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Discrimination in Healthcare

WORKSHOP for the ENVI Committee

EN 2014



DIRECTORATE GENERAL FOR INTERNAL POLICIES POLICY DEPARTMENT A: ECONOMIC AND SCIENTIFIC POLICY

WORKSHOP

Discrimination in Healthcare

Brussels, 22 January 2014

PROCEEDINGS

Abstract

This report summarises the presentations and discussions at the Workshop on 'Discrimination in Healthcare' held at the European Parliament in Brussels on Wednesday, 22 January 2014. The aim of the workshop was to discuss the challenges faced by discriminated groups in the sector of healthcare, and the solutions taken by the EU and its Member States. The workshop was hosted by MEP Glenis WILLMOTT (S&D, UK) and MEP Alojz PETERLE (EPP, SL), Co-chairs of the Health Working Group within the European Parliament's Committee on Environment, Public Health and Food Safety (ENVI).

This document was requested by the European Parliament's Committee on Environment, Public Health and Food Safety.

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LIST OF ABBREVIATIONS

UN United Nations

ACQUIRED Immunodeficiency Syndrome

EC European Commission

ECPI Euroregional Center for Public Initiatives

ENVI Committee on Environment, Public Health and Food Safety

EU European Union

FRA European Union's Fundamental Rights Agency

GDP Gross domestic product

HIV Human Immunodeficiency Virus

ID Identity

LGBT Lesbian, gay, bisexual, and transgender

MEP Member of the European Parliament

NGO Non-governmental organisation

TasP HIV treatment as prevention

UK United Kingdom

EXECUTIVE SUMMARY

On 22 January 2014, the Committee on Environment, Public Health and Food Safety (ENVI) of the European Parliament held a workshop on 'Discrimination in Healthcare'. The workshop was hosted by Ms Glenis WILLMOTT (MEP) Mr Alojz PETERLE (MEP), Co-chairs of the Health Working Group within the ENVI Committee. The workshop was structured in two parts. The first part was dedicated to the manifestation of discrimination in the sector of health, whereas the second one focused on the measures taken to improve the situation of discriminated groups.

In her opening statement, Ms WILLMOTT highlighted that, despite being a basic right, access to healthcare is hindered by various factors in the European Union. Vulnerable groups, such as LGBT people, the Roma, migrants and people living with mental health problems are at a greater risk of discrimination. The speakers at the workshop described the scale of the problem and the measures that the different Member States have put in place to address the issue.

Mr PETERLE noted that, in addition to discrimination, patients often experience unequal situations in the sector of health. To address the problem, policy documents such as the European Health Strategy play an important role. The Strategy contains important principles, such as 'health for all' and 'health in all policies', which should be implemented.

Prof. Graham THORNICROFT, Head of Health Service Research Department at the Institute of Psychiatry, Professor of Community Psychiatry King's College of London, described the vulnerable situation of people with mental health problems. Vulnerability is mainly linked to the so-called 'treatment gap' which refers to the phenomenon that most people in the world who have mental illnesses receive no treatment. As a second issue, Prof. THORNICROFT referred to the reduced life expectancy of people with mental health problems. Higher rates of unnatural deaths, e.g. suicide and accident, and poorer healthcare, e.g. lack of treatment, contribute to premature mortality. Health inequalities and discrimination can be addressed both at local level, e.g. by increasing social interaction between health professionals and their patients, and at national level, e.g. by awareness-raising campaigns. Prof. THORNICROFT in his concluding remarks referred to the necessity of implementing existing legal and policy measures, such as the UN Convention on the Rights of Persons with Disabilities.

The presentation of the second speaker, Mr Anthony BABAJEE – a young LGBT activist, focused on the types of discrimination and health inequalities that gay men with HIV living in London face, including cases where HIV positive people disappear from the list of patients, or when general practitioners are reluctant to give them advice or refer them to the right specialists. Mr BABAJEE said that knowledge-sharing and awareness-raising play a key role in improving the situation of LGBT people in the UK. Sources similar to the FS magazine and campaigns, such as the 'It starts with me' campaign, play a key role in ensuring greater awareness. Mr BABAJEE welcomed legislative changes similar to the one which was adopted in 2013, i.e. the Health and Social Care Act 2012, as a result of which, the competence of commissioning HIV testing and prevention services has been transferred to the local authorities. In his view, local communities can commission more effective campaigns and testing work.

