

Written Contribution from ILGA-Europe¹

Communication from the Commission – Consultation regarding Community action on health services (SEC (2006) 1195/4)

January 2007

Introduction

Health services are a core pillar of the European social model, and play a crucial role in relation to fostering social inclusion and cohesion, implementing human rights, and meeting fundamental human needs. As such, health services are of key significance to every individual in society. Unfortunately, available, accessible, acceptable and good quality services are not a reality for everyone in the European Union (EU). Lesbian, gay, bisexual and transgender (LGBT) people, like other groups who experience forms of discrimination and exclusion, often face many obstacles in their access to health care, treatment and services.

In this context, ILGA-Europe welcomes the consultation regarding Community action on health services and would like to contribute to the consultation by highlighting areas which require further legal clarity in relation to cross-border health care in Europe. This contribution is intended to emphasise the importance of a rights-based approach to Community action and policies related to health services through a discussion of the specific issues and concerns of LGBT people in terms of access to and relationship with health care service in Europe. This paper also provides a response to the questions raised by the Commission in the Communication from a human rights perspective aimed at combating discrimination on the grounds of sexual orientation and/or gender identity² and promoting equality.

1 ILGA-Europe, the European Region of the International Lesbian and Gay Association, is a European NGO with more than 200 national and local lesbian, gay, bisexual and transgender (LGBT) member organisations in 40 European countries. ILGA-Europe is a member of the Platform of European Social NGOs (Social Platform).

2 "Gender identity" refers to a person's sense of conformity between their biological and psychological gender. This is the individual's gender concept of self, which does not necessarily depend on the sex they were assigned at birth. Gender Expression relates to the expression of oneself in external presentation and/or appearance through behaviour, clothing, hair-cut, voice, body characteristics, etc. "Sexual orientation" in turn is used to depict a person's sexual and emotional attraction to people of the same and/ or different sex. ILGA-

ILGA-Europe welcomes the opportunity to contribute to this consultation process, and looks forward to an ongoing debate in this important policy area with all the relevant stakeholders.

I. Health services and LGBT people

Access to health care and related services is of concern and relevance to everyone in society, but not everyone shares the same health status, nor has equal access to quality health services. Lesbian, gay, bisexual and transgender (LGBT) people, like other groups who experience forms of discrimination and exclusion, often face many obstacles in accessing health services, including unequal treatment, limited enjoyment of their right to health and discrimination. Such obstacles to health care and related services exist when seeking health services in other EU Member States as well as in one's country of residence; as such, it is important to define the main factors affecting LGBT people's access to health care in the European Union in the context of this consultation on Community action on health services.

1.1 Prejudice and discrimination in health services

Stigma and discrimination play an important role in LGBT people's experience with health services, and often act as a barrier to persons seeking care and treatment. Indeed, many LGBT people are reluctant to seek care, because they fear insensitivity, dismissal, and discrimination from the medical community. Recent studies show that many physicians, clinicians, and therapists view LGBT people and their lifestyles as strange or irrelevant.³ Many providers claim that they do not feel comfortable treating LGBT people, and others see them as problematic, confusing, and dismissible. Many LGBT people recognize these perspectives and as a result often become reluctant to seek medical care. The most common reasons for this unwillingness are:

- Delaying a visit to a medical provider or not visiting at all because of the fear of one's sexual orientation or gender identity being revealed
- Less than full trust in doctor's ability to keep information confidential
- Inability to talk about sexual orientation and/or gender identity, even when understood to be crucial to proper treatment
- Belief that doctors are not sensitive to people of different sexual orientation or gender identity
- Being known to or perceived to be of a different sexual orientation, or having to reveal one's sexual orientation or gender identity

Research has indicated that fear of discrimination and stigma causes many LGBT individuals to postpone or decline seeking medical care. Others, once in care,

Europe uses the umbrella term transgender for people whose gender identity and/or gender expression differs from the sex they were assigned at birth. The term may include, but it is not limited to: transsexuals, intersex persons, cross-dressers, and other gender variant people. ILGA-Europe is aware that the issues relating to inter-sex people can be significantly different and need to be addressed separately where relevant.

