

# IACHR

## Access to Information on Reproductive Health from a Human Rights Perspective

INTER-AMERICAN COMMISSION ON HUMAN RIGHTS



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**ACCESS TO INFORMATION ON REPRODUCTIVE HEALTH  
FROM A HUMAN RIGHTS PERSPECTIVE**

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## **ACCESS TO INFORMATION ON REPRODUCTIVE HEALTH FROM A HUMAN RIGHTS PERSPECTIVE**

### **I. INTRODUCTION**

1. The Inter-American Commission on Human Rights (hereinafter “the Inter-American Commission”, “the Commission”, or the “IACHR”) has consistently, through its various mechanisms, received information on the various barriers women in the Americas face in gaining access to information on health, particularly in the area of sexual and reproductive health. Women who have historically been marginalized based on their race, ethnicity, economic status, or age are those who face the most barriers in access to information on health, and these barriers become even greater when the information has to do with matters related to sexual and reproductive health. Access to information is closely linked to the attainment of other human rights; thus, a failure to respect and guarantee this right for women can lead to an infringement of other rights, such as their right to personal integrity, the right to privacy, rights of the family, and the right to be free from violence and discrimination. This report identifies and analyzes, from a human rights perspective, international and regional standards on access to information on reproductive health, with a view that the States might eliminate barriers and effectively guarantee and protect this right of women without discrimination.

2. Access to information is a basic tool for building citizenship in a democratic system.<sup>1</sup> The American Convention on Human Rights (hereinafter “the Convention”) expressly enshrines the concept of access to information in its Article 13, and the Inter-American Court of Human Rights (hereinafter the “Inter-American Court”) has interpreted it as a human right. The Court indicated that by expressly stipulating, in Article 13, the right to “seek” and “receive” information, the Convention protects everyone’s right to access information.

3. The right to access to information is especially relevant in the area of health, and specifically in the area of sexuality and reproduction, since it helps to ensure that everyone is prepared to make free and informed decisions with regard to intimate aspects of their life. In the inter-American system, access to information on sexual and reproductive health involves a series of rights such as the right to freedom of expression, to personal integrity, to the protection of the family, to privacy, and to be free from violence and discrimination.

4. In this regard, the IACHR notes that in recent decades, access to information on sexual and reproductive matters has gained considerable relevance at the regional and international level. In fact, the IACHR has established that it is not possible for women to attain the full enjoyment of human rights without timely access to comprehensive healthcare services, as well as to information and education in this area, so that they can make free, informed, and responsible decisions regarding reproduction,

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<sup>1</sup> IACHR, *The Inter-American Legal Framework regarding the Right to Access to Information*. Office of the Special Rapporteur for Freedom of Expression, December 30, 2009.

including family planning.<sup>2</sup> The Commission has also said that information and education enables women to make decisions at all levels and in all areas of their lives, especially in the sphere of health, sexuality, and reproduction.

5. At the international level, the provisions contained in the Convention on the Elimination of All Forms of Discrimination against Women (hereinafter “CEDAW”) establish the obligation of the States Parties to ensure, on a basis of equality of men and women, the same rights to decide freely and responsibly on the number and spacing of their children and to have access to the information, education, and means to enable them to exercise these rights. Specifically, the Committee on the Elimination of Discrimination against Women (hereinafter the “CEDAW Committee”) has emphasized that the States' duty to ensure, on a basis of equality, access to healthcare services, information, and education "implies an obligation to respect, protect and fulfil women's rights to health care."<sup>3</sup> For its part, the Committee on Economic, Social and Cultural Rights (hereinafter the “ESCR Committee”) has interpreted the right to health as an inclusive right extending not only to timely and appropriate health care but also to the underlying determinants of health, such as "access to health-related education and information, including on sexual and reproductive health".<sup>4</sup>

6. Nevertheless, the Inter-American Commission has consistently, through its various mechanisms, received information regarding various barriers women in the Americas face in their access to information on sexual and reproductive health. For example, the limited access to information on family-planning services despite a high unmet need for such services.<sup>5</sup> In addition, the Commission has received information about problems in access to basic information and adequate medical and social services related to reproductive health,<sup>6</sup> as well as about distortions in the information on reproductive matters provided by public servants for the purpose of dissuasion.<sup>7</sup> The Commission has also received information and processed individual petitions regarding the practice of sterilizing women without their consent in some OAS Member States, a practice that in some cases has led to their deaths.<sup>8</sup>

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<sup>2</sup> IACHR, Report No. 21/07, Petition 161/02, Friendly Settlement, *Paulina del Carmen Ramírez Jacinto* (Mexico), March 9, 2007.

<sup>3</sup> United Nations, CEDAW Committee, General Recommendation 24, Women and health, para. 13.

<sup>4</sup> United Nations Committee on Economic, Social and Cultural Rights. The right to the highest attainable standard of health (article 12 of the International Covenant on Economic, Social and Cultural Rights), General Comment 14, August 11, 2000, para. 11.

<sup>5</sup> IACHR, *Fifth Report on the Situation of Human Rights in Guatemala*, OEA/Ser.L/V/II.111, doc. 21, April 6, 2001, see Chapter XIII, The Rights of Women; IACHR, *Third Report on the Situation of Human Rights in Paraguay*, OEA/Ser.L/VII.110 doc. 52, March 9, 2001, see Chapter VIII, Women's Rights. Available at: <http://www.cidh.oas.org/countryrep/Paraguay01eng/chap8.htm>.

<sup>6</sup> IACHR, *Fifth Report on the Situation of Human Rights in Guatemala*, see Chapter XIII, The Rights of Women.

<sup>7</sup> IACHR, Report No. 21/07, Petition 161/02, Friendly Settlement, *Paulina del Carmen Ramírez Jacinto* (Mexico), March 9, 2007.

<sup>8</sup> IACHR, Report No. 71/03, Petition 12.191, Friendly Settlement, *María Mamérita Mestanza Chávez* (Peru), October 3, 2003.

7. In particular, women who are poor, indigenous, and/or of African descent, women who live in rural areas and migrant women, are the ones who face greater obstacles in their access to information on sexual and reproductive health. In some cases, the barriers are of such a magnitude that they may constitute violations of women's rights to personal integrity, privacy, and family life, and the right to be free from violence and discrimination in contravention of the obligations the States of the Americas have assumed in the area of human rights.<sup>9</sup> One example of this situation is the sterilization of women without their consent.

8. Consequently, the Inter-American Commission on Human Rights decided to prepare this report, thanks to the support of the Governments of Spain and Finland, in order to identify and analyze regional and international human rights standards on access to information on reproductive health, with a view that the States might eliminate barriers and effectively guarantee and protect this right of women without discrimination.

9. This report is divided into three sections. The first section describes standards on the right to access to information and the second section details standards on the right to access to information on reproductive health. In that section, the IACHR addresses several dimensions of access to information that should be taken into account to guarantee this right. The third section addresses some recommendations to the States in this area.

## **II. STANDARDS ON ACCESS TO INFORMATION AS A HUMAN RIGHT**

10. Article 13 of the American Convention establishes the following:

1. Everyone has the right to freedom of thought and expression. This right includes freedom to seek, receive, and impart information and ideas of all kinds, regardless of frontiers, either orally, in writing, in print, in the form of art, or through any other medium of one's choice.

2. The exercise of the right provided for in the foregoing paragraph shall not be subject to prior censorship but shall be subject to subsequent imposition of liability, which shall be expressly established by law to the extent necessary to ensure:

- a. respect for the rights or reputations of others; or
- b. the protection of national security, public order, or public health or morals.

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<sup>9</sup> The IACHR has noted that the protection of women's right to integrity under conditions of equality is achieved in the area of maternal health through the provision of information and education on the subject so that women will adopt free, well-founded, and responsible decisions regarding reproduction, including on family planning.

3. The right of expression may not be restricted by indirect methods or means, such as the abuse of government or private controls over newsprint, radio broadcasting frequencies, or equipment used in the dissemination of information, or by any other means tending to impede the communication and circulation of ideas and opinions.....

11. The American Declaration of the Rights and Duties of Man (hereinafter the "American Declaration"), in Article IV, enshrines "the right to freedom of investigation, of opinion, and of the expression and dissemination of ideas, by any medium whatsoever," as a right inherent to every human being. In addition, Article XXIV of the Declaration establishes that everyone "has the right to submit respectful petitions to any competent authority, for reasons of either general or private interest, and the right to obtain a prompt decision thereon."

12. Moreover, the IACHR Declaration of Principles on Freedom of Expression establishes, in Principle 2, that "Every person has the right to seek, receive and impart information and opinions freely under terms set forth in Article 13 of the American Convention on Human Rights," and that "All people should be afforded equal opportunities to receive, seek and impart information...."

13. In its Advisory Opinion OC-5/85, the Inter-American Court stated that "a democratic society requires the guarantee of the widest possible circulation of news, ideas and opinions as well as the widest access to information by society as a whole...." It also found that it is "inherent in the American Convention that the right of each individual to express himself freely and that of society as a whole to receive information be scrupulously respected."

14. According to the Inter-American Court, under the protection granted by the American Convention, the right to freedom of thought and expression includes "not only the right and freedom to express one's own thoughts, but also the right and freedom to *seek, receive and impart* information and ideas of all kinds."<sup>10</sup> Like the American Convention, other international human rights instruments, such as the Universal Declaration of Human Rights and the International Covenant on Civil and Political Rights, establish a positive right to seek and receive information.<sup>11</sup> As has been explained in case law, freedom of information is a right in and of itself and not just a manifestation of the right of freedom of expression of which it is a part.<sup>12</sup>

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<sup>10</sup> I/A Court H.R., *Claude-Reyes et al. v. Chile Case*. Merits, Reparations and Costs. Judgment of September 19, 2006. Series C No. 151, para. 76. *López Álvarez v. Honduras Case*. Judgment of February 1, 2006. Series C No. 141, para. 163; *Ricardo Canese v. Paraguay Case*. Judgment of August 31, 2004. Series C No. 111, para. 77; and *Herrera Ulloa v. Costa Rica Case*. Judgment of July 2, 2004. Series C No. 107, para. 108.

<sup>11</sup> I/A Court H.R., *Claude-Reyes et al. v. Chile Case*. Merits, Reparations and Costs. Judgment of September 19, 2006. Series C No. 151, para. 76.

<sup>12</sup> IACHR, *2008 Annual Report*, Office of the Rapporteur for Freedom of Expression, para. 141.

