furnished by providers that are not part of these panels<sup>285</sup>. This is the main characteristic of the managed care system, which has been elaborated from the assumption that there is a use of health care superior to the real need, and therefore a corporate supervision would eliminate this dissipation, providing also a reduction of costs<sup>286</sup>. As a result, the change in the type of contract represents a change in who is entitled for the decisions concerning the patient's care<sup>287</sup>.

### **1.1. A brief History of the Attempts to Create a National Health Care System in the United States**

The problem of health care in the United States is a relevant one that has been addressed in different way throughout U.S. history. Already in 1932 guaranteeing access to satisfactory medical services for all Americans was a matter of discussion and research<sup>288</sup>; various presidents have also tried to establish a national health care system, but until now they all failed; anyway, some of them succeeded in reinforcing the role of the Government in the system, especially in protection of low income social classes and vulnerable population, such as disabled and elderly. The first real attempt to create a national health care system that would have guaranteed almost universal access to health care failed in 1947, it was sponsored by Senator Robert Wagner and by President Truman, but it was blocked at the Congress not only by the Republicans but also by the Democrats from the South. It was labeled as socialist and there was also a strong opposition from the American Medical Association (AMA)<sup>289</sup>. The role played by the AMA to obstruct the reform is relevant, the

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<sup>284</sup> Steven Jonas (2007). *Supra* note (271). pp.132-3

<sup>285</sup> Howard P. Greenwald (2010). *Supra* note (282), p. 22

<sup>286</sup> Patrick Rooney, Dan Perrin (2008). *America's Health Care Crisis Solved Money-Saving Solutions, Coverage for Everyone*. John Wiley & Sons, Inc.. Hoboken, New Jersey., p.27

<sup>287</sup> Steven Jonas (2007). *Supra* note (271)., pp.132-3

<sup>288</sup> *Ibid.*, p. 24

<sup>289</sup> Arnaldo Testi (2017). *Il Secolo degli Stati Uniti*. Il Mulino., p. 185

association launched a campaign called “National Education Campaign” during which it promoted private health insurance; with the help of a well-rooted racism, the perfectly organized campaign against the national health care system contributed strongly to shape Americans’ opinion about the reform: in 1945, 75% of Americans supported the establishment of a national health care insurance, by 1949 the percentage declined to 21<sup>290</sup>. A fact worth mentioning in this context is the fact that trade unions, which had strongly sponsored the law, preferred to start negotiations with private insurance to obtain employment-based insurance plans instead of insist on the public policies path<sup>291</sup>. A fundamental year in the discourse of Government role in health care system is 1965, which was a year of social reforms in various field and when Medicare and Medicaid (the two government-sponsored insurance for elderly and indigents) were established<sup>292</sup>.

In the ‘90s, due especially to continually increasing costs of health care, the enlargement of the number of uninsured, and the decreasing health condition of certain parts of the population, the matter of national health care system reappeared in the political agenda, because such a system would have established a single-payer system, able to cover the entirety of the population<sup>293</sup>. Clinton interpreted this renewed interest and one of the ambitious objectives of his presidency was to create a national health care system; the two goals of his reform were to establish compulsory health care insurance for everyone, included 39 millions of uninsured, and to lower the costs of the system, which was extremely expensive, even though not universal<sup>294</sup>. The plan, called Health Security Act, which represents the most comprehensive proposal since 1965<sup>295</sup>, was boycotted by Republicans, by physician associations, and by private insurance, and then it was blocked at the Congress<sup>296</sup>. It also encountered a strong public opposition, due especially to its extreme complexity and to a lack of transparency in the development process<sup>297</sup>: in September 1993, 59% of the population was in favor of the reform, in June 1994 support had declined to 44%<sup>298</sup>. This decrease

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<sup>290</sup> Jill Quadagno (2004). Why the United States Has no National Health Insurance: Stakeholder Mobilization Against the Welfare State, 1945-1996. *Journal of Health and Social Behavior*, Vol. 45 (extra issue), pp.30-1

<sup>291</sup> Arnaldo Testi (2017). *Supra* note (289), p.185

<sup>292</sup> *Ibid.*, p.211

<sup>293</sup> Steven Jonas (2007). *Supra* note (271), pp.242-3

<sup>294</sup> Arnaldo Testi (2017). *Supra* note (289), p.261

<sup>295</sup> Jill Quadagno (2004). *Supra* note (290), p.37

<sup>296</sup> Arnaldo Testi (2017). *Supra* note (289), p.262

<sup>297</sup> Howard P. Greenwald (2010). *Supra* note (282), pp.315-6

<sup>298</sup> Jill Quadagno (2004). *Supra* note (290), p.38

in the popular consensus was also due to the fact that its lengthy planning gave the opportunity to the opponents to organize a strategy to contrast it, addressing it as “socialized medicine”, or framing the system that the plan would have created as one in which people were unable to choose their health plan<sup>299</sup>.

The last attempt to establish an almost universal health care coverage system has been the Patient Protection and Affordable Care Act of President Obama, which will be analyzed in details later in the chapter. Signed in 2010, the reform’s main objectives were to lower the costs of the system and extend the coverage, improving Medicaid, with small interventions on the organization of the system; the hypothesis of creating a national health care system close to European or Canadian ones was not taken into consideration<sup>300</sup>.

## 1.2. Medicare

In a system based on private insurance, coverage of the elderly is a relevant matter, since they usually utilize more health care than younger people. Since they usually utilize a considerable amount of health care, during the ‘50s and the ‘60s, many Americans became concerned about the financial burden that the costs of health care posed on the elderly, especially because health care coverage retirement benefit were rare<sup>301</sup>, and commercial insurers usually started to offer policies to this category when a governmental solution on the political floor was starting to obtain support<sup>302</sup>; on a regular basis, commercial insurers were not interested in covering the elderly, and when it became clear that ensuring this category was not profitable, insurance companies stopped opposing governmental solutions to the problem, and Medicare could finally be established<sup>303</sup>. Medicare was established in 1965, under the presidency of Johnson, it was part of the President’s “Great Society” plan and was authorized by Title XVIII of the Social Security Act; at the beginning it was designed to give coverage for some health services to the elderly, from 1973 it also covered permanently disabled<sup>304</sup>.

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<sup>299</sup> Ibid., p.37

<sup>300</sup> Arnaldo Testi (2017). *Supra* note (289)., pp.302-3

<sup>301</sup> Howard P. Greenwald (2010). *Supra* note (282), p.191

<sup>302</sup> Jill Quadagno (2004). *Supra* note (290), p.32

<sup>303</sup> Ibid., p.33

<sup>304</sup> Steven Jonas (2007). *Supra* note (271)., p.135

Medicare is divided into four parts: the first one, part A, which is a hospital insurance and also covers some skilled nursing facility care, it is funded primarily through Social Security taxes and establishes deductibles but no premiums; part B, which covers physicians and certain health professional services, and hospital outpatient care, it is mostly funded by general revenues, requires deductibles and monthly premiums, which guarantee balance; part C, which allows to Medicare beneficiaries to enroll in MCOs, and provides various premiums; and part D, which attempts to lower the costs of prescription drugs for Medicare beneficiaries, is funded through premiums, and requires deductibles<sup>305</sup>. This last part is a relevant introduction to the program, come into force in 2006, before this date, in fact, Medicare did not provide prescription drugs coverage to those who were not “dual eligibles”, namely those who were eligible to both Medicare and Medicaid<sup>306</sup>.

Medicare, anyway, does not provide access to a comprehensive health care package, even after the implementation of part D, because it does not pay for many preventive and early diagnostic services, and long-term care<sup>307</sup>. Furthermore, the program requires specific premiums and deductibles for each of its parts and covers only a fixed number of hospitalization days<sup>308</sup>, which may not, in the end, avoid consistent “out-of-pocket” payments for people with disabilities or chronic illnesses, compromising their effective ability to access health care, even though some scholars, such as Jost affirms that, at least concerning part A and B, the cost-sharing expected (part B premiums) by the program is rarely a real issue since premiums are usually strongly subsidized<sup>309</sup>. The matter of accessibility under Medicare is a complex one, for example, in many States, disabled Medicare enrollees under 65 years of age with incomes below the poverty line are entitled to have Medicare part B premiums, deductibles, and co-insurance covered through Medicaid<sup>310</sup>; however, people under 65 years of age and who qualify for Social Security Disability Income (SSDI) are eligible for Medicare after a two years waiting period<sup>311</sup>, these two years represent, quite obviously, a significant barrier to access to care, because the costs for medical care could be unbearable without the support of Medicare<sup>312</sup>. Moreover, concerning actual accessibility

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<sup>305</sup> Howard P. Greenwald (2010). *Supra* note (282), p.195

<sup>306</sup> Steven Jonas (2007). *Supra* note (271)., pp.135-6

<sup>307</sup> Janet O’Keeffe (1994). The Right to Health Care and Health Care Reform. In *Health Care Reform: A Human Rights Approach*. Georgetown University Press. Edited by A. R. Chapman., 38

<sup>308</sup> *Ibid.*, p.38

<sup>309</sup> Timothy Stoltzfust Jost (2003). *Supra* note (283), p.16

<sup>310</sup> Lu Ann Aday (2001). *Supra* note (10)., pp.166-7

<sup>311</sup> *Ibid.*, p.160

<sup>312</sup> *Ibid.*, p.185

it is relevant to highlight that most beneficiaries of the program can use providers of their choice, and physicians are paid on a fee-for-service basis, which has sometimes created problems concerning the actual accessibility of health care for Medicare beneficiaries since the program physicians fee is inferior to the payment that physicians receive with patients who have a private insurance<sup>313</sup>.