³ See S.Quinn, *Accessing Health: the Context and the Challenges for LGBT People in Central and Eastern Europe*, ILGA-Europe, 2006.

sometimes withhold from their providers personal information, which may be critical to their well-being.

In terms of policy, related issues include, for instance: making mainstream mental health services more LGB friendly; providing training for health practitioners to incite a change in attitudes about LGB sexuality and may even see homosexuality, bisexuality or the gender identity, as well as to ensure that these practitioners have a better understanding of health problems specific to LGBT people.

1.2 The impact of lack of recognition of same-sex partnerships on access to health services

The recognition and acceptance of same-sex couples as well as of the marital status of LGBT people is another factor affecting their access to health services, often in a limitative way. Same-sex couples – whether they are married, registered or de facto partners – often experience forms of discrimination within health services. For instance, health practitioners may favour birth family over LGBT partners when it comes to seeking authorization for a patient's treatment or may not agree to share medical information with a patient's same-sex partner, even with this patient's approval.⁴ Lack of legal recognition of same-sex partnership and marriage can also limit health insurance coverage for couples, including health insurance for treatment and care sought abroad. In addition, same-sex couples face discrimination in accessing fertility treatment and assisted reproduction in many European countries.

1.3 Health services and transgender people

Access to health services is also a problem for transgender people who often encounter a general lack of knowledge about transgender issues among health providers. On one hand very little has been written on male-to-female transsexual issues and even less on female-to-male ones. On the other hand, social stigma around transgender issues persists and leads sometimes to the lack of inclusion of transgender health concerns within national health policies.

A lot of transgender people who seek help on issues of gender identity get counter productive advices – such as to learn to live with their birth gender role – or are not redirected to people who could provide adequate services. Many transgender people experience severe depression and other mental health problems as a result of lack of medical and psychological support to address issues around their gender identity. This is a serious concern taking into account that transgender people need the support of mental health providers all the way along their transitional process. Furthermore the legislation often allows a person to undergo hormone treatment and gender reassignment surgery only if a 'gender dysphoria' is diagnosed by a mental health practitioner.

The availability of specific surgeries is a key element to allow transgender people to embark upon the transitional process. In some cases surgeons lack experience in gender reassignment surgeries but also in surgeries other than those targeting the

⁴ Stonewall's Website, section on mental health: www.stonewall.org.uk/information_bank/health/1287.asp

genitals, such as Adam apple's reduction, which could contribute to the social acceptance of the patient as a member of the gender she/he is transitioning to.

Furthermore transgender people should get comprehensive information on risks linked to the therapies they undergo during the transition process such as the increasing risk of cancer linked to the hormone treatment.

II. The right to health in international law

In the context of this Communication on Community action on health services, ILGA-Europe wants to recall the right to health care and the right to health which have been recognized by international and European human rights instruments, which all EU Member States have adhered to. We welcome the reference in the introduction of the Communication to the right to health care inscribed in the Charter of Fundamental Rights of the EU⁵ as we strongly believe that fundamental rights should be put at the core of all Community action in relation to health services and health care.

To this end, we highlight the fact that the right to health is enshrined in the main international human rights instruments such as the Universal Declaration on human rights, the International Covenant on Economic, Social and Cultural rights (ICESCR), the Programme of Action of the United Nations Conference on Population and Development and the Platform for Action of the Fourth World Conference on Women. Having ratified all these instruments, EU Member States engaged themselves in respecting, promoting and fulfil the right to health.

We would also like to underline that **the right to health**, as defined in international human rights instruments, **is broader than the right to be healthy**. This definition has been stressed by the World Health Organisation and the Committee on Economic, Social and Cultural Rights⁶ with respect to the article 12.1 of the International Covenant on Economic, Social and Cultural Rights. Indeed, the Committee outlined that:

'The right to health must be understood as a right to the enjoyment of a variety of facilities, goods, services and conditions necessary for the realization of the highest attainable standard of health.'