15. So then, the right of access to information falls within the general framework of freedom of expression.<sup>13</sup> As the Inter-American Commission has interpreted it, Article 13 of the American Convention includes a positive obligation on the part of the State to provide citizens with access to information in its power, and a related right of individuals to access information held by the State. Along these lines, the IACHR Declaration of Principles on the Right to freedom of Expression establishes the following, in Principle 3: "Every person has the right to access...information about himself or herself or his/her assets expeditiously and not onerously, whether it be contained in databases or public or private registries, and if necessary to update it, correct it and/or amend it." In Principle 4, it establishes: "Access to information held by the state is a fundamental right of every individual. States have the obligation to guarantee the full exercise of this right."

16. The IACHR has established that to guarantee the full and effective exercise of the right of access to information, the public administration must follow the principles of maximum disclosure and good faith.<sup>14</sup> The principle of maximum disclosure calls for the design of a legal regime in which transparency and the right of access to information are the general rule, subject only to strict and limited exceptions.<sup>15</sup> The principle of good faith implies that those bound to guarantee this right act in good faith; that is, that they interpret the law in such a way that it meets the aims of the right of access and that they ensure the strict application of the right, provide the necessary measures of assistance to petitioners, promote a culture of transparency, contribute to making public administration more transparent, and act with due diligence, professionalism, and institutional loyalty.<sup>16</sup>

17. The Office of the Special Rapporteur for Freedom of Expression has maintained that the right of access to information creates obligations for all public persons of all branches of government and autonomous bodies at all levels of government.<sup>17</sup> This right also affects those who carry out public functions, provide public services, or manage public funds on behalf of the State. Reiterating existing case law, the Resolution of the Inter-American Juridical Committee on "Principles on the Right of Access to Information" states the following in Principle 2: "The right of access to information applies to all public bodies, including the executive, legislative and judicial branches at all levels of government, constitutional and statutory bodies, bodies which are owned or controlled by government, and organizations which operate with public funds or which perform public functions."<sup>18</sup>

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<sup>13</sup> *Ibid.*, para. 142.

<sup>14</sup> IACHR, *The Inter-American Legal Framework regarding the Right to Access to Information*, para. 8.

<sup>15</sup> The IACHR has maintained that the following consequences are derived from this principle: (1) the right of access must be subject to a limited regime of exceptions, and these exceptions must be interpreted restrictively; (2) denials of information must be reasoned, and in this sense the burden of proving that the requested information cannot be released falls to the State; and (3) the right of access to information should take precedence in the event of doubts or legal vacuums. IACHR, *The Inter-American Legal Framework regarding the Right to Access to Information*, para. 10.

<sup>16</sup> IACHR, *The Inter-American Legal Framework regarding the Right to Access to Information*, para. 15.

<sup>17</sup> *Ibid.*, para. 20.

<sup>18</sup> *Ibid.*

18. In addition, the exercise of the right to information pertains to different types of information that is, or should be, in the possession of the authorities or private citizens.<sup>19</sup> The types of information that this right covers include the following in particular: information in the State's custody, management, or possession; information the State produces, or information it is obliged to produce; information in the possession of those who manage public services or public funds; information the State receives, or is required to collect in the course of performing its duties; and information concerning one's own personal data (*habeas data*) or property held by those who administer private databases or registries and are legally required to provide it.<sup>20</sup>

19. The Inter-American Court of Human Rights, in a historic judgment, interpreted that Article 13 of the American Convention establishes access to information as a human right.<sup>21</sup> The Court stated:

[T]he Court finds that, by expressly stipulating the right to "seek" and "receive" "information," Article 13 of the Convention protects the right of all individuals to request access to State-held information, with the exceptions permitted by the restrictions established in the Convention. Consequently, this article protects the right of the individual to receive such information and the positive obligation of the State to provide it, so that the individual may have access to such information or receive an answer that includes a justification when, for any reason permitted by the Convention, the State is allowed to restrict access to the information in a specific case.<sup>22</sup>

20. The Court moreover indicated that the information "should be provided without the need to prove direct interest or personal involvement in order to obtain it, except in cases in which a legitimate restriction is applied. The delivery of information to an individual can, in turn, permit it to circulate in society, so that the latter can become acquainted with it, have access to it, and assess it. In this way, the right to freedom of thought and expression includes the protection of the right of access to State-held information, which also clearly includes the two dimensions, individual and social, of the right to freedom of thought and expression that must be guaranteed simultaneously by the State."<sup>23</sup>

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<sup>19</sup> IACHR, *2008 Annual Report*, Office of the Rapporteur for Freedom of Expression, para. 154.

<sup>20</sup> IACHR, *2008 Annual Report*, Office of the Rapporteur for Freedom of Expression, para. 155. See IACHR, *The Inter-American Legal Framework regarding the Right to Access to Information*, para. 21.

<sup>21</sup> I/A Court H.R., *Claude-Reyes et al. v. Chile Case*. Merits, Reparations and Costs. Judgment of September 19, 2006. Series C No. 151.

<sup>22</sup> I/A Court H.R., *Claude-Reyes et al. v. Chile Case*. Merits, Reparations and Costs. Judgment of September 19, 2006. Series C No. 151, para. 77.

<sup>23</sup> I/A Court H.R., *Claude-Reyes et al. v. Chile Case*. Merits, Reparations and Costs. Judgment of September 19, 2006. Series C No. 151, para. 77; I/A Court H. R., *López Álvarez v. Honduras Case*. Judgment of February 1, 2006. Series C No. 141, para. 163; *Ricardo Canese v. Paraguay Case*. Judgment of August 31, 2004. Series C No. 111, para. 80; and *Herrera Ulloa v. Costa Rica Case*. Judgment of July 2, 2004. Series C No. 107, paras. 108-111.

21. In a resolution on recommendations regarding access to information, the Permanent Council of the Organization of American States summed up the following guidelines on Article 13 established by the Inter-American Court in its decision:<sup>24</sup>

- That by expressly stipulating the rights “to seek and receive information,” Article 13 of the Convention protects the right of all persons to have access to information held by the state, with the safeguards permitted under the Convention’s system of restrictions.
- That the state must follow the principles of the public nature of information, transparency, and maximum disclosure—the latter of which establishes the presumption that all information is accessible, subject only to a narrow system of exceptions.
- That silence cannot be a response to a request for information.
- That this right has the counterpart of specific obligations by the state.
- That the state must eliminate norms and practices that result in the violation of the rights protected by the Convention, and enact laws and develop practices leading to the effective respect for these guarantees.
- That the state must guarantee the efficacy of an appropriate administrative procedure for processing and responding to requests for information, with deadlines for response and delivery of the information, handled by duly trained officials.
- That the state must guarantee the right to be heard and provide a rapid and simple remedy for exercising this right.
- That the state must train agencies, officials, and public agents in access to information.

22. The IACHR has established the following State obligations generated by the right of access to information: the obligation to respond to requests in a timely, complete, and accessible manner; to offer a legal recourse that satisfies the right of access to information; to provide an adequate and effective legal remedy for reviewing denials of requests for information; to provide the maximum quantity of information proactively (also called the obligation of active transparency); to produce or gather information; to create a culture of transparency; to adequately implement access laws; and to adjust domestic legislation to the demands of the right of access to information.<sup>25</sup>

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<sup>24</sup> Permanent Council of the Organization of American States, Committee on Juridical and Political Affairs. Recommendations on Access to Information. CP/CAJP-2599/08 , April 21, 2008.

<sup>25</sup> IACHR, *The Inter-American Legal Framework regarding the Right to Access to Information*, pp. 6-12.

23. Moreover, as this is one of the protected forms of the right to freedom of expression, limitations to the right of access to information must be prescribed by law expressly and in advance, and their establishment must be sufficiently clear and specific so as to not grant an excessive degree of discretion to the public officials who decide whether or not to disclose the information.<sup>26</sup> Thus, the American Convention establishes that any laws establishing restrictions to the right of access to information must be expressly established to the extent necessary to ensure respect for the rights or reputations of others or protect national security, public order, or public health or morals.<sup>27</sup> Moreover, any limitations imposed on the right of access to information must be necessary in a democratic society to satisfy a compelling public interest. Among several options for accomplishing this objective, the one least restrictive to the right must be chosen, and the restriction must be conducive to the attainment of the objective, be proportionate to the interest that justifies it, and interfere to the least extent possible with the effective exercise of the right.<sup>28</sup>

24. There is a regional consensus among the States that make up the Organization of American States regarding the importance of access to public information and the need to protect it. This right has been the subject of specific resolutions issued by the OAS General Assembly.<sup>29</sup> For example, in a resolution dated June 4, 2009, the OAS General Assembly resolved to "urge member states to respect and promote respect for everyone's access to public information and to promote the adoption of any necessary legislative or other types of provisions to ensure its recognition and effective application."<sup>30</sup>

### III. STANDARDS ON THE RIGHT TO ACCESS TO INFORMATION ON REPRODUCTIVE HEALTH

25. The IACHR believes that the obligation to provide information proactively (also called the obligation of active transparency) lays the groundwork for the States' obligation to provide public information that is essential for people to be able to exercise their fundamental rights or satisfy their basic needs in this area. This is particularly relevant when the information has to do with issues related to sexuality and reproduction, since such information helps people be prepared to make free and informed decisions concerning these aspects that are so intimate to their lives.

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<sup>26</sup> IACHR, *The Inter-American Legal Framework regarding the Right to Access to Information*, para. 49.

<sup>27</sup> Article 13(2) of the American Convention.

<sup>28</sup> IACHR, *The Inter-American Legal Framework regarding the Right to Access to Information*, para. 53.

<sup>29</sup> See judgment of I/A Court H.R., *Claude-Reyes et al. v. Chile Case*. Merits, Reparations and Costs. Judgment of September 19, 2006. Series C No. 151, para. 78. Resolution AG/RES. 1932 (XXXIII-O/03) of June 10, 2003, on "Access to Public Information: Strengthening Democracy"; Resolution AG/RES. 2057 (XXXIV-O/04) of June 8, 2004, on "Access to Public Information: Strengthening Democracy"; Resolution AG/RES. 2121 (XXXV-O/05) of June 7, 2005, on "Access to Public Information: Strengthening Democracy"; and AG/RES. 2252 (XXXVI-O/06) of June 6, 2006, on "Access to Public Information: Strengthening Democracy."

<sup>30</sup> Resolution AG/RES. 2514 (XXXIX-O/09) of June 4, 2009, on "Access to Public Information: Strengthening Democracy," resolution point 2.

26. In this regard, women's right of access to information on reproductive health gives rise to a proactive obligation by the State, due to the recognition of the limitations that tend to affect women—particularly those who are poor, indigenous, and/or of African descent, or who live in rural areas—in terms of accessing reliable, complete, timely, and accessible information that allows them to exercise their rights or meet their needs. In these cases, as will be set forth below, the right of access to information takes on an instrumental nature that is usually, though not necessarily, associated with the satisfaction of other human rights enshrined in the American Convention.