### 1.3. Medicaid

Medicaid is the other Government program established in 1965, providing health care coverage for the poor, authorized by Title XIX of the Social Security Act<sup>314</sup>; it could be seen as a completion of Medicare in insuring the vulnerable population of the U.S., its adoption can also be analyzed in the context of a long struggle toward universal health coverage, since its recipients were not a category that attracts sympathy among Americans, as the ones to whom Medicare is directed<sup>315</sup>. Also, for this reason, providing health care insurance to the poor has always been seen as a simple measure of public welfare supported by taxes<sup>316</sup>, this conception of the program has brought some problems to its enforcement and its expansion, and it was also fundamental in excluding young non-disable men without children from the eligibility criteria.

Medicaid is a state-administered program (even though at least half of the program is paid by the Federal Government, and therefore States must comply with certain federal provisions)<sup>317</sup>, therefore each state has different guidelines and eligibility criteria<sup>318</sup>, this condition affects the program in a relevant way, since when the federal role in financing it has diminished, benefits and eligibility criteria have become more restrictive, excluding certain parts of the population from having access to the program<sup>319</sup>; however, it must be said that certain States have interpreted this freedom in managing eligibility criteria by expanding the program to beneficiaries with higher

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<sup>313</sup> Steven Jonas (2007). *Supra* note (271)., p.136

<sup>314</sup> *Ibid.*, p. 137

<sup>315</sup> Colleen Grogan, Eric Patashnik (2005). Medicaid at the Crossroads. In "Healthy, Wealthy, and Fair. Health Care and the Good Society." *Oxford University Press*. Edited by Morone, J. A.; Jacobs, L. R., p.270

<sup>316</sup> June Mary Zekan Makdisi (2015). Affordable Care Act: Does it Improve Health and Does it Live Up to Human Rights Standards. *Intercultural Human Rights Law Review, Vol. 10.*, p.121

<sup>317</sup> Timothy Stoltzfust Jost (2003). *Supra* note (283), p.15

<sup>318</sup> Shalonda Horton, Regina J. Johnson (2010). Improving Access to Health Care for Uninsured Elderly Patients. *Public Health Nursing, Vol.27, No.4.*, p.364

<sup>319</sup> Lu Ann Aday (2001). *Supra* note (10), p.160

incomes<sup>320</sup>. The Patient Protection and Affordable Care Act (ACA) tried to uniform condition providing federal rules for eligibility, but the Supreme Court considered unconstitutional this part of the reform<sup>321</sup>. States also decide reimbursement rates for physicians and hospitals who accept to treat Medicaid enrollees<sup>322</sup>. This is one of the main problems of Medicaid, because theoretically it offers a consistent amount of benefits, which sometimes exceed the benefits provided by certain commercial insurance, but in reality, access to health care through Medicaid can be extremely difficult due to low rates paid to physicians and hospitals and due to delayed payments by States<sup>323</sup>; this burden to access is strengthened by the fact that physicians can legally refuse to see patients on the basis of their health care insurance<sup>324</sup>. Women have often been victims of this practice in various communities where physicians refused to provide obstetrician-gynecologist services to women eligible for Medicaid<sup>325</sup>.

Medicaid provides coverage also for an extremely expensive health care services that is long-term nursing home care, the problem is that the means-test necessary to become eligible for Medicaid often oblige families to become poor enough to qualify for Medicaid nursing home care coverage<sup>326</sup>; this is one of the fields in which the ACA tried to make some changes, through the modification of the criteria of the income-test<sup>327</sup>, since the program had reached a situation in which extremely rigorous eligibility criteria and extremely low-income requirements consistently reduced the number of poor effectively eligible for Medicaid<sup>328</sup>.

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<sup>320</sup> Mary E. Wiktorowicz (2006). Health Care Systems in Evolution. In "Staying Alive. Critical Perspectives on Health, Illness, and Health Care." *Canadian Scholars' Press Inc., Toronto*. Edited by Raphael, D., Bryant, T., Rioux, M., p.254

<sup>321</sup> Keon- Hyung Lee, et Al. (2016). Expelled Uninsured Patients in a Less-Competitive Hospital Market in Florida, USA. *International Journal for Equity in Health*, 15:85., pp.1-2

<sup>322</sup> Deborah Stone (2005). How Market Ideology Guarantees Racial Inequality. In "Healthy, Wealthy, and Fair. Health Care and the Good Society." *Oxford University Press*. Edited by Morone, J. A.; Jacobs, L. R., pp.70-1

<sup>323</sup> *Ibid.*, p.77

<sup>324</sup> *Ibid.*, pp.82-3

<sup>325</sup> Lu Ann Aday (2001). *Supra* note (10), p.183

<sup>326</sup> *Ibid.*, pp.185-6

<sup>327</sup> *Ibid.*, p.163

<sup>328</sup> Janet O'Keeffe (1994). *Supra* note (307), p.38



## 2. The Patient Protection and Affordable Care Act

President Obama signed the Patient Protection and Affordable Care Act in March 2010, the two objectives of the law were to reduce the costs of American health care, and to enlarge coverage<sup>329</sup>, as already mentioned, it did not aim at creating a national and universal health care system, even though it should be noted, in this perspective, that its attempt to establish public insurance plans, which would have substituted some private plans, was rejected<sup>330</sup>. The ACA can be considered the most significant act to reform the American health care system since the establishment of Medicare and Medicaid, it represents a response to some of the most relevant problem of the system at the beginning of the XXI century, such as increasing costs, lack in coverage, inequality in access to health care<sup>331</sup>.

As already happened to the Clinton reform, one of the strongest accused moved by the opponents was that the ACA would have introduced a system of socialized medicine<sup>332</sup>, anyway unlike the Clinton's Health Security Act, the so-called Obamacare entered into force, even though some of the pillars of its original text has been repealed. In 2009, 16% (about 49 million people) of the American population did not have health care coverage<sup>333</sup>; in 2014 the percentage of uninsured decreased to 12% and about 8 million American were enrolled under the ACA<sup>334</sup>. If fully implemented, the ACA would have brought the level of health insurance coverage to 94% of Americans, reducing the number of uninsured by 31 million people, and expanding Medicaid eligibility to 15 million Americans<sup>335</sup>. Therefore, apparently, the reform was achieving one of its main goals: expanding coverage; from a right to health point of view, this achievement could be considered from the perspective of progressive realization; therefore, it is important to highlight the points of the ACA that can relate to the right to equal access to health care.

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<sup>329</sup> Arnaldo Testi (2017). *Supra* note (289)., p. 302

<sup>330</sup> *Ibid.*, p.303

<sup>331</sup> Jonathan E. Fielding, et Al. A Perspective on the Development of the Healthy People 2020 Framework for Improving U.S. Population Health. *Public Health Reviews*, Vol.35, No.1., p.18

<sup>332</sup> Arnaldo Testi (2017). *Supra* note (289)., p.306

<sup>333</sup> *Ibid.*, p.302

<sup>334</sup> *Ibid.*, p.320

<sup>335</sup> Sara Rosenbaum (2011). The Patient Protection and Affordable Care Act: Implications for Public Health Policy and Practice. *Public Health Reports*, Vol. 126., p.130

## 2.1. The main Provision Related to the Right to Equal Access to Health Care

The original text of the ACA presents some relevant points that can seem to represent a step of the U.S. health care reforms toward the path of the human right to health, even though the standpoint of the reform was not human rights-based<sup>336</sup>, in fact Obama advocated the right to health during the electoral campaign, but then his reform was made according to principles of economic sustainability and cost effectiveness<sup>337</sup>. Through the ACA, the Obama administration seems to have partially recognized the human rights obligations for the right to health that emerges for all the members of the UN, even though it is clear that the U.S. is not adequately using its resources to achieve the scope<sup>338</sup>; anyway, some of the provisions established in the matter of extending health care coverage, mainly through the expansion of Medicaid eligibility, actually contributes, in theory, to guaranteeing access to health care to a considerable portion of the population that previously could not enroll in the program<sup>339</sup>.

One of the most evident discriminations of the insurance market in the U.S. was the possibility for insurers to refuse to offer an insurance plan to people on the basis of preexisting conditions or of a particular family history concerning chronic or hereditary disease<sup>340</sup>. This practice can strongly affect accessibility to health for those who are not eligible for Medicare or Medicaid, and for those who lose their employment-based insurance for example due to the loss of their job and have to seek for a new insurance policy. The ACA tried to address this problem establishing immediate access to insurance for people with preexisting condition<sup>341</sup>, enrolling components of this group who has been uninsured for several months in a temporary insurance program with financial assistance<sup>342</sup>; moreover, it provides that no insurer or group health plan can exclude people according to their preexisting conditions or to the fact that they have been sick in the past<sup>343</sup>, moreover, it also prohibits insurers to drop beneficiaries from a certain plan after their incurrence in

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<sup>336</sup> Andrea S. Christopher, Dominic Caruso (2015, October). promoting Health as a Human Right in the Post-ACA United States. *American Medical Association Journal of Ethics*, Vol. 17, No. 10: 958-965., p.960

<sup>337</sup> John Tobin (2012), *Supra* note (92), pp.3-4

<sup>338</sup> Mariah McGill, Gillian MacNaughton (2016). Struggle to Achieve the Human Right to Health Care in the United States. *Southern California Interdisciplinary Law Journal*, Vol.25, Iss. 3., p.661

<sup>339</sup> *Ibid.*, p.683

<sup>340</sup> Deborah Stone (2005). *Supra* note (322), pp.75-6

<sup>341</sup> The Patient Protection and Affordable Care Act (2010). s.1101

<sup>342</sup> *Idem.*

<sup>343</sup> *Ibid.*, s.2704

high costs<sup>344</sup>; in order to avoid discriminations based on health status, the ACA also prohibits the existence of eligibility rules based on medical history, genetic information, health status, and medical conditions<sup>345</sup>; it also tries to safeguard health care providers in this matter, proscribing that they could be discriminated on the basis of their acts, when they are performing in accordance to their professional license and State laws<sup>346</sup>.