Equal access to health and fundamental rights of patients are intrinsic to this approach: States have the responsibility to do all in their power to remove barriers in accessing health which also includes taking into account specific needs of vulnerable groups and the difficulties they encounter in accessing health.

Moreover, as Paul Hunt, the United Nations (UN) Special Rapporteur on the right to health, underlined in its 2004 report on sexual and reproductive health and rights⁷, States have **the duty to guarantee an equal access to health care and to fight**

⁵ "Everyone has the right of access to preventive healthcare and the right to benefit from medical treatment under the conditions established by national law and practices" (art. 35). Charter of Fundamental Rights of the EU, adopted in Nice, December 2000

⁶ General Comment No. 14 (2000) par. 9

⁷ Commission on Human Rights, resolution E/CN.4/2004/49

discrimination, including on the ground of sexual orientation, in the enjoyment of this right:

'International human rights law proscribes discrimination in access to health care and the underlying determinants of health, and to the means for their procurement, on the grounds or race, colour, sex, language, religion, political or other opinion, national or social origin, property, birth, physical or mental disability, health status (including HIV/AIDS), sexual orientation, and civil, political, social or other status that has the intention or effect of nullifying or impairing the equal enjoyment or exercise of the right to health.'

We also want to bring to the attention of the Commission the Special Rapporteur's acknowledgement that the right to health is closely related to the enjoyment of a number of other human rights and fundamental freedoms contained in the major international human rights treaties, including the rights to food, housing, work, education, life, non-discrimination, equality, privacy, participation [...].⁸

In addition to these international human rights obligations, we want to highlight commitments under the European Social Charter (revised 1996) which recognizes that "Everyone has the right to benefit from any measures enabling him to enjoy the highest possible standard of health attainable (art.11). In addition, we want to draw the attention of the Commission to the WHO's Declaration on promotion of patients' rights in Europe (1994) which calls for human values expressed in intergovernmental human rights instruments⁹ to be reflected in the health care system. Patients' rights are also partially recognised in the Charter of Fundamental Rights, as highlighted by the European Commission in the Outcome of the Reflection Process, which says "Everyone has the right of access to preventive health care and the right to benefit from medical treatment under the conditions established by national laws and practices" (art.35).¹⁰

ILGA-Europe considers that any European Union action in the field of health has to take into account the rights and principles recognized by international human rights law, as well as the rights enshrined in the Treaty of Amsterdam (article 13 on anti-discrimination), the EU Charter of Fundamental Rights, the European Social Charter and the European Convention of Human Rights.

III. ILGA-Europe's comments on the Communication (SEC(2006) 1195/4)

ILGA-Europe welcomes the opportunity to comment on the Communication from the Commission (SEC (2006) 1195/4) and wishes to respond to Questions 7 and 8 raised in this Communication.

⁸ E/CN.4/2003/58, 13 February 2003 (p.9).

⁹ "In drafting these Principles of the Rights of Patients in Europe, the following intergovernmental instruments, which together offer a framework and a set of basic concepts which can be applied to the rights of patients, have been taken into account: Universal Declaration of Human Rights (1948); International Covenant on Civil and Political Rights (1966); International Covenant on Economic, Social and Cultural Rights (1966); European Convention on Human Rights and Fundamental Freedoms (1950) the European Social Charter (1961).", A Declaration on the Promotion of Patients' Rights in Europe, WHO, (Amsterdam, 1994), http://www.who.int/genomics/public/eu_declaration1994.pdf

¹⁰ Outcome of the Reflection Process, 9/12/2003, Doc. HLP/2003/16, European Commission, DG Health and Consumer Protection, p.4

Question 7 - Are there other issues where legal certainty should also be improved in the context of each specific health or social protection system? In particular what improvements do stakeholders directly involved in receiving patients from other Member States – such as healthcare providers and social security institutions – suggest in order to facilitate cross-border health care?