27. The IACHR began to address the issue of access to information on reproductive matters some time ago. In its 1998 regional report on the status of women in the Americas, the Commission established, based on responses sent in by the States on health and reproductive health, the existence in the region of serious problems of access to basic information and adequate medical care and social services. The IACHR recommended that the States adopt measures to keep proper statistical data and to have the necessary resources in order to ensure plans and programs that allow women to fully exercise the right to health.

28. In its country visits, the IACHR has expressed its concern over the limited access to these services despite a high level of unmet needs.<sup>31</sup> On this point, the IACHR has indicated that ongoing limitations on family-planning information and services are related to barriers in access to public health care and education.<sup>32</sup>

29. Moreover, the IACHR has established that information and education enable women to make decisions at all levels, in all aspects of their lives, especially in the area of health, sexuality, and reproduction. Specifically in the area of maternal health, the IACHR has emphasized that protecting women's right to integrity under conditions of equality is achieved by providing information and education on the subject so that women will make free, well-founded, and responsible decisions regarding reproduction, including family planning. Moreover, to address the high rates of maternal mortality, the IACHR has recommended implementing measures and publicity campaigns, targeted to the general public, on the duty to respect women's civil, political, economic, social, cultural, sexual, and reproductive rights.<sup>33</sup>

30. The Commission has also maintained that it is important that women and their families and communities be aware of health services and that they also be able to identify warning signs that require medical attention.<sup>34</sup> Thus, it has stated that the lack of information on reproductive health acts as a barrier to obtaining access to maternal health

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<sup>31</sup> IACHR, *Fifth Report on the Situation of Human Rights in Guatemala*, Chapter XIII, The Rights of Women.

<sup>32</sup> IACHR, *Fifth Report on the Situation of Human Rights in Guatemala*, Chapter XIII, The Rights of Women; IACHR, *Third Report on the Situation of Human Rights in Paraguay*, Chapter VIII, Women's Rights.

<sup>33</sup> IACHR, *Access to Justice and Social Inclusion: The Road towards Strengthening Democracy in Bolivia*, June 28, 2007, see Chapter V, Women's Rights.

<sup>34</sup> IACHR, *Access to Maternal Health Services from a Human Rights Perspective*, June 7, 2010, para. 33.

services because it prevents women from making free and informed decisions about their health, resulting in a lack of appropriate prevention and health promotion behaviors to protect their own health and that of their children.<sup>35</sup>

31. For its part, the Office of the Rapporteur for Freedom of Expression has stated that "the right of access to information is a key instrument for the exercise of other human rights, particularly by the most vulnerable individuals."<sup>36</sup> With respect to access to information on reproductive matters, it has indicated that women throughout the region are entitled to have the State fully guarantee to them the right of access to information on their sexual and reproductive rights through its mass and targeted campaigns, for example, at all centers providing basic health care.<sup>37</sup>

32. Specifically with respect to adolescent girls' access to information on reproductive health, the Committee on the Rights of the Child has established States' obligation to provide them with access to information on the potential harm that can be caused by early pregnancy. It has also established that adolescent girls who become pregnant should have access to health services that are sensitive to their rights and particular needs.<sup>38</sup>

33. The IACHR draws attention to the comprehensive treatment of this issue by the Committee on Economic, Social and Cultural Rights (hereinafter, "the ESCR Committee"). The ESCR Committee has expounded on the importance of access to information in the field of health, including reproductive health. It interpreted the right to health as an inclusive right that extends not only to timely and appropriate health care but also to the underlying determinants of health, such as access to health-related education and information, including on sexual and reproductive health.<sup>39</sup>

34. According to the ESCR Committee, the right to health is closely related to and dependent upon the realization of other human rights, including that of access to information.<sup>40</sup> Moreover, in laying out the dimensions of the right to health, the ESCR Committee established that access to information includes the right to seek, receive, and impart information and ideas concerning health issues.<sup>41</sup> Specifically the ESCR Committee established that the realization of women's right to health as regards reproduction

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<sup>35</sup> IACHR, *Access to Maternal Health Services from a Human Rights Perspective*, June 7, 2010, para. 33.

<sup>36</sup> IACHR, *2008 Annual Report*, Office of the Rapporteur for Freedom of Expression, para. 147.

<sup>37</sup> *Ibid.*, para. 91. See also, IACHR, *Fifth Report on the Situation of Human Rights in Guatemala*, 6 April, 2001, Chapter XIII, The Rights of Women, para. 36.

<sup>38</sup> United Nations, Committee on the Rights of the Child, General Comment No. 4.

<sup>39</sup> United Nations, Committee on Economic, Social and Cultural Rights. The right to the highest attainable standard of health, General Comment No. 14, para. 11.

<sup>40</sup> *Ibid.*, para. 3.

<sup>41</sup> *Ibid.*, para. 12.

"requires the removal of all barriers interfering with access to health services, education and information, including in the area of sexual and reproductive health."<sup>42</sup>

35. In terms of States' obligations to respect, protect, and fulfill the right to health in relation to access to information on reproductive matters, the ESCR Committee indicated that the States must have a role in ensuring that third parties do not restrict people's access to information and health-related services. It also stated that other obligations include the promotion of medical research and health education, as well as information campaigns, in particular with respect to HIV/AIDS, sexual and reproductive health, traditional practices, and domestic violence.

36. Meanwhile, the provisions contained in the CEDAW underscore the importance of guaranteeing access to information, particularly as regards health. Article 10, paragraph (h), establishes States' obligation to adopt all appropriate measures to eliminate discrimination against women, in order to ensure to them equal rights with men in the field of education and in particular to ensure, on a basis of equality of men and women, "access to specific educational information to help ensure the health and well-being of families."<sup>43</sup>

37. Moreover, Article 16, paragraph 1, subparagraph (e), of CEDAW establishes the obligation of States Parties to ensure, on a basis of equality of men and women, the same rights to decide freely and responsibly on the number and spacing of their children, and to have access to the information, education, and means to enable them to exercise these rights. Along these lines, the CEDAW Committee has stated the following:

The duty of States parties to *ensure, on a basis of equality between men and women, access to health care services*, information and education implies an obligation to respect, protect and fulfil women's rights to health care. States parties have the responsibility to ensure that legislation and executive action and policy comply with these three obligations.<sup>44</sup>

38. Meanwhile, the CEDAW Committee has emphasized that adult women and adolescent girls in many countries lack sufficient access to necessary information and services to ensure sexual health. This is particularly relevant in the case of women and adolescents who are in a situation of exclusion. Thus it has maintained that "States parties should ensure, without prejudice and discrimination, the right to sexual health information, education and services for all women and girls."<sup>45</sup> In particular, the CEDAW Committee has noted States' obligation to ensure the necessary information and services to address issues

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<sup>42</sup> *Ibid.*, para. 21.

<sup>43</sup> United Nations, Convention on the Elimination of All Forms of Discrimination against Women, Article 10(h).

<sup>44</sup> United Nations, Committee on the Elimination of Discrimination against Women, General Recommendation No. 24, Women and health, para. 13.

<sup>45</sup> *Ibid.*, para. 28.

related to HIV/AIDS and other sexually transmitted diseases, including information and counseling on all methods of family planning.<sup>46</sup>

39. The IACHR notes that the Inter-American Court, in its judgment in *Claude-Reyes et al. v. Chile*, reiterated that "the general obligation contained in Article 2 of the Convention involves the elimination of norms and practices of any type that result in violations of the guarantees established in the Convention, as well as the enactment of laws and the development of practices conducive to the effective observance of these guarantees."<sup>47</sup> This reasoning, applied in the sphere of access to information in the area of reproduction, implies that States have the obligation to adopt the necessary measures to ensure protection of the right of access to information. This should include guaranteeing the effectiveness of an appropriate administrative procedure for processing and deciding on requests for information, one which sets deadlines for making a determination and providing the information, and which falls under the responsibility of properly trained officials.

40. The IACHR believes that Article 2 of the American Convention, with regard to access to information on reproductive matters, presupposes the provision of effective, accessible, and transparent accountability mechanisms in the event that States fail to fulfill their international obligations in this area.

41. The Court, in the *Case of Claude-Reyes*, went a step further and ordered the State to provide training to the public entities, authorities, and agents responsible for responding to requests for access to State-held information on the laws and regulations governing this right. Based on this premise, the States have the obligation to train their professionals to inform women regarding their health, including information on aspects related to reproductive health. Along these lines, the IACHR considers that access to information on sexual and reproductive matters requires a State response across sectors. While this report is based primarily on aspects of access to health-related information, the right of access to information on sexual and reproductive matters requires various sectors to be involved in order to address this subject comprehensively.

42. The IACHR will now analyze certain specific standards on access to information on sexual and reproductive matters, which the States should observe in order to guarantee this right: (a) access to information and informed consent; (b) access to information and the protection of confidentiality; (c) access to information and the obligation to provide information that is timely, complete, accessible, reliable, and proactive; (d) access to information and access to medical records; and e) access to information and the obligation to produce reliable statistics.

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<sup>46</sup> United Nations, Committee on the Elimination of Discrimination against Women, General Recommendation No. 24, Women and health.

<sup>47</sup> I/A Court H.R., *Claude-Reyes et al. v. Chile Case*. Merits, Reparations and Costs. Judgment of September 19, 2006. Series C No. 151, para. 163.

## **A. Access to information and informed consent**

43. The IACHR recognizes that access to information is an essential factor to be able to receive medical care. Consent constitutes an ethical principle of respect for individual autonomy, one that requires that people understand the different treatment options among which they can choose.<sup>48</sup> Informed consent, meanwhile, implies the existence of a horizontal relationship between doctor and patient. While health professionals are the ones who best understand the physical conditions of the patients' disorders and the most appropriate means for prevention and treatment, it is the patients who better understand their disposition and temperament, including their prior experience with earlier treatments, preferences, and fears.<sup>49</sup>

44. As will be laid out below, the issue of informed consent in reproductive health has been subject to discussion and development by the various international, regional, and national bodies for the protection of human rights. The IACHR notes some factors that are an integral part of a process of informed consent: (i) informing patients about the nature of the procedure, treatment options, and reasonable alternatives, including the potential benefits and risks of proposed procedures; (ii) taking into account the person's needs and ensuring that the person understands the information provided; and (iii) ensuring that any consent provided is free and voluntary.