Anyway, access to health insurance coverage, even though fundamental since uninsured individuals receive less appropriate care and also have worse health outcomes in comparison with those who are insured<sup>347</sup>, does not directly imply access to health care<sup>348</sup>, therefore enlarging Medicaid eligibility, probably, would have not alone brought a significant change in actual access to health care because, as highlighted in the subchapter concerning Medicaid, physicians can decide not to treat a person on the basis of his or her insurance, which together with the fact that Medicaid compensations were significantly below the level of private insurance ones, *de facto* Medicaid beneficiaries were often denied access. In this respect, the ACA provided an increase of these rates for the two years subsequent to the entry into force of the law, to bring them to the same level of Medicare reimbursement rates, which were far superior to Medicaid ones, in fact Medicare reimbursements were usually the 80% of private insurance reimbursement rates, while Medicaid ones correspond approximately only to their 56%<sup>349</sup>. This step has proved effective in expanding real access to health care for Medicaid beneficiaries; unfortunately, many States decided not to continue such reimbursement rates after 2015<sup>350</sup>.

The ACA extends eligibility for Medicaid to all those with an income at or below 133% of the federal poverty level (including childless adults and certain parents)<sup>351</sup>, and it reduces cost-sharing for those whose income is too high to enroll in Medicaid, but cannot afford insurance in the private market. The maximum limits of “out-of-pocket” expense are reduced to one-third of the

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<sup>344</sup> Howard P. Greenwald (2010). *Supra* note (282), p.335

<sup>345</sup> ACA (2010). *Supra* note (341) s.2705

<sup>346</sup> *Ibid.*, s.2706

<sup>347</sup> Milda R. Saunders, et Al. (2016). Association between Insurance Status and Mortality in Individuals with Albuminuria: an Observational Cohort Study. *BMC Nephrology*, 17:27., p.1

<sup>348</sup> Douglas F. Scutchfield, Richard C. Ingram (2013). Public Health Systems and Services Research: Building the Evidence Base to Improve Public Health Practice. *Public Health Reviews*, Vol. 35, No.1., p.643

<sup>349</sup> *Ibid.*, pp.641-2

<sup>350</sup> *Ibid.*, pp.61-2

<sup>351</sup> ACA (2010). *Supra* note (341)., s.2001

previous limits for those between 100-200% of the poverty line, one-half for those between 200-300%, and two-thirds for those between 300-400%<sup>352</sup>. The percentages of the plan's share of the total allowed costs of benefits have been modified through the Reconciliation Act as follows: 94% for those between 100-150% of the poverty line, 87% for those between 150-200%, 73% for those between 200-250%, and 70% for those between 250-400%<sup>353</sup>. Moreover, the income eligibility criteria would rely on a measure based on modified adjusted gross income (MAGI), which would exclude the asset test from the income-test for everyone, with the exception of those eligible for long-term care<sup>354</sup>. In order to facilitate the expansion of Medicaid eligibility criteria, the Federal Government would guarantee to States the complete payment for the costs of services for newly eligible individuals for 2014, 2015, and 2016; federal contribution would decrease to 95% for 2017, 94% for 2018, 93% for 2019, and 90% for 2020 and the following years<sup>355</sup>.

This expansion of income eligibility for Medicaid has been one of the most discussed provisions of the law, it was also brought before the Supreme Court that established that the Federal Government could not create a similar imposition upon States since it represents an unconstitutional exercise of Congressional power with concern to the Spending Clause; therefore States are not obliged to comply with this provision and are free to establish their own income eligibility line<sup>356</sup>. This decision of the Supreme Court constitutes a fundamental step in the implementation of the ACA and its success since the expansion of coverage under Medicaid was one of its pillars. Anyway, this decision has not come to surprise since according to the Tenth Amendment to the American Constitution States have all the powers not delegated to the Federal Government by the Constitution itself<sup>357</sup>; in fact, in motivating its decision, the Supreme Court stated that through the expansion of eligibility criteria, the ACA did not merely modify Medicaid, which is a legitimate act of the Federal Government, but it represents a complete change in the essence of the program; in fact, it was established, originally, to provide coverage only to well-defined categories of needy recipients, therefore the expansion to everyone under a certain level of income corresponding to a change in the scope of the program<sup>358</sup>, especially because through this general expansion based only

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<sup>352</sup> Ibid., s.1402

<sup>353</sup> Health Care and Education Reconciliation Act (2010), s.1001

<sup>354</sup> ACA (2010). *Supra* note (341) s.2002

<sup>355</sup> HCERA (2010). *Supra* note (353) s.1201

<sup>356</sup> June Mary Zekan Makdisi (2015). *Supra* note (316), pp.124-5

<sup>357</sup> Steven Jonas (2007). *Supra* note (271)., p.111

<sup>358</sup> June Mary Zekan Makdisi (2015). *Supra* note (316), pp.124-5

on income, for the first time, adult childless men without disabilities would have had the possibility to become Medicaid beneficiaries<sup>359</sup>. In addressing eligibility criteria, the Court did not contest the use of the MAGI accounting system, which therefore prohibits to all States to use the asset-test in determining Medicaid eligibility, whether they decide to expand coverage or not<sup>360</sup>.

The ACA also provides a so-called “individual mandate”, which means that individuals, starting from 2014, are obliged to maintain a minimum essential coverage<sup>361</sup>. People who fail at keeping the minimum coverage would incur in a penalty; exemptions for individual responsibility are made for certain categories of persons, such as religious objectors, prisoners, and people not lawfully present, some exemptions for penalties are also permitted to those who cannot afford coverage, those who were not covered for a period shorter than three months during the year, and those who have received waivers due to certain kind of hardships<sup>362</sup>. This provision is of fundamental importance not only in expanding coverage, but also in trying to control the costs. One of the problem that has emerged in the evolution of the health care system in the U.S. is that risk pools have tended to divide people on the basis of similar risk levels; this process constitutes an extremely relevant problem with respect to guaranteeing accessibility to health since high risk people coverage is very expensive (this is one of the main problem concerning Medicare financing)<sup>363</sup>. The introduction of the “individual mandate”, obligating low risk people to join the insurance pool, contributes to the enlargement of the risk pool<sup>364</sup>, which is a cardinal step also in the elimination of discriminatory pricing and coverage practices by private health insurance, because without the balance between high risk and low risk people, which is fundamental for the financial sustainability of the insurance they would not, and actually could not, eliminate those practices<sup>365</sup>.

## 2.2. The Relevance for Women Rights

Analyzing the ACA from a human rights perspective, it is important to briefly highlight the impact of this reform on women rights. Health care needs of women during their reproductive years

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<sup>359</sup> Howard P. Greenwald (2010). *Supra* note (282), pp.334-5

<sup>360</sup> June Mary Zekan Makdisi (2015). *Supra* note (316), p.126

<sup>361</sup> ACA (2010). *Supra* note (341)., s.5000A

<sup>362</sup> HCERA (2010). *Supra* note (353)., s.1002

<sup>363</sup> Howard P. Greenwald (2010). *Supra* note (282), p.202

<sup>364</sup> *Ibid.*, p.202

<sup>365</sup> Sara Rosenbaum (2011). *Supra* note (335), p.131

are usually superior to those of men of the same age, this has brought to a situation in which women were charged more than men by private insurance, and they were also often denied coverage for certain necessary services, such as maternity care<sup>366</sup>, this also lead to a situation in which women were less likely than men to have access to employment-based plans<sup>367</sup>. The ACA addressed this problem through the provisions that prohibit discrimination based on preexisting conditions, and also through the prohibition for private insurance to impose to women premiums which are higher than those proposed to men<sup>368</sup>. Moreover, an important introduction of the ACA consists in the fact that all the plans purchased on the exchanges have to guarantee coverage for gynecological and obstetric care and also for maternity care; the reform also provides the elimination of cost-sharing for certain categories of preventive care, including FDA-approved contraceptives<sup>369</sup>. Women should have gained an improvement in access to health care through these ACA provisions, but, especially concerning coverage for contraceptives, significant setbacks have been made. Churches and organizations that are considered religious employers are completely exempt from obligations concerning contraceptives; also non profit organizations qualify for some kind of exemption in this matter since they have to include contraceptive coverage in the insurance plans they offer, but they can decide not to pay for the portion of the insurance premiums that regard contraceptives<sup>370</sup>.

In reality, the implementation of the ACA provisions concerning women were not so strict and many women had difficulties in accessing reproductive health care services provided for in the ACA even after its entry into force, for example, certain insurers imposed a limit on the number of prenatal visits covered, or required cost-sharing for contraception; some also excluded from the coverage genetic testing for ovarian and breast cancer for high-risk women<sup>371</sup>. Moreover, even when the law is fully implemented, it still allows discriminations against women since it does not provide coverage for abortion. Concerning abortion, first of all, it is not included in the list of essential benefits, therefore insurance are not obliged to cover it; moreover, the ACA incorporates the Hyde Amendment, which guarantees the use of federal funds for this practice only in limited cases, namely pregnancies that are the consequence of rape, incest, or that can put the life of the woman in danger; to ensure the enactment of this Amendment, an administrative procedure has

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<sup>366</sup> Mariah McGill, Gillian MacNaughton (2016). *Supra* note (338), p.629

<sup>367</sup> *Ibid.*, p.652

<sup>368</sup> *Ibid.*, p.653

<sup>369</sup> *Idem.*

<sup>370</sup> *Idem.*

<sup>371</sup>*Ibid.*, p.654

been established, which provides that each plan receiving federal subsidies and providing abortion coverage has to collect two different and separate premiums from the enrollee: one covering abortion, and the other one for all the other services. Additionally, States can decide to limit the access to abortion in the plans sold in their state<sup>372</sup>, and many States are actually using this possibility<sup>373</sup>. Thus, whether the ACA tries to cancel discrimination practices towards women, it actually only diminish them because it allows religious beliefs to interfere with the law, failing in this way in ensuring an effective non-discriminatory access to health care to this category of the American population<sup>374</sup>.