Marian MANDACHE, Executive Director of Romani CRISS, described the challenges that ethnic minorities, such as the Roma, face in the healthcare sector. It was explained that due to poor living conditions and the lack of financial means to eat healthy food, Roma people often have poor health conditions and, thus, are more dependent on health services.

Despite their needs, Roma people often receive poor healthcare services, as health professionals lack awareness of their culture and living conditions, and the Roma also often lack social insurance or health insurance. Mr MANDACHE referred to the most urgent forms of discrimination against the Roma, which are the forced sterilisation of Roma women, the segregation of Roma women and children in hospitals, the discrimination of Roma patients by medical staff, and the 'state-sponsored' discrimination of the Roma, e.g. placing the Roma into polluted neighbourhoods. To address these issues Mr MANDACHE highlighted: the importance of training health professionals on diversity and anti-discrimination; the necessity of taking legal steps against those who commit discrimination; and the need to invest more in projects that could have positive impacts on the Roma community.

The second part of the workshop started with the presentation of Mr Ioannis N. DIMITRAKOPOULOS, Head of Department of the Equality and Citizens' Rights, Fundamental Rights Agency of the European Union, who mainly described the applicable legislative framework and its shortcomings. Legal protection against discrimination is provided by the Charter of Fundamental Rights of the European Union, and the Equality Directives, i.e. Racial Equality Directive 2000/43/EC and Employment Equality Directive 2000/78/EC. Legislation currently in force does not provide protection to all groups who could be discriminated against, fails to extend to all sectors, and does not provide protection against discrimination on multiple grounds. According to Mr DIMITRAKOPOULOS, if adopted, the Horizontal Directive on Discrimination might resolve the existing problems.

The last speaker, Dr Gianfranco COSTANZO, Head of Unit for International Relations, of the National Institute for Health, Migration and Poverty Institute (Italy), provided a practical insight into the way the Institute tackles discrimination on a daily basis. The Institute provides cost-effective solutions to vulnerable groups, such as migrants and poor people. Dr COSTANZO said that costs linked to specialised services are lower than those linked to emergency treatments, thus providing access to specialised outpatient services was considered as a cost-effective measure. Dr COSTANZO concluded that measures should not only be cost-effective, but accessible. Regarding accessibility, he referred to physical access, e.g. suitable opening hours; relational access, e.g. health professionals speaking foreign languages; and economic access, e.g. affordable services.

In their concluding remarks, Ms WILLMOTT and Mr PETERLE emphasised the importance of the topic and called on the European Institutions to take action. Mr PETERLE highlighted the importance of workshops in helping people to become better informed; whereas Ms WILLMOTT mentioned the significance of projects that target all discriminated groups and all forms of discrimination.

1. LEGAL AND POLICY BACKGROUND

The right to health is recognised as a fundamental right in many international and European human rights instruments and in national laws. At the EU level, Article 21 of the Charter of Fundamental Rights of the European Union¹ recognises the right to non-discrimination on any ground, including race, ethnic or social origin, age or sexual orientation. Article 35 guarantees the right of access to preventive healthcare and the right to benefit from medical treatment under the conditions established by national laws and practices. Protection against discrimination is reinforced by the so-called 'Equality Directives', i.e. the Racial Equality Directive 2000/43/EC² and Employment Equality Directive 2000/78/EC³. The Racial Equality Directive provides protection from discrimination on the grounds of race or ethnic origin in various sectors, including the sector of health; whereas the Employment Equality Directive provides protection in the sector of employment to groups characterised by religion or belief, sexual orientation, disability and age. The legal protection provided by these Directives does not extend to all groups and to all sectors. Moreover, a recent FRA opinion⁴, assessing the implementation of the existing Directives shows that discrimination and health inequalities still exist across the EU.