### **1. Informing patients about the nature of the procedure, treatment options, and reasonable alternatives, including the potential benefits and risks of proposed procedures**

45. Access to information on reproductive matters requires that women have sufficient information to make decisions about their health. To attain this objective, the information provided must be timely, complete, accessible, reliable, and proactive. It must also be understandable, using language that is accessible, and must be current. According to Rebecca Cook, information that health professionals should offer includes, in principle:<sup>50</sup>

- The patient's current reproductive health condition in terms of the risks of an unplanned pregnancy, sexually transmitted infections, the conception and birth of a child affected by a reasonably preventable disability, and infertility.
- Reasonable access to the medical, social, and other means that respond to the patient's conditions and reproductive intentions, including

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<sup>48</sup> B.M. Dickens and R.J Cook, Dimensions of informed consent to treatment, *Ethical and legal issues in reproductive health. International Journal of Gynecology & Obstetrics* 85 (2004), pp. 309-314.

<sup>49</sup> The phrase "informed consent" is the most commonly used term. However, some would argue that the term could be misinterpreted and that it should be replaced by the term "informed choice." This is due to the fact that the choice not to consent is essential to the overall concept of voluntariness, or consent granted voluntarily. See B.M. Dickens and R.J Cook, *Dimensions of informed consent to treatment*.

<sup>50</sup> Rebecca J. Cook, Bernard M. Dickens, and Mahmoud F. Fathalla, *Reproductive Health and Human Rights: Integrating Medicine, Ethics, and Law*, p. 104.

expected rates of success, side effects, and the risks involved with each option.

- The implications for the patient's sexual and reproductive health, as well as for her general health and lifestyle, of declining any of the options.
- The provider's recommendations and the reasons behind them.

46. Through its various mechanisms, the CEDAW Committee has addressed the relevance of access to information on reproductive matters and has maintained that women "have the right to be fully informed, by properly trained personnel, of their options in agreeing to treatment or research, including likely benefits and potential adverse effects of proposed procedures and available alternatives."<sup>51</sup>

47. Indeed, access to information helps women make informed decisions regarding the most intimate realm of their life, deciding to have children. On this point, the IACHR has established that a couple's decision to have children falls within the most intimate sphere of their private and family life.<sup>52</sup> It also stated that the way in which couples arrive at that decision is part of a person's autonomy and identity, both as an individual and as a partner, and is therefore protected under Article 11 of the American Convention. The European Court of Human Rights established that the concept of private life, in addition to covering the physical and psychological integrity of a person,<sup>53</sup> can embrace aspects of an individual's physical and social identity, including the right to personal autonomy, personal development, and the right to establish and develop relationships with other human beings and the outside world.<sup>54</sup> It also held that the protection of private life incorporates the right to respect decisions regarding whether or not to become a parent.<sup>55</sup> Moreover, the European Court recently determined that the right to timely access to information with regard to a prenatal genetic test falls within the ambit of private life and includes a right to obtain available information on one's condition.<sup>56</sup>

48. The IACHR considers that for the OAS Member States to ensure women's right to access to information on reproductive matters, they should provide all available information with respect to family- planning methods as well as to other lawfully provided sexual and reproductive health services. With respect to family-planning services, this at the least includes making available all information regarding the family-planning services

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<sup>51</sup> United Nations, CEDAW Committee, General Recommendation 24, para. 20.

<sup>52</sup> Application to the Inter-American Court of Human Rights, Gretel Artavia Murillo (*In Vitro* Fertilization).

<sup>53</sup> European Court of Human Rights, *Pretty v. The United Kingdom*, Application 2346/02, April 29, 2002, para. 61.

<sup>54</sup> European Court of Human Rights, *Tysiac v. Poland*, para. 107; European Court of Human Rights, *Pretty v. The United Kingdom*, para. 61.

<sup>55</sup> European Court of Human Rights, *Pretty v. The United Kingdom*, para. 61; European Court of Human Rights, *Evans v. The United Kingdom*, Application 6339/05, April 10, 2007, para. 71.

<sup>56</sup> European Court of Human Rights, *R.R. v. Poland*, Application 27617/04, May 26, 2011, para. 197.

allowed by law and the scope, risks, benefits, and side effects of each of them. With respect to sexual and reproductive health services, this includes information on the prevention of sexually transmitted infections, including HIV/AIDS, as well as a discussion of the nature of any medical procedures that may be required, reasonable alternatives to the proposed intervention, and information on the relevant risks and benefits. In both situations, as will be explained below, health professionals should assess the patient's level of understanding so that she can make a decision regarding the intervention or treatment. That involves taking into account the specific information needs that some groups of women may have due contexts of exclusion, marginalization or discrimination, including indigenous and Afro-descendant women, adolescent girls, women who live in rural areas and migrant women<sup>57</sup>.

49. It is important to note that in some States of the Americas, case law has developed the concept of access to information in the sphere of health as a guarantee obligation of the States. By way of illustration, the Supreme Court of Canada, in its judgment in *McInerney v. MacDonald*, established the positive obligation of healthcare professionals to provide information to patients regarding their diagnosis and treatment.<sup>58</sup> For its part, the United States Court of Appeals for the District of Columbia, in *Canterbury v. Spence*, rejected the proposition that a patient must request information before the doctor is required to inform him or her. The Court indicated that the doctor has the obligation to provide information, even if it has not been requested, so that the patient can make an informed decision.<sup>59</sup>

50. Along these same lines, the European Court of Human Rights sanctioned one of its Member States for failing to provide information on the health services permitted by law. The Court found that the failure to provide the information constituted a violation of the right to receive and impart information.<sup>60</sup> The Court in particular underscored the possible prejudicial effects of the lack of information in some cases in which an injunction imposed to prevent information from being provided may have had more adverse effects on women who were not sufficiently resourceful or did not have the necessary level of education to have access to alternative sources of information.<sup>61</sup>

51. In another decision, the Court established that during pregnancy, the condition and health of the fetus constitute an element of the pregnant woman's health. As a result, the effective exercise of the right of access to information is often decisive for the possibility of exercising personal autonomy by deciding, on the basis of such

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<sup>57</sup> The IACHR also highlights the specific needs on reproductive health information that women of age require.

<sup>58</sup> Supreme Court of Canada, *McInerney v. MacDonald* [1992] 2 S.C.R. 138.

<sup>59</sup> Court of Appeals for the District of Columbia Circuit, *Canterbury v. Spence* 464 F.2d 772 (D.C. Cir. 1972).

<sup>60</sup> European Court of Human Rights, *Open Door Counseling and Dublin Well Women v. Ireland* (1992). Judgment of October 29, 1992.

<sup>61</sup> *Ibid.*, para. 77.

information, on the future course of events relevant for the individual's quality of life.<sup>62</sup> The Court indicated that timely access to information concerning a particular health condition "applies with particular force to situations where rapid developments in the individual's condition occur and his or her capacity to take relevant decisions is thereby reduced." It added that in the context of pregnancy, the effective access to relevant information on the health of the mother and the fetus is directly relevant for the exercise of personal autonomy, specifically where domestic legislation allows for abortion in certain situations.<sup>63</sup>

52. Similarly, as will be laid out below, in *A.S. v. Hungary* the CEDAW Committee affirmed that Article 10 of CEDAW includes a right to receive specific information on family-planning methods, in order to prevent procedures from being performed on women without their being able to make fully informed decisions.

**2. Providing appropriate information, taking into account the person's needs and ensuring that the person understands the information provided**

53. The IACHR observes that healthcare professionals are under the obligation to guarantee that any decisions that women make regarding sexual and reproductive matters are made freely, for example when it comes to choosing a preferred contraceptive method. The IACHR has stated that when women's decision-making freedom is compromised by circumstances such as poverty, or the fact that they belong to a particular race or social origin, their human rights are at risk. This is especially pertinent when it comes to certain groups of women who are particularly vulnerable, such as indigenous women, women of African descent, migrant women, women living in rural areas, and women living in poverty, who because of their particular circumstances face greater difficulties in accessing information on reproductive health.<sup>64</sup>

54. According to the Inter-American Court, "any person who is in a vulnerable condition is entitled to special protection, which must be provided by the States if they are to comply with their general duties to respect and guarantee human rights."<sup>65</sup> This requires the elimination of provisions or practices that discriminate against women, such as for example requiring that their partners be present to receive information about their health.

55. The former United Nations Special Rapporteur on the right of everyone to the enjoyment of the highest attainable standard of physical and mental health has indicated that States have a duty to ensure that health information and services are made available to vulnerable groups, in the context of their obligations to combat discrimination. As an example, he notes that States "must take steps to empower women to make

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<sup>62</sup> European Court of Human Rights, *R.R. v. Poland*, para. 197.

<sup>63</sup> *Ibid.*

<sup>64</sup> IACHR, *Access to Maternal Health Services from a Human Rights Perspective*.

<sup>65</sup> I/A Court H.R., *Ximenes Lopes v. Brazil Case*. Judgment of July 4, 2006. Series C No. 149, para. 103.

decisions in relation to their sexual and reproductive health, free of coercion, violence and discrimination."<sup>66</sup> In this regard, the CEDAW Committee has maintained that acceptable healthcare services are those that are delivered in a way that ensures that a women gives her fully informed consent, respects her dignity, guarantees her confidentiality, and is sensitive to her needs and perspectives.<sup>67</sup>

56. CEDAW General Recommendation No. 21 states that in order to make an informed decision about safe and reliable contraceptive measures, women must have information about contraceptive measures and their use, and guaranteed access to sex education and family-planning services, as provided in Article 10 (h) of CEDAW.<sup>68</sup>

57. For that purpose, the information should be complete, understandable, and up to date.<sup>69</sup> The IACHR underscores the importance that the information provided be adapted to the language of the person who requests or needs it. The Office of the Special Rapporteur for Freedom of Expression has held that ethnic and cultural groups have the right to have the State design policies aimed at adapting the right of access to their cultural needs, such as their language.<sup>70</sup> Thus, to guarantee effective access to information on sexual and reproductive matters, the States must ensure that women receive information and education in their own languages and in such a way that respects their cultures. Along these lines, the ESCR Committee has held that information about public services, for example, should be available, as far as possible, in languages spoken by minorities.<sup>71</sup>

58. The Human Rights Council recently indicated that States should ensure the availability of a wide range of prevention programs that take into account local circumstances, ethics, and cultural values, including information, education, and communication in languages most understood by communities and respectful of their cultures, aimed at reducing risk-taking behaviors and encouraging responsible sexual behavior.<sup>72</sup>

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<sup>66</sup> United Nations, Report of the Special Rapporteur, Paul Hunt. The right of everyone to the enjoyment of the highest attainable standard of physical and mental health, E/CN.4/2004/49, February 16, 2004, para. 39.

<sup>67</sup> United Nations, Committee on the Elimination of Discrimination against Women, General Recommendation 24, para. 22.

<sup>68</sup> United Nations, Committee on the Elimination of Discrimination against Women, General Recommendation 21, para. 22; United Nations, Committee on the Elimination of Discrimination against Women, *A.S. v. Hungary*, Communication No. 4/2004, CEDAW/C/36/D/4/2004.