### **3. President Trump Interventions on the Patient Protection and Affordable Care Act**

President Trump took office in January 2017, at that moment the percentage of uninsured among the U.S. population had decreased to 8.8%, mostly because of the expansion of Medicaid and the other federal financial support for health insurance granted to low-income Americans<sup>375</sup>. Anyway, health care and the repealing of the ACA were extremely relevant topic of Trump's electoral campaign; the importance that the President gives to this matter is also reflected by the fact that the first executive order of his presidency concerned the ACA. The executive order "Minimizing the Economic Burden of the Patient Protection and Affordable Care Act Pending Repeal", issued by the President on January 20th, was directed to administrative agencies that would have to:

"exercise all authority and discretion available to them to waive, defer, grant exemptions from, or delay the implementation of any provision or requirement of the Act that would impose a fiscal burden to any State or a cost, fee, tax, penalty, or regulatory burden on individuals, families, health care providers, health insurers, patients, recipients of healthcare services, purchasers of health insurance, or makers of medical devices, products, or medications"<sup>376</sup>.

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<sup>372</sup> ACA (2010). *Supra* note (341) s.1303

<sup>373</sup> Mariah McGill, Gillian MacNaughton (2016). *Supra* note (338), pp.654-5

<sup>374</sup> *Ibid.*, p.655

<sup>375</sup> Frank J. Thompson, et Al. (2018). Trump and the Affordable Care Act: Congressional Repeal Efforts, Executive Federalism, and Program Durability. *Publius: The Journal of Federalism.*, pp.3-4

<sup>376</sup> Executive Order 13765 of January 20, 2017. "Minimizing the Economic Burden of the Patient Protection and Affordable Care Act Pending Repeal". *Federal Register/Vol. 82, No. 14, Tuesday, January 24, 2017.*, s.2

Moreover, it also stresses the attention on the fact that the goal is to develop a free and open market for health care insurance able to achieve and preserve the maximization of options for patients and consumers<sup>377</sup>. The lack of a satisfying variety of options for health insurance under the ACA is at the core of another executive order concerning health care, issued by the President on 12th October 2017; in this document Trump reaffirmed that one of the main objective of his administration with respect to the health care insurance market is to promoting competition in health care markets<sup>378</sup>.

At first, Trump demanded that the Congress should repeal and replace the ACA at the same time. However, this procedure appeared extremely complex and long; therefore the Congress opted for a different approach: initially, repealing the key feature of the ACA, and then developing an alternative<sup>379</sup>. President also galvanized the Congress to certain bills, even when they encountered massive public disapproval and the opposition of stakeholders<sup>380</sup>. The first step of the procedure aimed at dismantling and replace the Obamacare, not considering the President's executive order of January 20th, is represented by the American Health Care Act (AHCA) in May 2017<sup>381</sup>. One of the most vigorous attacks to the ACA was made through the tax reform at the end of 2017 that abolished the penalties related to the so-called "individual mandate"<sup>382</sup>, which were a pillar of the ACA, as explained previously<sup>383</sup>; 1st January 2016 was established as the effective date of enactment of this provision; therefore retroactive relief was settled for those impacted by the penalties during 2016<sup>384</sup>.

Even though the position of the President concerning the ACA has been quite clear and firm, providers, mainly nursing homes, safety-net hospitals, and managed care organizations, and various advocacy groups firmly opposed the idea of repealing and replacing the ACA<sup>385</sup>. This is also due to the fact that the opinion of many Americans in regard to Medicaid is changing: it increasingly represents an insurance program for working people, middle class, and "deserving" groups, rather

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<sup>377</sup> Ibid., s.4

<sup>378</sup> Executive Order 13813 of October 12, 2017. "Promoting Healthcare Choice and Competition Across the United States". Federal Register/Vol. 82, No. 199, Tuesday, October 17, 2017., s.1

<sup>379</sup> Frank J. Thomson, et Al. (2018). *Supra* note (375), p.5

<sup>380</sup> Idem.

<sup>381</sup> Idem.

<sup>382</sup> American Health Care Act of 2017, s.204

<sup>383</sup> Frank J. Thomson (2018). *Supra* note (375), et Al., p.7

<sup>384</sup> AHCA (2017). *Supra* note (382), s.204

<sup>385</sup> Frank J. Thompson (2018). *Supra* note (375), pp.20-1



than “welfare medicine”<sup>386</sup>. Moreover, an increasing number of Americans (85%) thinks that federal funding for Medicaid should continue to expand<sup>387</sup>. This glimpse of public opinion concerning Medicaid, in my opinion, is not only relevant to the analysis of both the effective success or failure of the ACA, and the approval of President Trump’s legislation, but it also offers an image of the fact that a rights-based discourse is probably not only absent in the political sphere, but also in people’s mind. On the one hand, it could be positively perceived, from a right to health perspective, that general opinion concerning Medicaid is shifting to a more positive one; however, on the other hand, the fact that the assumption behind this change is not the fact that everyone, regardless of how poor he or she is, and of the reason behind his or her poverty, deserves access to health care, may highlight how far away from people’s perception of health care the right to equal access to health care is.

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<sup>386</sup> *Idem*.

<sup>387</sup> *Idem*.

## **Chapter IV - Accessibility to Health Care in the United States between Reality and Human Rights Obligations.**

Table of contents: 1. Problems of Private Insurance - 1.1 The Importance of Coverage in Achieving Access to Health Care - 1.2 Health Care is not a Normal Good in the Marketplace - 2. Is a Human Rights-based Perspective of U.S. Health Care really Possible? - 2.1 The U.S. and International Human Rights Law Obligations - 2.2 Key Values of the American Society - 2.3 Lobbying and Interest Groups - 2.4 The Case of Vermont

### **1. Problems of Private Insurance**

The United States private insurance system for health care is based mainly on employment-based plans<sup>388</sup>, buying individual insurance in the marketplace is usually extremely expensive<sup>389</sup>; moreover, employment-based plans receive a kind of tax subsidies because these payments are excluded from taxable income<sup>390</sup>. Unemployment is not the only considerable problem of this system because the fact that employers are not obliged to guarantee health care coverage to their employees gives rise to a considerable amount of working people that do not have health care insurance, often because small employers cannot afford insurance<sup>391</sup>. This problem has worsened starting from the '80s due to a decrease in high-paying manufacturing jobs in favor of an increase in lower-paying jobs in the service sector<sup>392</sup>; even when these low-income employees are offered coverage, they may tend to refuse it because of the high cost-sharing provisions or high premiums<sup>393</sup>, "out-of-pocket" expenditures are, in fact, a relevant problem especially for vulnerable population<sup>394</sup>, also because they are made using after-tax money<sup>395</sup>. Additionally, the premiums provided by health care insurance can be considered as a regressive method of payment, because they do not consider the available resources of the enrollee; therefore the burden of the costs of premiums and "out-of-pocket" payments affects the most vulnerable<sup>396</sup>; moreover, it also

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<sup>388</sup> Howard P. Greenwald (2010). *Supra* note (282), p.5

<sup>389</sup> Timothy S. Jost (2003). *Supra* note (283), p.16

<sup>390</sup> David M. Cutler (2002, February). *Supra* note (270), pp.4-5

<sup>391</sup> Timothy S. Jost, (2003). *Supra* note (283) p.187

<sup>392</sup> Lu Ann Aday (2001). *Supra* note (10), pp.93-4

<sup>393</sup> *Ibid.*, pp.160-1

<sup>394</sup> *Ibid.*, p.203

<sup>395</sup> David M. Cutler (2002, February). *Supra* note (270), pp.4-5

<sup>396</sup> Lu Ann Aday (2001). *Supra* note (10), p.272

contradicts one of the pillars of the human right to health that affirms that health care should be available on the basis of need, and not of ability to pay.

A relevant outcome of the private insurance system is that a significant amount of uninsured and underinsured are employed<sup>397</sup>. This is due to the fact that there is a consistent gap between people who are eligible for public programs and those who can actually afford to buy insurance, with another relevant number of people who prefer to save money instead of buying health insurance<sup>398</sup>, contributing to the enlargement of the amount of uninsured at risk of enormous expenditures for health care services and to the impairment of the risk pool. In public systems, healthy people subsidize those who require treatment, this system works not only because of social justice principles but also due to the fact everyone is at risk of becoming ill at any moment of their lives<sup>399</sup>. A system based on private insurance does not provide security to people in the long-term<sup>400</sup>. On the one hand, the uninsured worry that they would not be able to afford health care services in case of necessity; on the other hand, the insured worry that they will lose the coverage and that an accident or a severe illness (the treatment of which may not be included by their insurance) can destroy their economic security<sup>401</sup>. In fact, Health care expenditures have also been addressed as one of the most common reasons of bankruptcy among American people<sup>402</sup>; the risk of being uninsured or underinsured is usually not perceived by American middle-class or high-income population as an immediate danger as, for example, terrorism, however, not so many Americans have the real wealth necessary to pay for health care services in the case of catastrophic events<sup>403</sup>. Additionally, hospitals' services rates for the uninsured are usually much higher (also three to five times higher) than what they accept as payment from insurance companies<sup>404</sup>.

The structure of health care insurance system permits a great disequilibrium between high risk and low-risk people: the former has to pay more, just because they are high risk; the latter usually does not obtain full insurance coverage, because they are low-risk<sup>405</sup>. This method of

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<sup>397</sup> Timothy S. Jost (2003). *Supra note (283)*., p190

<sup>398</sup> Steven Jonas, et Al (2007). *Supra note (271)*, p.190

<sup>399</sup> Colleen M. Flood (2000). *Supra note (71)*, p.248

<sup>400</sup> Janet O'Keeffe (1994). *Supra note (307)*, p.45

<sup>401</sup> *Ibid.*, pp.58-9

<sup>402</sup> Howard P. Greenwald (2010). *Supra note (282)*, p.4

<sup>403</sup> Timothy S. Jost (2003). *Supra note (283)*, p.2

<sup>404</sup> Patrick J. Rooney, Dan Perrin (2008). *Supra note (286)*, p.17

<sup>405</sup> David M. Cutler (2002, February). *Supra note (270)*, p.57

selection and insurance gives rise to discriminatory treatments that hit both groups (on the one hand, high-risk people have to pay more because they are sick, or because they are at greater risk of becoming sick; on the other hand, low-risk people are threatened by the fact that being low risk does not prevent them from falling sick and in this unfortunate case they may not be able to afford “out-of-pocket” payments). Moreover, health insurance is profoundly different from other insurance. Other kinds of insurance insure people’s existing wealth; health insurance deal with one person’s existing health, which is a much more vague concept<sup>406</sup>.