In light of the Council's call for action "[...] ensuring clarity for European citizens about their rights and entitlements when they move from one EU Member State to another and enshrining these values and principles in a legal framework in order to ensure legal certainty"¹¹, ILGA-Europe considers that there is a need **to clarify and define patients' rights in Europe**, an issue which is of significant importance for LGBT people as explained above (see section I).

The issue of patient's rights and entitlements is a fundamental one in relation to cross-border health care. Indeed, mobility of patients throughout Europe begs the question: can citizens of EU member states be assured of receiving high-quality care and of having their rights respected if they need health care beyond their national frontiers? As explained by the European Observatory on Health Systems and Policies:

"Many Member States have laws or charters securing the rights of patients, but there is no common standard throughout Europe as a whole. Yet the growing mobility of citizens within the European borders is reinforcing calls for more equal protection of patients' rights in Europe. It is becoming less politically acceptable that the rights of the patient differ, sometimes substantially, from one Member State to another."¹²

The definition of common understanding of patients' rights was further identified as an area requiring further attention by the High Level Process of Reflection on Patient Mobility and Healthcare developments in the European Union which recommended "to explore further the possibility of reaching a common understanding on patients' rights, entitlements and duties, both individual and social, at European level [...]".¹³

As stated in the Outcome of the High Level Process of Reflection on Patient Mobility and Healthcare Developments in the EU, "greater clarity at European level about these issues would be useful, covering questions such as general information about healthcare, personal information, protection of personal data, compensation, and informed consent."¹⁴ Moreover, as argued by the European Observatory on Health Systems and Policies, "[g]iven the common principles shared by Member States, however much their detailed application varies between systems, some form of European charter of patients' rights could help express the shared principles and values

11 Council Conclusions on Common values and principles in EU Health Systems, 2733rd Employment, Social Policy, Health and Consumer Affairs Council Meeting, Luxembourg, 1-2 June 2006

12 Policy Brief – Cross-Border Health Care in Europe, European Observatory on Health Systems and Policies, 2005, p.25 (<http://www.euro.who.int/Document/E87922.pdf>)

13 Outcome of the Reflection Process, 9/12/2003, Doc. HLP/2003/16, European Commission, DG Health and Consumer Protection, p.4.

14 Outcome of the Reflection Process, 9/12/2003, Doc. HLP/2003/16, European Commission, DG Health and Consumer Protection, p.4.

of all EU health systems in a way that would give patients increased confidence in seeking care throughout the EU.”¹⁵

In this context, ILGA-Europe asks the Commission to provide answers to the following questions:

- **Is there a common understanding on patients’ rights at European level?**
- **Can a European Charter of patients’ rights be considered to explicitly establish the rights of patients?**

In tackling these questions, ILGA-Europe calls on the Commission to establish its reflection on existing legal obligations of EU Member States and political commitments which recognize the existence of fundamental rights and common principles in relation to health. In particular, ILGA-Europe wants to highlight international and European human rights instruments which all EU Member States have ratified (as summarized above in section II). ILGA-Europe considers that, among others, these legal instruments – which recognize fundamental rights related to health for patients in the EU – provide a basis for the elaboration and the adoption of common rights and standards in health care services at the European level.

The issue of defining what constitute patients’ rights follows from these initial questions and constitutes another area where legal clarity is needed:

- **What are the rights of patients commonly recognized at the European level?**

ILGA-Europe believes that a number of rights and principles have already been recognized as common in the EU. Indeed, the European Council has affirmed a set of principles which it considered to be widely accepted in the work of the different EU institutions and to constitute a set of values shared across Europe. These common values and principles in EU health systems are “**universality, access to good quality care, equity and solidarity**”.¹⁶ The Council further recognized a set of shared operating principles in the provision of health care which are that of quality, safety, care that is based on evidence and ethics, and privacy and confidentiality. At its June 2006 meeting, the Council also reiterated that “the right of all EU citizens to confidentiality of personal information is recognised in EU and national legislation”. As mentioned above in section I, the **right to privacy and confidentiality** is of great significance to LGBT people, in particular in providing a safe environment in the provision of health services. This right has been included in the WHO’s Declaration on the promotion of patients’ rights in Europe.¹⁷