<sup>69</sup> IACHR, *The Inter-American Legal Framework regarding the Right to Access to Information*. Office of the Special Rapporteur for Freedom of Expression, December 30, 2009, para. 32.

<sup>70</sup> IACHR, *2008 Annual Report*, Office of the Rapporteur for Freedom of Expression.

<sup>71</sup> General Comment No. 20, Non-discrimination in economic, social and cultural rights (art. 2, para. 2, of the International Covenant on Economic, Social and Cultural Rights), July 2, 2009.

<sup>72</sup> United Nations, Resolution of the Human Rights Council, The protection of human rights in the context of human immunodeficiency virus (HIV) and acquired immunodeficiency syndrome (AIDS), A/HRC/RES/12/27, October 22, 2009, para. 6.

59. In addition, the IACHR notes that another group requiring access to timely, complete, accessible, reliable, and proactive information are adolescents. In its report on Access to Maternal Health Services from a Human Rights Perspective, the IACHR addressed the problem of high rates of maternal mortality among adolescent girls and the need to provide them with information and education on the subject.<sup>73</sup>

60. On this point, the ESCR Committee has established that "the realization of the right to health of adolescents is dependent on the development of youth-friendly health care, which respects confidentiality and privacy and includes appropriate sexual and reproductive health services."<sup>74</sup> Along these same lines, the former United Nations Special Rapporteur on the right of everyone to the enjoyment of the highest attainable standard of physical and mental health maintained that "States should ensure that adolescents are able to receive information, including on family planning and contraceptives, the dangers of early pregnancy and the prevention of sexually transmitted infections including HIV/AIDS, as well as appropriate services for sexual and reproductive health."<sup>75</sup>

### **3. Ensuring that any consent provided is free and voluntary**

61. The various systems for the protection of human rights have emphasized the need for States to ensure that the decisions women make about their reproductive health are free of any form of coercion. That accounts for the importance of guaranteeing women's consent in the provision of medical treatment or surgical intervention. The IACHR has deemed that the practice of a surgical intervention without the required consent may constitute a violation of the patient's human rights.<sup>76</sup> Specifically, it may constitute a violation of the person's right to personal integrity protected by Article 5 of the American Convention. This close relationship between access to information and women's right to integrity was addressed by the European Court in a recent judgment, in which the Court established that compliance with the State's positive obligation to secure to its citizens their right to effective respect for their physical and psychological integrity may necessitate the adoption of regulations concerning access to information about an individual's health.<sup>77</sup>

62. Indeed, a lack of voluntariness of medical procedures may constitute a violation of the rights to integrity, life, and equal protection before the law, pursuant to the American Convention, as well as forms of violence and discrimination against women,

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<sup>73</sup> For more information, see IACHR, Access to Maternal Health Services from a Human Rights Perspective.

<sup>74</sup> United Nations Committee on Economic, Social and Cultural Rights. The right to the highest attainable standard of health, General Comment No. 14, para. 23.

<sup>75</sup> United Nations, Report of the Special Rapporteur, Paul Hunt. The right of everyone to the enjoyment of the highest attainable standard of physical and mental health, para. 39.

<sup>76</sup> According to the World Health Organization, "Male and female sterilization should be regarded as permanent methods and all individuals and couples considering these methods should be counselled accordingly. No other methods result in permanent infertility." Medical eligibility criteria for contraceptive use (3<sup>rd</sup> Edition)(2005), p. 8.

<sup>77</sup> European Court of Human Rights, *R.R. v. Poland*, para. 188.

pursuant to provisions of the Inter-American Convention on the Prevention, Punishment and Eradication of Violence against Women (hereinafter "Convention of Belém do Pará"). The IACHR has expressed its concern over cases of sterilization performed in Peru without women's consent, related to the implementation of family-planning policy and the Voluntary Contraceptive Surgery program.<sup>78</sup> The IACHR held that when a family-planning program ceases to be voluntary and turns women into mere objects of control so as to make adjustments to population growth, it poses a danger of violence and direct discrimination against women.<sup>79</sup> The Commission found that "a campaign to disseminate family planning methods is a positive action, so long as it is voluntary family planning."

63. Through its case system, the IACHR received a petition that referred to a forced sterilization performed at a public health center in Peru, which resulted in the death of the victim, María Mamérita Mestanza. In this case, the victim was not informed about the procedure the medical authorities were going to perform on her and thus was deprived of the possibility of accepting or rejecting the medical intervention, which led to an infringement of various human rights. The case was resolved with a friendly settlement agreement between the parties signed in 2001, by which the State of Peru recognized its responsibility for violating the victim's right to life, to physical and psychological integrity and humane treatment, and to equality before the law, and the right to be free from violence.<sup>80</sup> Among its commitments, the State pledged to implement measures to ensure that women can provide informed consent within a 72-hour period prior to sterilization. The IACHR is monitoring compliance with the agreement.

64. On July 23, 2008, the IACHR admitted a petition in which the State of Bolivia is alleged to have international liability over the alleged forced sterilization of a woman in a public hospital. The petitioner maintains that in the year 2000, Mrs. I.V. was submitted to a tubal ligation surgical procedure without her informed consent, and that this was therefore an involuntary sterilization, in which she permanently lost her reproductive capacity. The State, for its part, indicates that while the alleged victim was undergoing a caesarean section, she presented with multiple adhesions and as a result was told that any future pregnancy could put her life at risk. Because of this, the State indicates, it was suggested to her that a ligation of her fallopian tubes be performed, to which she gave her verbal consent.<sup>81</sup> It is important to note that for the first time, the Commission deemed that the facts should be analyzed under Article 13 of the American Convention in relation to the obligations enshrined in Article 1(1) of the same instrument, insofar as it was argued that the alleged victim had not "been adequately informed of the effects, risks and consequences of the surgical operation she was submitted to, and/or

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<sup>78</sup> IACHR, *Second Report on the Situation of Human Rights in Peru*, June 2, 2000, see Chapter VII, Women's Rights.

<sup>79</sup> *Ibid.*

<sup>80</sup> IACHR, Report No. 71/03, Petition 12.191, Friendly Settlement, *María Mamérita Mestanza Chávez* (Peru), October 3, 2003.

<sup>81</sup> IACHR, Report No. 40/08, Admissibility, *I.V. (Bolivia)*, July 23, 2008.

alternative methods as demanded by Bolivian law and the international standards of human rights in this area."<sup>82</sup> This case is now in the merits stage.

65. In its report on *Access to Maternal Health Services from a Human Rights Perspective*, the IACHR stated that the Convention of Belém do Pará "recognizes the crucial linkage between the right to live free of discrimination and the recognition of other fundamental rights, particularly the right to be free of violence based on gender."<sup>83</sup> The Convention of Belém do Pará, in Article 6, establishes that the right of every woman to be free from violence includes, among others:

- The right of women to be free from all forms of discrimination; and
- The right of women to be valued and educated free of stereotyped patterns of behavior and social and cultural practices based on concepts of inferiority or subordination.

66. In accordance with the parameters established in the Convention of Belém do Pará, the lack of information with respect to a sterilization performed without a woman's consent, as well as the physical and psychological consequences of such an intervention, are examples of forms of violence against women. Likewise, failing to inform women victims of sexual violence about the services that are available to them in these circumstances may also amount to a form of violence.

67. The IACHR has stated that subparagraph (e) of Article 7 of the Convention of Belém do Pará imposes on States the obligation to take all appropriate measures, including legislative measures, to amend or repeal existing laws and regulations or to modify lawful or customary practices that sustain the persistence and tolerance of violence against women. Given the clear relationship that exists between discrimination and violence, this precept should be interpreted in the sense of imposing on States the obligation to review public regulations, practices, and policies that are discriminatory or could lead to discriminatory effects against women (for example, legal norms that do not guarantee women a process for free and voluntary consent for a medical intervention).

68. For its part, the CEDAW Committee has maintained the following:

States parties should not permit forms of coercion, such as non-consensual sterilization, mandatory testing for sexually transmitted diseases or mandatory pregnancy testing as a condition of employment that violate women's rights to informed consent and dignity.<sup>84</sup>

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<sup>82</sup> *Ibid.*, para. 81.

<sup>83</sup> IACHR, *Access to Maternal Health Services from a Human Rights Perspective*.

<sup>84</sup> United Nations, Committee on the Elimination of Discrimination against Women, General Recommendation No. 24, para. 22. It is important to note that Article 14(2)(b) of the Convention on the Elimination of All Forms of Discrimination against Women establishes that "States Parties shall take all appropriate measures to eliminate discrimination against women in rural areas in order to ensure, on a basis of equality of men and women, that they participate in and benefit from rural development and, in particular, shall ensure to such women the right...to have access to adequate health care facilities, including information, counselling and services in family planning."

69. In the *A.S. v. Hungary* case, the petitioner argued to the CEDAW Committee that Hungary had violated several provisions of CEDAW as a result of her having been subjected to sterilization, during a surgical intervention to extract a fetus, without having received specific or understandable information on the sterilization or on the effects it would have on her ability to reproduce. She also argued that she was unable to give informed consent on account of the incomplete information provided to her, which constituted a violation of the right to appropriate healthcare services. She also indicated that the surgical intervention to which she was subjected limited her capacity to reproduce.

70. An opinion issued on August 29, 2006, pursuant to paragraph 3 of Article 7 of the Optional Protocol of CEDAW, expanded on the interpretation of Article 10 of CEDAW. The Committee reasoned that the petitioner had a right protected by Article 10(h) of the Convention to specific information on sterilization and alternative procedures for family planning in order to guard against such an intervention being carried out without her having made a fully informed choice.<sup>85</sup> Given the circumstances of the particular case, the CEDAW Committee evaluated the petitioner's state of health on arrival at the hospital and determined that any counseling she received must have been given "under stressful and most inappropriate conditions."<sup>86</sup>

71. As a result, the CEDAW Committee found "a failure of the State party, through the hospital personnel, to provide appropriate information and advice on family planning," which constitutes a violation of the victim's right under Article 10(h) of the Convention and Article 16, paragraph 1(e) of the same instrument [CEDAW].<sup>87</sup>

72. The CEDAW Committee's decision emphasizes that, in order for consent not to be flawed, it must not be obtained under coercion or influence of any kind. On this point, the Commission emphasizes that while consent may be granted verbally or in writing, in practice, for greater legal protection and in the event of possible future disputes, consent should be granted in writing. The Commission understands that the greater the consequences of a decision to be made, the more rigorous the controls should be to ensure that consent was truly given. The situation and conditions under which consent is given should be strictly analyzed on a case-by-case basis. In addition, the Commission recognizes that the mere statement or record of consent does not constitute full proof of consent. The statement of consent is used as evidence with respect to the contents of the conversation between the healthcare provider and the patient.<sup>88</sup>

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<sup>85</sup> United Nations, Committee on the Elimination of Discrimination against Women, *A.S. v. Hungary*, Communication No. 4/2004, CEDAW/C/36/D/4/2004.