A private insurance system mainly characterized by employment-based plans does not guarantee universal coverage, and this results in a considerable degree of pro-rich inequity<sup>407</sup>. This condition is also the result of a health care system structure that considers health insurance as an economic good, not a social one; therefore physicians and hospitals act accordingly to this perspective<sup>408</sup>, allowing discriminations based on employment and income<sup>409</sup>. This kind of discrimination, related to the fact that there is a correlation between employment and health insurance status, which affects health, and which can also be seen in the broader perspective of the correlation between low socio-economic status and poor health<sup>410</sup>, brings to the not surprising fact that both uninsurance and insurance through public programs are connected to higher risks for mortality when compared to private insurance<sup>411</sup>.

## **1.1. The Importance of Coverage in Achieving Access to Health Care**

The free-market model applied to U.S. health care gives rise to a system that can provide the highest attainable standard of health care, the problem is that this possibility is guaranteed only to those who can afford it<sup>412</sup>. Americans can access health care services on the basis of their health insurance coverage, which is related to their ability to pay; because of that, analyzing levels of

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<sup>406</sup> Timothy S. Jost (2003). *Supra* note (283), p.10

<sup>407</sup> Eddy Van Doorslaer, et Al. (2006, January). Inequalities in Access to Medical Care by Income in Developd Countries. *CMAJ*, 174(2)., p.181

<sup>408</sup> Lawrence D. Brown (2003). Comparing Health Systems in Four Countries: Lessons for the United States. *American Journal of Public Health*, Vol.93, No.1., p.54

<sup>409</sup> Jack Donnelly (1994). International Human Rights and Health Care Reform. In *Health Care Reform: A Human Rights Approach*. Georgetown University Press. Edited by A. R. Chapman., 130

<sup>410</sup> Thomas J. Papadimos (2007). Healthcare Access as a Right, not a Privilege: a Construct of Western Thought. *Philosophy, Ethics, and Humanities in Medicine*, 2:2., p.1

<sup>411</sup> Milda R. Sauders, et Al. (2016). *Supra* note (347)., p.5

<sup>412</sup> Benjamin M. Meier (2010). *Supra* note (150)., p.201

coverage is essential to address the matter of equal access to health care<sup>413</sup>. Access to health care implies that people can physically and affordably access certain services, however, to have coverage is not always enough to receive health care services<sup>414</sup>. This condition permits a discriminatory system that allows distinctions based on various grounds, such as private or public source of insurance<sup>415</sup>; even though the ACA apparently tried to address this matter by increasing Medicaid reimbursement rates, the fact that this increase was temporary, and the fact that many States decided not to continue them, can be considered as a failure of the reform in addressing discrimination in access to health care, because even the original text presented only a temporary measure in addressing this matter, which is instead fundamental from a right to health perspective, because it avoids *de facto* discrimination. Addressing discriminations in coverage, one crucial aspect of the ACA, which has not been repealed until now, is the provision that insurers cannot refuse to offer coverage to people on the basis of health status, pre-existing conditions, and genetic predisposition. This provision has stopped an extremely common practice of private insurers that have denied coverage to a considerable amount of people throughout the years.

One of the recognized barriers to access to health care is absence of insurance also because not having insurance coverage often inhibits people, mainly elderly, from seeking medical care, which, consequently, put them not only at risk of adverse health due to lack of access to health care but also of social isolation<sup>416</sup>. In comparison with those who have health care insurance, the uninsured are not only sicker, but they also receive less health care and are also more likely to suffer premature death<sup>417</sup>. Inequality in access to health care also represents a cost for society since disparities in access are linked to disparities in outcomes: differences in access to health care services are connected to differences in infant mortality, birth weight, complication from common and preventable disease, and late-stage cancer diagnosis, and also in the quality of care patients receive<sup>418</sup>. Moreover, lack of health insurance has also an impact on the expenses of the system because it brings to increasing utilization of emergency rooms for problems that could have been

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<sup>413</sup> Idem

<sup>414</sup> Lu Ann Aday (2001). *Supra note (10)*, p.179

<sup>415</sup> Ibid., p.181

<sup>416</sup> Shalonda Horton, Regina J. Johnson (2010) *Supra note (318)*, p.363

<sup>417</sup> Jill Quadagno (2004). *Supra note (290)*, p.26

<sup>418</sup> Fahui Wang (2012). Measurement, Optimization, and Impact of Health Care Accessibility: A Methodological Review. *Annals of the Association of American Geographers*, 102:5, 1104-1112, DOI: 10.1080/00045608.2012.657146., p.1105

addressed through preventive or routine care in a definitely cheaper way<sup>419</sup>. The fact that U.S. health care coverage is not effective in addressing the health necessity of American can also be evaluated by an analysis of the life expectancy. Life expectancy can be used as an evaluator of the health care system in two ways: comparing life expectancy in different societies and comparing life expectancy among different groups of one society; both the ways highlight the fact that the U.S. has a problem in this matter<sup>420</sup>. The differences in the quality of health care people receive are an important indicator of inequalities in access to health care. Health care access is a significant problem for the uninsured that are more likely to seek health care, and, when they have access to it, are more likely to fail at following medications in a proper way since they usually spread them out a more extended period than the one proscribed in order to save money<sup>421</sup>.

Studies have been conducted to determine the real impact of public funded programs in addressing the problem of access to health care in the U.S. A good example is a study concerning access to tonsillectomy and adenoidectomy for children covered by Medicaid in Southern California. The result of this study highlight the fact that, among physicians who responded to the questionnaire, only the 19% would treat Medicaid children. The reasons behind the refusal of the other 81% of physicians lay in excessive administrative procedures and low monetary reimbursement for both office appointment and surgical treatment<sup>422</sup>. Another good example address the correlation between insurance status and breast cancer survival. Reduce access to health care is connected to advanced stage of cancer and higher mortality rates<sup>423</sup>. Medicaid beneficiaries and uninsured represent the majority of cases of diagnosis of breast cancer at stage III or IV; moreover, the survival rates of patients with private insurance is higher than that of women cover by Medicaid or uninsured: this difference may be explained by the fact that the latter has reduced access to preventive care and to high-quality care.<sup>424</sup> A similar situation has been found in studies dealing with colon cancer: access to treatment resulted superior for people with private insurance or

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<sup>419</sup> Steven Jonas, et Al. (2007), *Supra note (271).*, p.153

<sup>420</sup> *Ibid.*, p.170

<sup>421</sup> *Ibid.*, et Al., p.190

<sup>422</sup> Edward C. Wang, et Al. (2004, November). Inequality of Access to Surgical Specialty Health Care: Why Children with Government-Funded Insurance Have Less Access than those with Private Insurance in Southern California. *Pediatrics*, Vol.114, No.5., p.586

<sup>423</sup> Runhua Shi, et Al. (2015). Effects of Payer Status on Breast Cancer Survival: a Retrospective Study. *BMC Cancer*, 15:211., p.1

<sup>424</sup> *Ibid.*, p.6

enrolled in Medicare than for those insured by Medicaid or without coverage<sup>425</sup>. Quite obviously, there are many factors influencing access to health care, but it is undeniable that having health insurance is the primary prerequisite to access the system<sup>426</sup>. These studies represents an example of the fact that the extension of coverage, mainly through public funded programs, without a serious discourse about the definition of who would provide health care to the beneficiaries of these programs is not enough and would also worsen the situation<sup>427</sup>.

## **1.2. Health Care is not a Normal Good in the Marketplace**

Americans' perception of health care is also sometimes different from the one they have of other goods. When in need, it is rare that patients ask physicians how much a specific procedure may cost, because they feel a sense of entitlement to receiving the health care services they need, also because the atmosphere in which health care is provided is usually an emotional one<sup>428</sup>. By contrast, the market ideology applied to health care has created a system of competition between rich and poor, instead of a structure aimed at the distribution of medical care on the basis of medical needs<sup>429</sup>; even though physicians are trained to treat people according to their needs, the entirety of the system is dominated by market mechanisms, which, in the end, contribute to exacerbating inequalities<sup>430</sup>.

Most economists affirm that market for health care services, and goods is far from being perfect, and therefore requires Government intervention<sup>431</sup>. Moreover, some scholars, like Greenwald, add to this concept the fact that health care should be under the category of public good, because none can claim its ownership<sup>432</sup> since it is a union of many subsystems that integrate themselves in order to create this complex system<sup>433</sup>. Some of the main features that put consumers

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<sup>425</sup> Kevin M. Gorey, et Al. (2014). Lack of Access to Chemotherapy for Colon Cancer: Multiplicative Disadvantage of Being Extremely Poor, Inadequately Insured and African American. *BMC Health Services Research*, 14:133., p.2

<sup>426</sup> Runhua Shi, et Al. (2015), *Supra note (423)* p.1

<sup>427</sup> Edward C. Wang, et Al. (2004, November). *Supra note (422)*, p.587

<sup>428</sup> Howard P. Greenwald (2010). *Supra note (282)*, pp.10-1

<sup>429</sup> Deborah Stone (2005). *Supra note (322)*, p.66

<sup>430</sup> *Ibid.*, p.66

<sup>431</sup> Howard P. Greenwald (2010). *Supra note (282)* p.319

<sup>432</sup> *Ibid.*, p.17

<sup>433</sup> *Ibid.*, p.22

of health care in a position of disadvantage are that there is a situation of consistent information asymmetry where consumers of health care rarely know prices or quality of the services that are included in their insurance, and of those they receive, and that the exit from the market is not free since the consumer cannot foresee whether or which health care services he or she would need<sup>434</sup>. Moreover, leaving health care to the rules of the market does not always lead to the best long-term solutions, because it appears intrinsic in this choice that various disadvantaged Americans remain without health care coverage, and therefore without access to the system<sup>435</sup>, also because vulnerable population is not a profitable portion of the society, therefore, following market principles, it is not convenient to provide them health care services<sup>436</sup>. In connection with the decision of letting market principles driving the health care system should be analyzed the fact that health care costs are escalating, due to always new and extremely expensive technologies and drugs, and do not seem to stop<sup>437</sup>, making health care inaccessible to an always increasing number of people.