15 Policy Brief – Cross-Border Health Care in Europe, European Observatory on Health Systems and Policies, 2005. <http://www.euro.who.int/Document/E87922.pdf>

16 2733rd Employment, Social Policy, Health and Consumer Affairs Council Meeting, Luxembourg, 1-2 June 2006. The Council defined these values as follows: “Universality means that no-one is barred access to health care; solidarity is closely linked to the financial arrangement of our national health systems and the need to ensure accessibility to all; equity relates to equal access according to need, regardless of ethnicity, gender, age, social status or ability to pay.”

17 A Declaration on the Promotion of Patients’ Rights in Europe, WHO, (1994), www.who.int/genomics/public/eu_declaration1994.pdf

ILGA-Europe considers that the principles identified by the European Council as common values should be included in a definition of patients' rights at the European level. However, drawing from international and European human rights standards, we believe that other rights also need to be recognized. These include, among others, the following¹⁸:

- The **right to the enjoyment of the highest attainable standard of physical and mental health** (as enshrined in the Universal Declaration of human rights (art.25), the ICESCR (art. 12))
- The right to equality, and **to be free from all forms of discrimination** including in one's sexual and reproductive life (following from the Treaty of Amsterdam (art.13), the European Social Charter (art. E), as well as interpretation of the right to health by international bodies (see section II above)).
- The **right to information and education** (e.g. as it relates to having access to all relevant information pertinent to one's health, including one's sexual and reproductive health)
- The right to respect of his or her person as a human being (e.g. as it relates to treating a person with dignity, regardless of her/his sexual orientation, gender identity and/or gender expression.)

In short, ILGA-Europe regard the right to health as closely related to the enjoyment of a number of other human rights and therefore believes that the right to health care and health protection should include the rights of health care clients to: information, access, choice, safety, privacy, confidentiality, dignity, comfort, continuity, and opinion. We would welcome the opportunity to further elaborate on these rights and principles which we consider to be fundamental and common at European level in the context of the follow-up to this consultation on health services.

Question 8- In what ways should European action help support the health systems of the Member States and the different actors within them? Are there areas not identified above?

The European action in the field of health should aim at strengthening the compliance with the international legal framework mentioned above and at helping Member States to protect, promote and fulfil the right to health.

ILGA-Europe believes that cross-border mobility within the European Union can provide a unique opportunity to improve access to health and the enjoyment of the right to health for EU citizens. We also recognise the specific nature of health services and therefore we support the vision according to which they should be regulated by a specific legal framework. A common and clear legal framework would be a key factor in fostering patients' cross-mobility throughout Europe, as suggested by the 2003 EU Commission report on application of the internal market rules in the field of health care services.¹⁹

18 Such rights are proposed in the following documents: A Declaration on the Promotion of Patients' Rights in Europe, WHO, (Amsterdam, 1994) and the International Planned Parenthood Federation (IPPF) Charter on Sexual and Reproductive Rights, <http://www.ifpa.ie/about/charter.html>

19 Report on the application of the internal market rules to health services. SEC (2003) 900.

This common framework should take into account principles set out by the jurisprudence of the European Court of Justice (ECJ)²⁰ in the area of cross-border health care such as the removal of the prior-authorisation to get refund for a non-hospital treatment undergone abroad and the non-consistency of refusing the authorization for a hospital treatment if an identical or equally effective treatment cannot be obtained without undue delay in the country of residence.

In relation to this jurisprudence, the European Union should clarify some points such as the distinction between a hospital and a non-hospital treatment or the basis over which a delay should be considered as undue. This is important given that Member States give a different interpretation to the principles established by the ECJ. For example, Member States are free to set up their own definition of hospital and non-hospital treatment; it follows that one-day treatments at hospital are considered as hospital services in some countries and as non-hospital services in other. This is likely to lead to discriminatory access to the same treatment on the ground of nationality because the requirement of a prior-authorisation could be seen as a barrier to the enjoyment of a given health service. We think that the clarification of this common framework may improve equal access to certain health treatments for vulnerable groups, such as LGBT people.