<sup>86</sup> *Ibid.*

<sup>87</sup> *Ibid.*

<sup>88</sup> Jocelyn Downie, Timothy Caulfield, Colleen Flood, *Canadian Health Law and Policy*, Second Edition, 2000, p. 112.

73. The United Nations International Conference on Population and Development, held in Cairo in 1994, emphasized the importance of people being well-informed so they can make decisions responsibly, based on their needs.

The success of population education and family-planning programmes in a variety of settings demonstrates that informed individuals everywhere can and will act responsibly in the light of their own needs and those of their families and communities. The principle of informed free choice is essential to the long-term success of family-planning programmes. Any form of coercion has no part to play.<sup>89</sup>

74. The Commission recognizes that exceptional circumstances exist in which consent does not apply. Such exceptions are related to emergency situations, for example when it is necessary to treat a person medically to save his or her life or health but neither the person nor a close family member can provide consent. Other cases in which consent may not apply involve the existence of legal mandates tied to issues of mental health and public health. In this regard, the IACHR considers it important that in those cases in which public health is invoked to not apply consent, the States ensure that situations do not exist in which the obligatory nature of some evidence runs contrary to women's right to be free from all forms of discrimination.

#### **B. Access to information and the protection of confidentiality**

75. The IACHR deems that one important aspect to consider in terms of access to information on sexual and reproductive matters is closely tied to the professional relationship between healthcare professionals and women who use health services. The World Health Organization (WHO) defines confidentiality as the duty of providers "to protect patients' information against unauthorized disclosures."<sup>90</sup>

76. Confidentiality is a duty of healthcare professionals who receive private information in a medical environment, and maintaining the confidentiality or privacy of information they obtain from their patients is of critical interest in sexual and reproductive health.<sup>91</sup> Professional confidentiality and secrecy were addressed by the Inter-American Court of Human Rights in its judgment in *De La Cruz-Flores v. Peru*. This case involves María Teresa De La Cruz, a medical professional who was prosecuted, convicted, and sentenced for terrorism, based on the argument that she was providing health treatment to alleged terrorists. In its decision, the Inter-American Court established that "the medical act is acknowledged in numerous normative and declarative documents relating to the medical profession." For informational purposes, the Court made reference to Article 18 of the First Geneva Convention of 1949, which states that "[n]o one may ever be molested or

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<sup>89</sup> United Nations, International Conference on Population and Development, Cairo, 1994, Programme of Action, para. 7.12.

<sup>90</sup> World Health Organization. *Safe Abortion: Technical and Policy Guidance for Health Systems*. Geneva: WHO, 2003, p. 68.

<sup>91</sup> Rebecca J. Cook, Bernard M. Dickens, and Mahmoud F. Fathalla, p. 115.

convicted for having nursed the wounded or sick.” It also referred to Article 16 of Protocol I and Article 10 of Protocol II, both Protocols to the 1949 Geneva Conventions, which establish that “Under no circumstances shall any person be punished for carrying out medical activities compatible with medical ethics, regardless of the person benefiting therefrom.”<sup>92</sup>

77. The Court also established that the information a physician obtains in the exercise of his or her profession is privileged by professional confidentiality. On that point, it referred to a provision in International Code of Medical Ethics of the World Medical Association establishing that “a physician must keep absolutely secret everything that has been confided in him, even after the death of the patient.”<sup>93</sup> The Court also emphasized that the Human Rights Committee has already recommended that domestic legislation be modified to protect the confidentiality of medical information.<sup>94</sup>

78. In its decision, the Court considered that physicians have a right and an obligation to protect the confidentiality of the information to which, as physicians, they have access.<sup>95</sup> The Inter-American Court of Human Rights determined that the State of Peru had violated the principle of legality established in Article 9 of the American Convention, among other reasons because it penalized a medical activity which is not only an essential lawful act, but which it is also the physician’s obligation to provide.<sup>96</sup> It also found a violation of the principle of legality for imposing on physicians the obligation to report the possible criminal behavior of their patients, based on information obtained in the exercise of their profession.<sup>97</sup>

79. In his separate opinion, Judge Sergio García Ramírez indicated that the State may not violate the protection of health and life for which doctors are responsible, through norms or interpretations of norms that dissuade a doctor from complying with his duty, either because they threaten him with the imposition of a penalty (a threat that could prevent him from providing medical services), or because they induce him to make distinctions contrary to the principles of equality and non-discrimination, or because they force him to deviate from his proper functions and assume others that conflict with them, pose unacceptable dilemmas, or change the basis of the relationship between doctor and patient, as would happen if doctors were obliged to inform on the patients they treat.<sup>98</sup>

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<sup>92</sup> I/A Court H.R., *De La Cruz-Flores v. Peru Case*. Judgment of November 18, 2004. Series C No. 115, para. 95.

<sup>93</sup> *Ibid.*, para. 97.

<sup>94</sup> *Ibid.*, para. 100, citing the Final observations of the Human Rights Committee, Chile, U.N. Doc. CCPR/C/79/Add.104. (1999).

<sup>95</sup> I/A Court H.R., *De La Cruz-Flores v. Peru Case*. Judgment of November 18, 2004. Series C No. 115, para. 101.

<sup>96</sup> *Ibid.*, para. 102.

<sup>97</sup> *Ibid.*

<sup>98</sup> *Ibid.*, para. 100, citing the Final observations of the Human Rights Committee, Chile, U.N. Doc. CCPR/C/79/Add.104. (1999).

A similar situation would arise, if lawyers were forced to report the unlawful acts committed by their clients (which they learn about through their relationship of assistance and defense), or priests to reveal the secrets of the confessional.

80. Judge García Ramírez emphasized the need to prohibit incriminating the conduct of a doctor who abstains from providing information to the authorities about his patient's punishable conduct, which he is aware of through information provided to him by the patient in connection with the medical procedure.<sup>99</sup>

I consider that it is inadmissible—a consideration that coincides with the opinion of the Inter-American Court, as stated in the judgment in this case—to criminally penalize the conduct of a doctor who provides care designed to protect the health and life of other individuals, notwithstanding their characteristics, activities and beliefs, and the origin of their injuries or illnesses.

81. The IACHR notes that issues related to sexuality and reproduction are extremely sensitive, and thus the fear that confidentiality will not be respected can have the effect of women not seeking the medical care they need. By contrast, if a person feels safe and trusting, she will provide all the information needed so the medical professional can more effectively diagnose and treat her.

82. On that specific point, the CEDAW recognizes the importance of respecting the confidentiality of the information obtained in the medical environment, especially so that women are not deterred from seeking needed care.

While lack of respect for the confidentiality of patients will affect both men and women, it may deter women from seeking advice and treatment and thereby adversely affect their health and well-being. Women will be less willing, for that reason, to seek medical care for diseases of the genital tract, for contraception or for incomplete abortion and in cases where they have suffered sexual or physical violence.<sup>100</sup>

83. The former United Nations Special Rapporteur on the right of everyone to the enjoyment of the highest attainable standard of physical and mental health has also expressed himself in this regard, indicating the importance of confidentiality in the medical context. In the words of the former Rapporteur:

...in the context of sexual and reproductive health, breaches of medical confidentiality may occur. Sometimes these breaches, when accompanied by stigmatization, lead to unlawful dismissal from

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<sup>99</sup> *Ibid.*, Separate opinion of Judge Sergio Ramírez.

<sup>100</sup> United Nations, Committee on the Elimination of Discrimination against Women, General Recommendation 24, Women and health, para. 12(d).

employment, expulsion from families and communities, physical assault and other abuse. Also, a lack of confidentiality may deter individuals from seeking advice and treatment, thereby jeopardizing their health and well-being. Thus, States are obliged to take effective measures to ensure medical confidentiality and privacy.<sup>101</sup>

84. For its part, the ESCR Committee has noted that "accessibility of information should not impair the right to have personal health data treated with confidentiality."<sup>102</sup> Consequently, guaranteeing confidentiality in access to information regarding reproductive matters is critical to guaranteeing that women seek medical care in a timely manner. This is particularly relevant in some countries of the region where some medical services have been completely criminalized and healthcare professionals are required to report them. In this regard, the Committee Against Torture has classified as torture the practice of providing life-saving medical care for women suffering complications from illegal abortions only on condition that they first provide information on whether they had had an abortion.<sup>103</sup>

**C. Access to information and the obligation to provide information that is timely, complete, accessible, reliable, and proactive**

85. As has already been noted, it is important that the information that is provided helps women make informed decisions about their reproductive health. In this framework, the obstruction of access to information or the provision of inadequate or erroneous information contravenes the right to access to information.

86. On this point, the IACHR emphasizes that States have an obligation to refrain from censoring, either administratively or judicially, information on reproductive matters that falls within existing laws in this area, for example on the effects and effectiveness of family-planning methods. This means, for the States, that the public

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<sup>101</sup> United Nations, Report of the Special Rapporteur, Paul Hunt. The right of everyone to the enjoyment of the highest attainable standard of physical and mental health, para. 40.

<sup>102</sup> United Nations Committee on Economic, Social and Cultural Rights. The right to the highest attainable standard of health General Comment 14, para. 12.

<sup>103</sup> The Committee Against Torture has expressed its concern about reports "that life-saving medical care for women suffering complications after illegal abortions is administered only on condition that they provide information on those performing such abortions. Such confessions are reportedly used subsequently in legal proceedings against the women and against third parties, in contravention of the provisions of the Convention." Conclusions and recommendations of the Committee against Torture, Chile, U.N. Doc. CAT/C/CR/32/5 (2004), para. 6(j).

The Committee therefore recommended that the State should: "Eliminate the practice of extracting confessions for prosecution purposes from women seeking emergency medical care as a result of illegal abortion; investigate and review convictions where statements obtained by coercion in such cases have been admitted into evidence, and take remedial measures including nullifying convictions which are not in conformity with the Convention. In accordance with World Health Organization guidelines, the State party should ensure immediate and unconditional treatment of persons seeking emergency medical care." Conclusions and recommendations of the Committee against Torture, Chile, U.N. Doc. CAT/C/CR/32/5 (2004), para. 7(m).

policies and programs on sexual and reproductive health should be based on scientific evidence that provides certainty.