Arrow identified in the health care substantial differences with respect to other sectors of the economy, namely information asymmetries, uncertainty, and risks related to medicine and medical services that are not marketable; therefore he affirms that health care cannot be equated to other sectors of the economy<sup>438</sup>; usually people do not have an in-depth knowledge of what they are buying on the health care marketplace, they just want to get better<sup>439</sup> and therefore they trust physicians. There are sufficient reasons to affirm that a market-driven health care system, which aims at making profits, is not compatible with the real scope of health care<sup>440</sup> that is to meet the health care needs of the population, enabling it to be as healthy as possible and to support a productive society<sup>441</sup>. The problem concerning health care and the market is not in the fact that Government policies distort the market, it is the market in itself and the premises on which it works<sup>442</sup>.

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<sup>434</sup>Ibid., p.292

<sup>435</sup> Ibid., p.37

<sup>436</sup> Deborah Stone (2005). *Supra note (322)*, p.71

<sup>437</sup> Howard P. Greenwald (2010). *Supra note (282)*, p.174

<sup>438</sup> Steven Jonas, et Al. (2007). *Supra note (271)*., p.129

<sup>439</sup> Ibid., p.251

<sup>440</sup> Ibid., p.271

<sup>441</sup> Janet O'Keeffe (1994). *Supra note (307)*, pp.47-8

<sup>442</sup> Benjamin M. Meier (2010). *Supra note (150)*, p.201



## 2. Is a Human Rights-based Perspective of U.S. Health Care really Possible?

Entitlement to health care access is not mentioned in the U.S. Constitution, nor in the Bill of Rights, additionally, health care has usually been seen as a commodity or a private good rather than as a social one<sup>443</sup>, this approach has also discouraged the creation of citizens interest groups representing people interest<sup>444</sup>. However, even though the right to health is not part of the American Constitution, the U.S. has recognized this idea having ratified the WHO Constitution and being a member of this organization<sup>445</sup>. A human rights approach to health care is based on the fact that the State is responsible for guaranteeing the consistency of the system with human rights provisions; States, therefore, assumes a guarantor role that must be implemented irrespective of the private or public nature of the health care system<sup>446</sup>. With regard to the U.S. health care system, which is extremely fragmented, it is undeniable that guaranteeing the compliance with the right to health is complex, also because usually private systems have different priorities than human rights implementation; however, it is important to reaffirm that international human rights provisions concerning the right to access to health care have not provided guidelines in the matter of how health care services should be delivered and paid for<sup>447</sup>.

Usually, one of the first observations made to U.S. public programs concerning health care, which provide coverage to the vulnerable, is that their costs are extremely high, and that, therefore, Federal and States Government already invest a lot in providing health care for the disadvantaged<sup>448</sup>, however, this observation sometimes fails to address the fact that these programs cost a considerable amount of money precisely because they cover only those who use the most of health care services, so that balance between high and low-risk people necessary for the financial sustainability of the insurance lacks in these programs. National health insurance of any kind would address the majority of U.S. health care system problems. The creation of a system that is not fragmented and can operate in a comprehensive, coordinated, planned and national way would not only contribute to address the problem of equal access to health care but also concentrate on the

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<sup>443</sup> Audrey R. Chapman (1994). *Supra note (6)*, pp.18-9

<sup>444</sup> *Ibid.*, p.21

<sup>445</sup> Virginia A. Leary (1994). *Supra note (34)*, p.93

<sup>446</sup> Audrey Chapman (2014). The Impact of Reliance on Private Sector Health Services on the Right to Health. *Health and Human Rights Journal, Vol.16, No.1.*, p.123

<sup>447</sup> *Ibid.*, p.123-5

<sup>448</sup> Howard P. Greenwald (2010). *Supra note (282)*, p.6

problem of financial sustainability of the system<sup>449</sup>, also because, concerning resources, the problem appears to be the allocation of them and not the quantity of resources invested in the system<sup>450</sup>.

Equality, interpreted as having equal opportunities of participating in public life, is a crucial value of the American culture<sup>451</sup>. This idea represents a chance for the right to health perspective to enter the health care reform discourse in the U.S. since, as explained in the first chapter of this thesis, the highest attainable standard of health is an essential prerequisite for people to live their life at the fullest; a basic standard of health, being a prerequisite to almost every other aspect of life, is also a necessary condition for all the forms of merit-based distributions<sup>452</sup>.

## **2.1. The U.S. and International Human Rights Law Obligations**

The U.S. Constitution, as already mentioned, does not recognize a right to health and, in general, the United States has been reluctant to sign and ratify international treaties and covenants concerning human rights. However, concerning the applicability of international human rights obligations to the U.S., it is relevant to highlight the fact that the UDHR is commonly considered customary international law and that they have signed, even though not ratified, the ICESCR, therefore they are obliged to avoid acting against its provisions<sup>453</sup>; moreover, they have ratified the ICCPR that includes a general provision concerning discriminations, as already analyzed in the second chapter, but the Congress has also declared that this Covenant was not self-executing, therefore, until the Congress establishes laws to implement it, it is not enforceable before U.S. courts<sup>454</sup>. This situation, however, does not nullify the obligations that the ICCPR imposes to the U.S., but it somehow weakens their power.

The U.S. made some official observations concerning the Fact Sheet No.31. They felt the necessity to explain the American position toward the document and the right to health because the Fact Sheet appeared as referring to all States and not only to those who had ratified the ICESCR<sup>455</sup>, which is where some provisions of the Fact Sheet has been defined. First of all, in the observations,

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<sup>449</sup> Steven Jonas, et Al. (2007). *Supra note (271)*, pp.232-3

<sup>450</sup> *Ibid.*, p.251

<sup>451</sup> Howard P. Greenwald (2010). *Supra note (282)*, p.32

<sup>452</sup> Deborah Stone (2005). *Supra note (322)*, p.68

<sup>453</sup> Carol Castleberry (2015). *Supra note (126)*, p.190-2

<sup>454</sup> *Ibid.*, pp.206-7

<sup>455</sup> Observations by the United States of America on “The Right to Health, Fact Sheet No. 31”, s.8

one of the main problems of the document is highlighted: its vagueness<sup>456</sup>, connected to a lack of a general consensus on the actual nature and scope of obligations related to the right to health<sup>457</sup>. The focus of the observations, however, is the fact that the U.S. has ratified two documents recognizing the right to health (the WHO Constitution and the CERD), but this does not bind them to the obligations of respecting, protecting, and fulfilling with respect to the right to health introduced by other documents dealing with this right<sup>458</sup>. In the conclusion, it is claimed that the obligations provided in the Fact Sheet represent for the United States neither obligations derived from treaties, nor customary law principles<sup>459</sup>.

Relevant is the fact that the U.S. is part of the CERD. Being part of the CERD the U.S. has a legal obligation to eliminate all forms of racial discrimination, guaranteeing everyone, among other provisions, without discriminations, the enjoyment of “the rights to public health and to medical care”<sup>460</sup>; the responsibility of the implementation of the provisions of the Convention is of the Federal Government that has to act as a supervisor of single States behaviors<sup>461</sup>. The fact that the concluding observation of the CERD does not have a direct impact on U.S. legislation and that does not originate binding provisions does not mean that the U.S. is not entitled to the implementation of the Convention<sup>462</sup>. The last concluding observation related to the implementation of the CERD emphasizes the fact that with respect to the elimination of racial discriminations, access to health care is still a problematic sector in the U.S. In addressing the topic a clear reference is made to the decision of many States not to implement the Medicaid coverage expansion under the ACA, decision that has penalized racial and ethnic minorities, which are substantially present in these States<sup>463</sup>. It also reaffirms the necessity to address the problem of persisting racial disparities in access to sexual and reproductive health care services, especially concerning high maternal and

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<sup>456</sup> Ibid., s.3

<sup>457</sup> Ibid., s.5

<sup>458</sup> Ibid., ss. 10-12

<sup>459</sup> Ibid., conclusion

<sup>460</sup> CERD (1963). *Supra note (127)*.

<sup>461</sup> Alicia Ely Yamin (2005, July). The Right to Health under International Law and its Relevance to the United States. *American Journal of Public Health, Vol. 95, No. 7.*, p. 1158

<sup>462</sup> Ibid., p.1159

<sup>463</sup> Concluding Observations on the Combined Seventh to Ninth Periodic Reports of the United States of America (2014), para 15

infant mortality among African Americans, a problem already stressed in previous concluding observations made by the Committee<sup>464</sup>.

Concerning right to health obligations, the U.S. has not taken any actions with respect to the regional document “Additional Protocol to the American Convention on Human Rights in the Area of Economic, Social and Cultural Rights” (Protocol of San Salvador) of 1988. Article 10 of this additional protocol addresses the right to health affirming that “Everyone shall have the right to health, understood to mean the enjoyment of the highest level of physical, mental and so-called social well-being”<sup>465</sup>, and that provides States Parties to recognize health as a public good and to enact certain measures, such as making primary care available to everyone and extending health services benefits to all the people subject to the State’s jurisdiction<sup>466</sup>.