Moreover, we would like to bring to your attention examples and issues of relevance to LGBT people, which can contribute to a better understanding of the impact of cross-border healthcare on access to health services for vulnerable groups and people with specific needs.

➤ *Treatments not offered in a given Member State*

Some European countries adopted laws to restrict the access to medically-assisted procreation. This is the case of Italy where a law, adopted in March 2004, ruled out the possibility for same-sex couples and for single women to seek fertility treatment or artificial insemination in the country. In the wake of these developments, the number of people seeking these kinds of treatments abroad has dramatically increased (by 20% five months after the law was approved by the Parliament). Most of people involved in this fertility “tourism” seek treatments in other EU countries such as Spain, the UK, Belgium and Austria without having access to reliable information since the law does not allow health professionals in Italy to provide patients with information on health treatments that are forbidden in the country.

Patients seeking fertility treatments abroad cannot be eligible for the reimbursement because these very treatments are not covered by the relevant National Health System. Reimbursement of fertility treatment abroad is also impossible because the Italian law does not acknowledge the distinction between hospital and non-hospital treatments with respect to the prior-authorisation and reimbursements of health care sought abroad, as set out by the European Court of Justice.²¹

²⁰ Kohll and Decker judgements (1998), Smits and Peerbooms and Vanbraekel judgments (2001), Müller-Fauré/van Riet judgement

²¹ For example Case C-368/98 Vanbraekel (2001), Case C-157/99 Smits and Peerbooms(2001), Case C-385/99 Muller-Fauré and Van Riet (2003).

Similarly, the current Portuguese law on medically-assisted procreation guarantees the access to fertility treatment and artificial insemination only to women who are either married or in a *de facto* union with a man. This leads to an increasing number of lesbian women seeking these treatments in other EU Member States.

➤ *Specific needs of transgender people*

There are reported cases of transgender people seeking surgery abroad because of the ineffectiveness of treatments in their country of residence. For instance, in Portugal a problematic issue is the unavailability of surgeries for transgender people other than those targeting genitals and breasts and those that would enable the approximation of other physical traits to those of the target gender. The lack of experience on the part of the surgeons is another very critical problem. Although gender reassignment surgery is funded by the Portuguese National Health System, the public health system is limited in its capacity to offer surgery to transgender people. As a result, some cases of transgender people undergoing repairing treatments abroad, after negative surgical experiences in Portugal, have been reported. Moreover, transgender patients are sometimes led to seek surgery abroad because of the excessive amount of time the transitional process takes in Portugal.

While acknowledging that the competence to rule over issues, such as access to fertility treatment and surgery for transgender people, relies entirely on Member States, ILGA-Europe would like to stress that:

- The right of information should be guaranteed to patients in any case, even if a treatment is not available in a given Member States;
- Promoting the cross-border mobility could make access to certain treatments more equal for patients seeking a given treatment not available in his/her country of residence.

Furthermore, although Member States have the responsibility for the organisation and delivery of health services and medical care, ILGA-Europe is convinced that they have to comply with basic principles enshrined in the EU law such as the prohibition of discrimination on the ground of sexual orientation.

Conclusion

ILGA-Europe welcomes the consideration of possible areas for Community action in relation to health services and wants to stress the potential contribution of Community action in affirming and strengthening patients' rights in the European Union. To this end, we want to recall the importance of existing international and European human rights standards as a framework in which to define the rights to which everyone in the EU should be entitled to when seeking health care, whether in one's country of residence or abroad.

In light of these comments, ILGA-Europe recommends that more research be done on the impact of cross-border health care on groups who experience discrimination, including LGBT people. We also want to encourage cooperation between the DG Health and Consumer Protection and the DG Employment, Social Affairs and Equal

Opportunities in order to link Community action in health to the EU social agenda in relation to combating discrimination and promoting social inclusion.

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