87. The IACHR has maintained that prior censorship “implies restricting or preventing expression before it has been circulated, so preventing not only the individual whose expression has been censored, but also all of society, from exercising their right to the information. In other words, prior censorship produces ‘a radical suspension of freedom of expression through preventing the free circulation of information, ideas, opinions, or news.’” This “constitutes a radical violation not only of the right of each person to express himself, but also of the right of every person to be well informed, and therefore constitutes one of the basic conditions of a democratic society.”<sup>104</sup>

88. As the case law of the inter-American system has held, cases of prior censorship “result in the radical violation of each person's right of expression, as well as the right of all people to be well-informed and to receive and know the expressions of others; as such, one of the basic conditions of a democratic society is adversely affected.”<sup>105</sup> The Declaration of Principles on Freedom of Expression establishes, “Prior censorship, direct or indirect interference in or pressure exerted upon any expression, opinion or information transmitted through any means of oral, written, artistic, visual or electronic communication must be prohibited by law.”<sup>106</sup> It also states, “Restrictions to the free circulation of ideas and opinions, as well as the arbitrary imposition of information and the imposition of obstacles to the free flow of information violate the right to freedom of expression.”<sup>107</sup>

89. In the area of reproductive health, the ESCR Committee noted that States have an obligation to refrain from censoring, withholding, or intentionally misrepresenting health-related information such as contraceptive methods—including sexual education and related information—as well as from preventing people's participation in health-related matters.<sup>108</sup>

90. For its part, the Committee on the Rights of the Child addressed prior censorship as regards children's access to information about HIV/AIDS. It emphasized that effective HIV/AIDS prevention requires States to refrain from censoring, withholding, or intentionally misrepresenting health-related information, including sexual education and information, and that consistent with their obligations to ensure the survival, life, and

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<sup>104</sup> IACHR, *2008 Annual Report*, Office of the Rapporteur for Freedom of Expression, citing IACHR. Report on the Merits No. 90/05. Case No. 12.142. *Alejandra Matus Acuña* (Chile). October 24, 2005, para. 35.

<sup>105</sup> IACHR, *2008 Annual Report*, Office of the Rapporteur for Freedom of Expression, citing IACHR. *Case of Palamara-Iribarne v. Chile*, Judgment of November 22, 2005, Series C No. 135, para. 68. I/A Court H.R., *Compulsory Membership in an Association Prescribed by Law for the Practice of Journalism (Arts. 13 and 29 American Convention on Human Rights)*, Advisory Opinion OC-5/85 of November 13, 1985, Series A No. 5, para. 54. IACHR, Arguments before the Inter-American Court of Human Rights in the *Case of Herrera-Ulloa v. Costa Rica*, cited in the judgment of July 2, 2004, Series C No. 107, para. 101(5).

<sup>106</sup> Declaration of Principles on Freedom of Expression, para. 5.

<sup>107</sup> *Ibid.*

<sup>108</sup> United Nations Committee on Economic, Social and Cultural Rights. The right to the highest attainable standard of health, General Comment 14, para. 34.

development of the child, they must ensure that children have the ability to acquire the knowledge and skills to protect themselves and others as they begin to express their sexuality.<sup>109</sup> For his part, the former Rapporteur on the Right to Health, Paul Hunt, has stated, "Some traditional views about sexuality are obstacles to the provision of sexual and reproductive health services, including reliable information, and these views have an especially damaging impact upon adolescents."<sup>110</sup>

91. As an example of this situation, on March 8, 2002, the IACHR received a petition alleging the violation of the human rights of the minor child Paulina Ramírez Jacinto, who was a victim of a rape that resulted in pregnancy and was prevented by State authorities from exercising her right to interrupt the pregnancy, in accordance with Mexican law. Among other methods employed to dissuade her from getting a legal abortion, she and her mother were given incomplete and erroneous information about the medical procedure and its consequences. The case was resolved through a friendly settlement agreement dated March 8, 2006. In that agreement, the IACHR stated that women cannot fully enjoy their human rights without having timely access to comprehensive health care services, and to information and education in this sphere.<sup>111</sup> The IACHR is monitoring compliance with the agreement.

92. Consequently, the IACHR considers that to guarantee access to information on reproductive matters, the OAS Member States must refrain from censoring, withholding, or misrepresenting information. Moreover, pursuant to the respect and guarantee obligations imposed by the IACHR, and under the principles of equality and non-discrimination, the States must guarantee that women have access to information that is timely, complete, accessible, reliable, and proactive on reproductive matters; this should include information about the sexual and reproductive health services that are legally available.

### **1. Access to information and conscientious objection**

93. The IACHR recognizes that health professionals have the right to have their freedom of conscience respected. Article 18(1) and (2) of the United Nations International Covenant on Civil and Political Rights establishes the following:

1. Everyone shall have the right to freedom of thought, conscience and religion. This right shall include freedom to have or to adopt a religion or belief of his choice, and freedom, either individually or in community with others and in public or private, to manifest his religion or belief in worship, observance, practice and teaching.

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<sup>109</sup> United Nations, Committee on the Rights of the Child, General Comment 3, HIV/AIDS and the rights of the child, March 17, 2003, para. 16.

<sup>110</sup> United Nations, Report of the Special Rapporteur, Paul Hunt. The right of everyone to the enjoyment of the highest attainable standard of physical and mental health, para. 14.

<sup>111</sup> IACHR, Report No. 21/07, Petition 161/02, Friendly Settlement, *Paulina del Carmen Ramírez Jacinto* (Mexico), March 9, 2007.

2. No one shall be subject to coercion which would impair his freedom to have or to adopt a religion or belief of his choice.

94. In addition, Article 18(3) establishes: "Freedom to manifest one's religion or beliefs may be subject only to such limitations as are prescribed by law and are necessary to protect public safety, order, health, or morals or the fundamental rights and freedoms of others." That is to say, while healthcare professionals demand respect for their right to conscience, they must also show equal respect for their patients' rights to conscience.

95. Conscientious objection is a very relevant issue when it comes to access to information in the area of reproductive health. Many health professionals have their own convictions with respect to the use of family-planning methods, emergency oral contraception, sterilization, and legal abortion, and they prefer not to provide these services. As was indicated in the preceding paragraph, the health professional's right to conscientious objection is a freedom. However, this freedom could come into conflict with patients' freedoms. Consequently, the balance between the rights of healthcare professionals and the rights of patients is maintained through referrals. In other words, a health professional may refuse to take care of a patient, but should transfer the patient without objection to another health professional who can provide what the patient is seeking. For example, if a woman needs family-planning information and services and/or other lawful reproductive health services, and the health professional has his or her own convictions with respect to the utilization of such services, the professional has the obligation to refer the patient to another health provider who can provide the information and services in question. This is in order not to create barriers in access to services.

96. The IACHR notes that the European Court addressed the issue of conscientious objection in the provision of family-planning services. In this case, the petitioners alleged that they refused to sell birth-control pills at a pharmacy because this went against their religious beliefs. The European Court held that "as long as the sale of contraceptives is legal and occurs on medical prescription nowhere other than in a pharmacy, the applicants cannot give precedence to their religious beliefs and impose them on others as justification for their refusal to sell such products." That is because they are able to manifest their beliefs "in many ways outside the professional sphere."<sup>112</sup> In another decision handed down recently, the European Court ruled that the States "are obliged to organise the health services system in such a way as to ensure that an effective exercise of the freedom of conscience of health professionals in the professional context does not prevent patients from obtaining access to services to which they are entitled under the applicable legislation."<sup>113</sup>

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<sup>112</sup> European Court of Human Rights, *Pichon and Sajous v. France*. App. No. 49853/99, 2001.

<sup>113</sup> European Court of Human Rights, *R.R. v. Poland*.

97. In addition, the IACHR notes that the Constitutional Court of Colombia, in a decision handed down in 2008, determined some factors that are worth noting with respect to objections of conscience.<sup>114</sup>

- Conscientious objection is not a right to which juridical persons or the State are entitled; it can be recognized only for natural persons;
- In cases in which a physician invokes a conscientious objection, he or she must proceed to refer the woman to another physician who can provide the medical service being requested, without prejudice to a later determination as to whether the conscientious objection was applicable and relevant through the mechanisms established by the medical profession.
- Conscientious objection is an individual, not an institutional or collective, decision.
- Conscientious objection applies only to direct providers and not to administrative personnel.
- Conscientious objection applies when it truly involves a religious conviction that is properly reasoned and submitted in writing. The physician who invokes it must follow the obligation to immediately refer the woman to a physician who can provide the reproductive health service being requested, this so as to prevent the refusal from becoming a barrier in access to reproductive health services.

98. In its decision, the Constitutional Court of Colombia underscores that the exercise of the right to conscientious objection must fall within the law, and thus may not constitute a mechanism for discrimination and the violation of women's fundamental rights.

99. In this regard, the IACHR considers that the States must guarantee that women are not prevented from accessing information and reproductive health services, and that in situations involving conscientious objectors in the health arena, the States should establish referral procedures, as well as appropriate sanctions for failure to comply with their obligation.

#### **D. Access to information and access to medical records**

100. The IACHR has indicated that, apart from the general right of access to State-held information, "Every person has the right to access to information about himself or herself, whether this is in the possession of a government or private entity." This right "includes the right to modify, remove or correct such information due to its sensitive, erroneous, biased or discriminatory nature."<sup>115</sup> Moreover, the Declaration of Principles on Freedom of Expression establishes: "Every person has the right to access to information

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<sup>114</sup> Constitutional Court of Colombia, Judgment T-209/08.

<sup>115</sup> IACHR, *2008 Annual Report*, Office of the Rapporteur for Freedom of Expression, para. 94. IACHR, Report on Terrorism and Human Rights. Chapter III, E): Right to Freedom of Expression. OEA/Ser.L/V/II.116. October 22, 2002. Available at: <http://www.cidh.oas.org/Terrorism/Eng/toc.htm>.

about himself or herself or his/her assets expeditiously and not onerously, whether it be contained in databases or public or private registries, and if necessary to update it, correct it and/or amend it."<sup>116</sup>

101. In addition, the IACHR has established, "The right to access to and control over personal information is essential in many areas of life, since the lack of legal mechanisms for the correction, updating or removal of information can have a direct impact on the right to privacy, honor, personal identity, property, and accountability in information gathering."<sup>117</sup>

102. The IACHR notes that the matter of access to personal information contained in medical records was addressed by the European Court of Human Rights. In *K.H. and Others v. Slovakia*, the applicants alleged a violation of their right to respect for private and family life, established in Article 8 of the European Convention on Human Rights, because they did not have access to photocopies of the medical records of the alleged victims, whom they considered to have been victims of sterilization without their consent and without having been informed. The European Court framed the case as one involving "the exercise by the applicants of their right of effective access to information concerning their health and reproductive status," and determined a violation of the victims' "right to respect for private and family life."<sup>118</sup>

103. In its reasoning, the Court reiterated that "in addition to the primarily negative undertakings in Article 8 of the Convention, there may be positive obligations inherent in effective respect for one's private life." According to the European Court, the original records, which could not be reproduced manually, contained information which the applicants considered important from the point of view of their moral and physical integrity, as they suspected that they had been subjected to an intervention affecting their reproductive status.<sup>119</sup>

104. The European Court determined that the obligations derived from the exercise of the right to respect for private and family life should extend, in particular in cases like the one that is the subject of the complaint, which concerned personal data. The Court indicated that "protection of medical data is of fundamental importance to a person's enjoyment of his or her right to respect for private and family life as guaranteed by Article 8 of the Convention and that respecting the confidentiality of health data is a vital principle in the legal systems of all the Contracting Parties to the Convention." The Court likewise determined that while protection of medical data is of fundamental

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<sup>116</sup> IACHR Declaration of Principles on Freedom of Expression.