## **2.2. Key Values of the American Society**

Speaking about equal access to health care and the U.S. health care system, it is essential to address some peculiar characteristics of the American society, because they appear consistent with certain features of that system<sup>467</sup>. Widespread is the opinion that poor and uneducated people are responsible for their poor health because it is the result of the risky behaviors they adopt; this idea of a direct correlation between one’s behaviors and his or her health matches perfectly with one of the cornerstones of the American culture: individualism<sup>468</sup>. All individuals have the right to freely decide their lifestyle as long as they take responsibility for the consequences and do not assume others would pay for them<sup>469</sup>. This conception connected to health and to the need of access to health care presents, however, several problems: first of all, claiming that poor people are free to decide their lifestyle is detached from reality; secondly, although some risky behaviors are deliberately chosen, it is difficult to establish the degree of individuals’ responsibility in certain situations and also to define whether or not a risk is avoidable<sup>470</sup>. This concept may also be seen in

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<sup>464</sup>Ibid., para 15

<sup>465</sup> Additional Protocol to the American Convention on Human Rights in the Area of Economic, Social, and Cultural Rights “Protocol of San Salvador” (1988), art.10

<sup>466</sup>Ibid., art.10

<sup>467</sup> Howard P. Greenwald (2010). *Supra note (282)*, p.35

<sup>468</sup> Ichiro Kawachi (2005). *Supra note (3)*, p.25

<sup>469</sup> Idem

<sup>470</sup> Idem

the fact that, usually, lower-income groups do not strongly exercise their political rights in order to improve their condition related to access to health care<sup>471</sup>; there are, obviously movements that support the establishment of a national health care system, but, compared to citizens of other industrialized countries, Americans have seemed less interest in Government policies aimed at the redistribution of income and wealth<sup>472</sup>. However, the success obtained by Bernie Sanders, who positively spoke of socialism for the first time in the mainstream American public rhetoric<sup>473</sup>, and who makes public health care one of the strong points of his political career, at the presidential primaries of 2016 may represent a sign of change in this matter. It is relevant to note that the initiatives proposed by movements advocating for health care as a human right have a completely different perspective from the ACA: they ask for universal health care, not for universal health coverage<sup>474</sup>.

Meritocracy represents another pillar of the American credo. The key aspect of this concept is that those who work hard and achieve certain objectives deserve the highest rewards<sup>475</sup>; this idea is applied to all the aspects of life accurately, seeing a direct responsibility of the person in the socio-economic level he or she belongs to; therefore it contrasts with the idea at the basis of the welfare state<sup>476</sup>. This framework contributes to a better understanding of the suspicious perception many Americans have of Medicaid as a welfare program, as already mentioned. The perception that poverty is a fault of the poor is still somehow well-rooted in Government activity and in public opinion related to the legacy of the Protestant work ethic, which perfectly matches with the discourse of personal responsibility in health<sup>477</sup>. This idea of poverty has brought to the division of poor people into two categories: “worthy poor” and “unworthy poor”. Disabled, elderly, and infirm fall into the first group; whereas unemployed people without physical and mental disabilities are included in the second one<sup>478</sup>. Necessities of the second group do not deserve public support<sup>479</sup>, this is one of the reasons why, until the ACA, they were not included in the beneficiaries of Medicaid.

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<sup>471</sup> Lawrence R. Jacobs (2005). Health Disparities in the Land of Equality. In “Healthy, Wealthy, and Fair. Health Care and the Good Society.” *Oxford University Press*. Edited by Morone, J. A.; Jacobs, L. R., p.55

<sup>472</sup> *Ibid.*, p.55

<sup>473</sup> Arnaldo Testi (2017). *Supra note (289)*, p.331

<sup>474</sup> Mariah McGill, Gillian MacNaughton (2016). *Supra note (338)*, p.630

<sup>475</sup> Howard P. Greenwald (2010). *Supra note (282)*, p.31

<sup>476</sup> *Idem*

<sup>477</sup> Steven Jonas, et Al. (2007). *Supra note (271)*, p.109

<sup>478</sup> Colleen M. Flood (2000). *Supra note (71)*, p.311

<sup>479</sup> *Ibid.*, p.311

However, health is not meritocratic, to be healthy is not (in most cases) a matter of personal merit<sup>480</sup>.

A majority of Americans appears to be in favor of universal health care access and considers it a fundamental right; however, they also appear reluctant to make the societal financial commitment and personal trade-off necessary to the establishment of a system able to guarantee this right<sup>481</sup>. Regardless of this contradiction, most U.S. citizens place health care at the center of their concept of a good, or at least tolerable, life; denial of health care services is not only a hazard to one's well-being, but it assumes the aspect of an assault to people self-respect<sup>482</sup>. However, Americans do not usually put their trust in the "big Government" (the Federal Government), many of them tend to believe that the market can act in a better way than the Government<sup>483</sup>. This feeling has also been enhanced by certain historical events, such as the Vietnam war and the Watergate scandal<sup>484</sup>. This distrust related to "big Government" or to what is "made in Washington", contributes to a situation in which grassroots movement concerning equality in health care arise with difficulty, and information and education about the system is lacking: many Americans think that the health care system is not working properly and it is not right, but often this idea fails at converging in movements or organizations asking for a change<sup>485</sup>.

### 2.3. Lobbying and Interest Groups

Extremely relevant in addressing the discourse of health care reforms in the United States are lobbies and interest groups. In the previous chapter the history of the attempts to establish a national health care system in the U.S. has been described; here it is relevant to mention the role of interest groups in that failure. The first major interest group that played a crucial role in undermining all the efforts aimed at the creation of a national health care system is organized medicine. Associations of physicians were real actors in the health care reforms procedure from the 1930s to the 1970s, when their interests met with those of other powerful groups, such as insurance

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<sup>480</sup> Ariel Pablos-Mendéz, Lesley Stone (2013). Health Development as Nation Strengthening. In "Advancing the Human Right to Health." *Oxford University Press*. Edited by Zuniga, J., Marks, S. P., Gostin, L. O., p.55

<sup>481</sup> Audrey R. Chapman (1994). *Supra note (6)*, p.14

<sup>482</sup> Larry R. Churchill (1994). Aligning Rights and Responsibilities. In *Health Care Reform: A Human Rights Approach*. Georgetown University Press. Edited by A. R. Chapman., p.140

<sup>483</sup> Howard P. Greenwald (2010). *Supra note (282)*, p.31

<sup>484</sup> Arnaldo Testi (2017). *Supra note (289)*, pp.220-1

<sup>485</sup> Lawrence D. Brown (2003). *Supra note (408)*, p.55

companies, and were supported by Republicans and Democrats from the South<sup>486</sup>. Relevant was the opposition of the American Medical Association (AMA) to the reform proposed by President Truman in 1945. The AMA organized a perfect campaign against the proposed national health insurance, preventing the passage of the reform and promoting private health insurance; trying to gain public support in its campaign against national health insurance, the AMA took advantages of the widespread racism present in the American society and framed the reform as a communist one<sup>487</sup>. Even though the advent of managed care diminished the role of the AMA<sup>488</sup>, interest groups also played a relevant role in the failure of the Clinton health care plan<sup>489</sup>.

What these interest groups do to influence policymakers is lobbying them, which consists in giving money and other resources to legislators, usually in the form of contributions for electoral campaigns, which are extremely expensive in the U.S.; obviously this money cannot buy a legislator's vote directly, but equally obviously the legislator who received money from a certain interest group will listen to their exigencies and opinions<sup>490</sup>. Health care professionals, pharmaceutical and health care product companies, and other organizations related to health care constitute incredibly influential interest groups<sup>491</sup>, hardly interested in actually implementing a human rights-based health care system in the U.S. Even though interest groups may be seen as a tool of democracy since their confrontations may avoid the dominion of a single perspective and allow the emergence of policies that represent the entire spectrum of views present in the country, their role in the U.S. policy making discourse is far from this idea: the most powerful among interest groups tend to cooperate in order to create relationships among them and with legislators so that their view assumes a prominent position<sup>492</sup>, actually weakening the democratic plurality<sup>493</sup>.

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<sup>486</sup> Jill Quadagno (2004). *Supra note (290)*, p.29

<sup>487</sup> *Ibid.*, p.30

<sup>488</sup> *Ibid.*, p.29

<sup>489</sup> *Ibid.*, p.37

<sup>490</sup> Howard P. Greenwald (2010). *Supra note (282)*, pp.306-7

<sup>491</sup> *Ibid.*, p.307

<sup>492</sup> Lawrence R. Jacobs (2005). *Supra note (471)*, p.48

<sup>493</sup> *Ibid.*, pp.48-9

## 2.4. The Case of Vermont

Speaking about the role played by the right to health in U.S. health care systems laws, it is relevant to mention the case of Vermont health care reforms since it can represent a possible approach to the development of a human rights-based discourse in this matter. In 2010, Vermont adopted a new law that establishes human rights-based guidelines for health care reforms; subsequently, in 2011, this State was the first U.S. State to make steps toward the creation of a universal health care system for all its residents<sup>494</sup>. This change in perspective is the result of years of support for the establishment of a single-payer system of health care with the Government as the unique insurer and a single package of health care benefits for everyone<sup>495</sup>. The reason behind this proposal are both costs containment and universal health care insurance affordable for everyone<sup>496</sup>. One of the first step taken by the Vermont Workers' Center has been the launch of a campaign called "Health Care Is a Human Right" that had the scope of educating citizens about the existence of this human right and, at the same time, mobilize support for the creation of a universal, affordable, and equal health care system<sup>497</sup>. As mentioned multiple times throughout this thesis, influencing public opinion has been a constant of politicians and interest groups that wanted to avoid the passage of national health care system reforms. The campaign rested on five basic human rights principles that should guide its work, among them two are extremely relevant to the discourse of access to health care, namely universality (everyone has to enjoy human rights, without exceptions) and equity, which provides that everyone should have the same ability to enjoy human rights<sup>498</sup> that perfectly match with the vision of health as a fundamental prerequisite to human life. The second part of the campaign, subsequent to the one of information and education of Vermonters, consisted in an effort to convince legislators that universal health care was the only one solution to health care crisis in the States, request also justified by the public opinion position<sup>499</sup>. Also due to the implementation of the ACA and the various amendment to it, it is not yet possible to understand to what extent the human rights discourse has succeeded in shaping health care reforms

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<sup>494</sup> Gillian MacNaughton, et Al. (2015, December). The Impact of Human Rights on Universalizing Health Care in Vermont, USA. *Health and Human Rights Journal*, Vol. 17, No.2., 83

<sup>495</sup> Ibid., p.84

<sup>496</sup> Idem

<sup>497</sup> Idem

<sup>498</sup> Ibid., p.86

<sup>499</sup> Ibid., pp.87-8



in Vermont, but it has achieved the goal of giving relevance to the human rights discourse, moreover, policy in Vermont are going in the direction of universal health coverage<sup>500</sup>.