<sup>117</sup> 2008 Annual Report, Office of the Rapporteur for Freedom of Expression, para. 94. IACHR, Report on Terrorism and Human Rights. Chapter III, E): Right to Freedom of Expression. OEA/Ser.L/V/II.116. October 22, 2002. Available at: <http://www.cidh.oas.org/Terrorism/Eng/toc.htm>.

<sup>118</sup> European Court of Human Rights, *K.H. and Others v. Slovakia*, Judgment 32881/04 of April 28, 2009.

<sup>119</sup> *Ibid.*, para. 50.

importance, the risk of abuse by third persons "could have been prevented by means other than denying copies of the files to the applicants."<sup>120</sup>

105. Meanwhile, in comparative case law, the IACHR has referred to case law of the Constitutional Court of Colombia, which has indicated that the right to petition, and indirectly the right to health, is breached when a patient is prevented from accessing his or her clinical records.<sup>121</sup> In that regard, in Judgment T-275 of 2005, the Constitutional Court held: "The clinical history held by the petitioned entity in principle comprises not simply a private document subject to confidentiality, which may be seen only by the patient and the institution, and in exceptional cases by a third party, but in addition, all the evaluations, tests, interventions, and diagnoses done on the patient, in the only file or database where they are legitimately kept. In this regard, not allowing the patient access to his clinical history violates the petitioner's right to petition, and indirectly his right to health...."<sup>122</sup>

106. The IACHR considers that the right to access to information is also adversely affected when access to information regarding medical history is denied. Consequently, the States of the Americas must guarantee that people can access the information contained in their clinical records, or face possible sanction.

#### **E. Access to information and the obligation to produce reliable statistics**

107. The obligation to produce information has been the subject of various pronouncements and specific recommendations at the international level. Information on people's health, whether through statistics or other means, is essential for identifying major problems, formulating public policies, and assigning the necessary resources. The IACHR has indicated that "the State has the obligation to produce or obtain the information it needs to fulfill its duties, pursuant to international, constitutional, or legal norms."<sup>123</sup> This obligation extends to the sphere of health. In fact, in its 1998 regional report on the status of women in the Americas, "the Commission was able to confirm serious deficiencies in statistics, generally owing to a lack of resources and suitable infrastructure."<sup>124</sup>

108. The IACHR has indicated that international laws include clear and explicit obligations on production of information tied to the exercise of the rights of sectors that historically have been excluded or discriminated against. Indeed, the Convention of Belém do Pará establishes the States' obligations to "ensure research and the gathering of statistics and other relevant information relating to the causes, consequences and

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<sup>120</sup> European Court of Human Rights, *K.H. and Others v. Slovakia*.

<sup>121</sup> Constitutional Court of Colombia, Judgment T-232/09, Reference: case file T-2171774, Injunction (*acción de tutela*) filed by María Isabel Isaza against Francisco Javier Villegas Alzate.

<sup>122</sup> Constitutional Court of Colombia, Judgment T-275 of 2005 (MP: Antonio Humberto Sierra Porto), See Judgment T-232/09, Reference: case file T-2171774, Injunction filed by María Isabel Isaza against Francisco Javier Villegas Alzate.

<sup>123</sup> IACHR, *2008 Annual Report*, Office of the Rapporteur for Freedom of Expression, para. 162.

<sup>124</sup> IACHR, *Report of the Inter-American Commission on Human Rights on the Status of Women in the Americas*, October 13, 1998.

frequency of violence against women, in order to assess the effectiveness of measures to prevent, punish and eradicate violence against women and to formulate and implement the necessary changes.<sup>125</sup>

109. In its report on Guidelines for Preparation of Progress Indicators in the Area of Economic, Social and Cultural Rights, the IACHR noted that the State's obligation to take positive steps to safeguard the exercise of social rights raises important implications, for example, concerning the type of statistical information the State should produce.<sup>126</sup> It also stated:

From this perspective, the generation of information suitably disaggregated to identify these disadvantaged sectors or groups deprived of the enjoyment of rights is not only a means to ensure the effectiveness of a public policy, but a core obligation that the State must perform in order to fulfill its duty to provide special and priority assistance to these sectors. For example, the disaggregation of data by sex, race or ethnicity is an essential tool for highlighting problems of inequality.<sup>127</sup>

110. In the same document, the IACHR recalled that "The Committee on Economic, Social and Cultural Rights has drawn attention to the state obligation to produce information bases with which to validate indicators and, in general, access to many of the guarantees covered by each social right. Accordingly, this obligation is essential for the enforceability of these rights."<sup>128</sup> The IACHR also noted that international law includes clear and precise obligations on the production of information tied to the exercise of rights by sectors that have traditionally suffered exclusion and discrimination.<sup>129</sup>

111. Specifically in the area of health, in the report on *Guidelines for Preparation of Progress Indicators in the Area of Economic, Social and Cultural Rights*, the IACHR included indicators relating to access to information and participation. These indicators include those relating specifically to information on reproductive matters: statutory protection of personal health information, including its scope and limits; government dissemination of information on sexual and reproductive health policy, including its scope and coverage; and advisory services for pregnant women on mother-child HIV/AIDS transmission.

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<sup>125</sup> Article 8(h), Convention of Belém do Pará.

<sup>126</sup> IACHR, *Guidelines for Preparation of Progress Indicators in the Area of Economic, Social and Cultural Rights*, July 19, 2008, para. 58.

<sup>127</sup> *Ibid.*

<sup>128</sup> IACHR, *Guidelines for Preparation of Progress Indicators in the Area of Economic, Social and Cultural Rights*, para. 78. IACHR, *The Inter-American Legal Framework regarding the Right to Access to Information*. Office of the Special Rapporteur for Freedom of Expression, December 30, 2009, para. 37.

<sup>129</sup> IACHR, *Guidelines for Preparation of Progress Indicators in the Area of Economic, Social and Cultural Rights*, para. 81. IACHR, *The Inter-American Legal Framework regarding the Right to Access to Information*. Office of the Special Rapporteur for Freedom of Expression, December 30, 2009, para. 37.

112. The IACHR considers that the States should compile information on the status of women's human rights and reproductive health—including specific information on groups that have suffered exclusion, such as indigenous women, women of African descent, migrant women and women who live in rural areas—in order to identify and address the specific problems of these populations in this sphere.

113. For its part, the CEDAW Committee has encouraged States to include in their reports information on diseases or conditions hazardous to health that affect women or certain groups of women differently from men, as well as information on possible intervention in this regard.<sup>130</sup> The CEDAW Committee has also maintained that the States should report on their understanding of how policies and measures on health care address the health rights of women from the perspective of women's needs and interests, and how health care addresses distinctive features and factors which differ for women in comparison to men.<sup>131</sup>

114. Likewise, the Committee on Economic, Social and Cultural Rights has stated that a gender-based approach recognizes that biological and socio-cultural factors play a significant role in influencing the health of men and women. The disaggregation of health and socio-economic data according to sex is essential for identifying and remedying inequalities in health.<sup>132</sup>

115. The IACHR concludes that the production of reliable statistics on reproductive matters and the dissemination of that information will help to bring greater attention to countries' public health policies so the States can meet their international obligations in this area. Moreover, being aware of the true situation regarding women's sexual and reproductive health will raise collective awareness about the real needs that must be addressed.

#### IV. RECOMMENDATIONS

116. This report has reviewed the minimum principles the OAS Member State should observe in order to guarantee the protection, under equal conditions, of the right of access to information on reproductive health. The Commission trusts that its recommendations will contribute to the efforts the States are carrying out in this area:

1. Adapt domestic laws on access to information and education on sexual and reproductive health so that they meet the international standards the States have pledged to follow with regard to the right of access to information. Ensure that policies and programs, designed with the participation of women themselves, are consistent with the goals

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<sup>130</sup> United Nations, CEDAW Committee, General Recommendation 24, Women and health, para. 10.

<sup>131</sup> *Ibid.*, para. 12.

<sup>132</sup> United Nations Committee on Economic, Social and Cultural Rights. The right to the highest attainable standard of health, General Comment 14, para. 20.

established by the States to improve the flow of information related to reproductive health.

2. Analyze—at the level of the legislative, executive, and judicial branches, and with strict scrutiny—all laws, regulations, practices, and public policies in the area of health so that they guarantee the right to access to information on sexual and reproductive health and the obligation of the State to provide such information. Ensure, therefore, that the information provided is timely, complete, accessible, reliable, and proactive.
3. Incorporate simple, effective, and appropriate administrative procedures which can be used by anyone to request needed information.
4. Incorporate effective judicial procedures for reviewing decisions by public officials that deny women the right of access to certain information or that simply fail to respond to requests.
5. Guarantee confidentiality in access to information on sexual and reproductive health.
6. Ensure health professionals' obligation to inform women about their health so that women can make free, informed, and responsible decisions related to sexuality and reproduction.
7. Ensure that the information provided is adapted to the audience that needs it, particularly so that women who speak other languages can have access to the information in their own tongue.
8. Establish protocols for effective access to information in cases involving conscientious objection.
9. Revise criminal-law provisions that force health professionals to violate confidentiality and professional secrecy in accordance with international standards in this area.
10. Guarantee that patients can have access to their medical records when needed, and establish mechanisms for sanctioning the failure to comply with such a provision.
11. Implement measures so that information systems adequately reflect the situation of women's health, at the national and local level, including figures on family-planning needs, maternal morbidity and mortality, and neonatal mortality, along with their causes, so that effective decisions and actions can be taken.

12. Establish systematic policies for training and capacitating government officials on the right of access to information in all spheres of the State.
13. Promote the widespread dissemination of information on the health and the rights of indigenous and Afro-descendant women, and women who live in rural areas, to ensure their effective participation in decision-making concerning their reproductive health. Include adolescent girls, with a focus on preventing early motherhood.
14. Ensure that national budgets contemplate producing reliable statistics on sexual and reproductive matters, broken down at the very least by sex, gender, ethnicity, and age.