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<sup>500</sup> Ibid., pp.91-2

## Conclusion

The aim of this thesis has been to provide a framework of the role of the human right to health in U.S. laws that establish rules of access to health care. The U.S. system appears extremely fragmented and complex<sup>501</sup>; these characteristics are also relevant when a human rights-based approach is applied because it is difficult to have a general idea of the various programs composing the system, which are not only managed by the Federal Government. However, to affirm that the U.S. has no obligations concerning the right to health appears to be incorrect. Even though the United States has not ratified the main international documents recognizing the right to health, they have nonetheless commit themselves to legal obligations related to this right by being part of the CERD and by the ratification of the WHO Constitution<sup>502</sup>; furthermore, also the signature of the ICESCR and of the CEDAW should somehow influence American health care policies. Therefore, even if there is no American court before which is possible to bring a violation of the human right to health, it cannot be said that the U.S. can exclude the human rights discourse from their health care reforms.

The peculiarity of the U.S. health care system cannot be considered as violating the right to health only because of its private insurance-based structure. In fact, international human rights law instruments that establish this right do not give specific indications for what concerns the financing and the delivery of the system. The problem with the U.S. system, however, arises anyway, because it does not guarantee equality in access to the entire population; moreover, it is extremely costly. In the analysis conducted in this work, both the problems have been taken into consideration. The reform of the health care, to solve both the major problems of the system, namely discrimination and increasing costs, is as urgent as complicate; one of the main problems of uninsurance and underinsurance is that these conditions, especially the second one, are not perceived as risky until a person become seriously ill<sup>503</sup>. The ACA tried in some way to make a change, it has not radically changed the system, but its failure has not been total; even though small changes are hardly a choice able to bring a real difference, because they will not affect the structure of the system<sup>504</sup>. In order to adequately address this matter, it is necessary to conciliate cornerstones of the American society like

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<sup>501</sup> Ibid., p.9

<sup>502</sup> Alicia Ely Yamin (2005, July). *Supra note (461)*, p.1158

<sup>503</sup> Janet O'Keeffe (1994). *Supra note (307)*, p.44

<sup>504</sup> Benjamin I. Page (2005). What Government Can Do. In "Healthy, Wealthy, and Fair. Health Care and the Good Society." *Oxford University Press*. Edited by Morone, J. A.; Jacobs, L. R., p.348

meritocracy, individualism, and equality<sup>505</sup>. Support for a human rights-based approach may be strengthened by emphasizing the value of solidarity<sup>506</sup>. This could represent a starting point in changing the structure of the system, even though it would be naive to state that people movements supporting national health care can make such a big change in the short-term, in the light of the influence that interest groups have in the political process. However, people mobilizations would constitute important signs.

One of the greatest weaknesses of the ACA with respect to human rights is that it did not have the aim of giving coverage to everyone<sup>507</sup>. Even though ACA has been one of the main issues of the American political and ideological discourse of the last years, it has only extended the eligibility for one public health care program (Medicaid), still leaving many Americans uninsured or underinsured<sup>508</sup>; furthermore it has not abolished premiums nor other forms of cost-sharing. The original text of the reform was surely more adequate in addressing the problem of health care coverage than what remains of it. The abolition of the individual mandate has undermined one of the pillar at the basis of ACA eventual success; moreover, also the decision of the Supreme Court concerning obligatory federal mandate to extend eligibility to everyone with an income at or under the 133% of the poverty line has played a role in maintaining differences among States and in leaving many people uninsured. Nevertheless, beside the fact that some of the most important provisions of the ACA has been repealed, it emerges from the reform that its aim was more related to costs containment than to human rights provisions, especially because it did not try to modify the structure of the health care system in itself. However, I still consider some provisions of the ACA as a step forward the realization of the right to equal access to health care, particularly the one prohibiting health insurance to deny coverage to patients with preexisting conditions or with particular genetic predispositions; even though they may still be victims of discriminations in the health care insurance market, this is a first step. Anyway, maybe a too little step for a country like the United States.

It appears quite clear that rely on a system that involves high “out-of-pocket” payments is not sustainable on financial nor equity ground and that in order to cover the increasing costs of health care only certain kinds of income transfers are equal and able to achieve the scope, one of

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<sup>505</sup> Howard P. Greenwald (2010). *Supra note (282)*, p.232

<sup>506</sup> Audrey Chapman (2014). *Supra note (446)*, p.127

<sup>507</sup> Mariah McGill, Gillian MacNaughton (2016). *Supra note (338)*, p.663

<sup>508</sup> Lycourgos Liaropoulos, Ilias Goranitis (2015). Health Care Financing and the Sustainability of Health Systems. *International Journal for Equity in Health*, 14:80., p.2

those is taxation<sup>509</sup>. If we analyze the U.S. health care system through a right to health lens, we can argue that probably the problem does not lay in how much the U.S. spends in health care, but in how they allocate resources<sup>510</sup>. In fact, one of the critics moved to U.S. allocation of resources for health care is that there is no coordinated financing system, which can contains the costs<sup>511</sup>. Therefore a human rights-based discourse can have a positive impact also from a financial point of view, because it would proscribe two kinds of financial barriers to health care, namely the fact that those who need more health care experience higher financial barriers than those who need less care, and the fact that financial barriers are greater for low-income people than for high-income people<sup>512</sup>. Consequently the introduction of the human right to health perspective would help in addressing two of the main problems of U.S. health care system, namely equality and costs containment.

It does not appear like a feasible option that the U.S. courts would enforce the right to health only on the basis of international instruments' provisions. Therefore, to establish a national legal framework in which the right to health is recognized and protected is the only option; however, as highlighted in the thesis, it is difficult to overcome the influence that interest groups have on the approval of reforms. Consequently, in a situation that does not appear open to radical changes, people mobilization may play a role. In relation to this, the way in which Vermont has addressed the problem of an unequal health care system through a campaign of education to the right to health may be a good example to follow. Even though, it is unlikely that the language of human rights alone can succeed at gaining the necessary consensus necessary to reform the U.S. health care system<sup>513</sup>; to achieve a proper result, it is necessary to address the social obligation to establish an equitable system of financing and delivery of health care<sup>514</sup>. People's movements are probably not able to contrast interest groups' interventions in health care related reforms, but in order to achieve some results, it is necessary to convince people that access to health care in a human right. Throughout U.S. history, movements against national health care has build part of their success on

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<sup>509</sup> Lycourgos Liaropoulos, Ilias Goranitis (2015). *Supra note (507)*, pp.2-3

<sup>510</sup> George P. Smith (2005). *Supra note (184)*, p.1318

<sup>511</sup> Donald W. Light (2003, January). Universal Health Care: Lessons from the British Experience. *American Journal of Public Health, Vol. 93, No.1.*, p.25

<sup>512</sup> Virginia A. Leary (1994). *Supra note (34)*, p.99

<sup>513</sup> Janet O'Keeffe (1994). *Supra note (307)* pp.58-9

<sup>514</sup> *Ibid.*, p.59

their ability to influence public opinion<sup>515</sup>: if there is a real will to establish such a system, the education and information of Americans should be its starting point<sup>516</sup>.

In the values at the basis of the American society there is a discrepancy between the values of meritocracy and the one of equality. To mobilize people in favor of a health care system based on human rights provisions, it may appear relevant to highlight this difference in favor of the value of equality. In convincing Americans that it is necessary to recognize access to health care as a human right, the current situation of increasing costs of medicines and health-related technologies<sup>517</sup> may be of help. Middle-class people will soon be incapable of buying a considerable amount of medicines or access to various services, this situation can contribute in mobilizing the population in favor of a national health care system. This step would represent an important step in the path toward a radical reform of the structure on which the U.S. health care is based, because it can provoke a change in people's minds: if middle-class working people cannot afford insurance coverage, who can? Is it still consistent to claim that the Government should intervene only with respect to vulnerable population? Can the value of meritocracy still be applicable to access to health care?

It is usually claimed that U.S. health care is the best in the world<sup>518</sup>, however I would say that such an affirmation is strictly related to the definition and scope one's associate with health care. From a human rights perspective, a system that has the best health care technologies, drugs, and services, but offers its best only to a restricted part of its population, those who can afford these treatments, and does not guarantee an equal access to health care and an equal quality of services cannot be defined as the best in the world.

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<sup>515</sup> For example, Truman attempt to establish a national health care system was contrasted by the AMA that was able to enact a massive campaign in favor of private insurance that had consistent results.

<sup>516</sup> It is important to remember that one of the reasons that brought to the failure of President Clinton's health care reform was that Americans felt they had not been adequately informed during the works of the reform.

<sup>517</sup> Jonathan E. Fielding, et Al. A Perspective on the Development of the Healthy People 2020 Framework for Improving U.S. Population Health. *Public Health Reviews*, Vol.35, No.1., p.18

<sup>518</sup> Howard P. Greenwald (2010). *Supra note (282)*, p.4

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#### USEFUL WEBSITES:

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- <https://www.ahrq.gov>
- <https://www.healthypeople.gov>