The lack of reliable and comparable EU level health statistics makes it difficult to obtain a full picture of all discriminated groups in the sector of health. The lack of data can be explained by the fact that the Member States are not obliged to collect data systematically in the sector of health. Existing data, targeting one discriminated group, e.g. LGBT people or the Roma, well-illustrates the scale and nature of the problem. For example, a recent FRA survey⁵ revealed that twice as many Roma women aged 50 and above, declared their health conditions as 'poor' or 'very poor' compared to non-Roma women of the same age group. Another survey⁶ found that one in 10 of the respondents who had accessed healthcare services, in the year preceding the survey, reported discriminatory practices. The collection of reliable statistics, including disaggregated data, would help to create better-targeted policy and legal measures⁷.

The Charter of Fundamental Rights of the European Union (2000/C 364/01) is available at: http://www.europarl.europa.eu/charter/pdf/text_en.pdf.

Council Directive 2000/43/EC of 29 June 2000 implementing the principle of equal treatment between persons irrespective of racial or ethnic origin, OJ L 180, 19.7.2000, p. 22–26, available at: http://eur-lex.europa.eu/LexUriServ/LexUriServ.do?uri=OJ:L:2000:180:0022:0026:EN:PDF.

³ Council Directive 2000/78/EC of 27 November 2000 establishing a general framework for equal treatment in employment and occupation, OJ L 303, 2.12.2000, p. 16–22, available at: http://eur-lex.europa.eu/LexUriServ/LexUriServ.do?uri=OJ:L:2000:303:0016:0022:EN:PDF.

FRA Opinion on the situation of equality in the European Union 10 years on from initial implementation of the equality directives, available at: http://fra.europa.eu/en/opinion/2013/fra-opinion-situation-equality-european-union-10-years-initial-implementation-equality.

FRA, 'Analysis of FRA Roma survey results by gender', available at: http://fra.europa.eu/sites/default/files/ep-request-roma-women.pdf.

FRA, 'European LGBT survey- European Union lesbian, gay, bisexual and transgender survey'- Results at a glance, available at: http://fra.europa.eu/sites/default/files/eu-lgbt-survey-results-at-a-glance_en.pdf.

Source: http://fra.europa.eu/en/speech/2013/improving-access-and-combating-discrimination-healthcare-focus-vulnerable-groups-fra.

Health inequalities⁸ and discrimination in the sector of health have significant economic implications for the EU and its Member States. A recent European Parliament resolution suggests that 'losses linked to health inequalities have been estimated to cost around 1,4% of the total GDP⁹. The European Commission document 'Investing in health'¹⁰, accompanying the Commission Communication 'Towards Social Investment for Growth and Cohesion'¹¹ shows how investment in reducing health inequalities contributes to the achievement of the Europe 2020 objective of smart, sustainable and inclusive growth. The proposed Health for Growth Programme¹², continuing to promote the principles and objectives of the EU's 2008-2013 'Together for Health' Strategy, i.e. 'health for all' and 'health in all policies'¹³, also acknowledges the importance of reducing health inequalities in order to achieve inclusive growth.

In terms of legislative developments, the Horizontal Directive¹⁴, if adopted, might address issues linked to health discrimination, by extending legal protection to discrimination in healthcare on all grounds, including disability, age and sexual orientation. The European Commission's proposal for the new Directive has been blocked in the Council since 2008.

The obligation for the EU to strengthen protection against discrimination will be reinforced once the EU accesses the European Convention on Human Rights. EU accession to the European Convention is required by Article 6(2) of the Treaty on the European Union¹⁵. The European Convention on Human Rights provides that the enjoyment of rights must be secured without discrimination on any grounds¹⁶. Moreover the European Social Charter¹⁷, complementing the European Convention on Human Rights, guarantees the right to health.

Protection against discrimination, including discrimination in the sector of health, is also enshrined in international conventions, e.g. the United Nations Convention on the Rights of Persons with Disabilities¹⁸ which the EU ratified in 2010. The ratification of this Convention entails that EU institutions and the Member States must consider and comply with the provisions of the Convention whilst developing and implementing laws and policies.

The term 'health inequalities' means differences in health status between individuals or groups, as measured by for example life expectancy, mortality or disease. More information is available at:

http://ec.europa.eu/health/archive/ph_determinants/socio_economics/documents/com2009_qa_en.pdf.

European Parliament Resolution of 8 March 2011 on reducing health inequalities in the EU (2010/2089(INI), available at:

 $[\]underline{http://www.europarl.europa.eu/sides/getDoc.do?type=REPORT\&reference=A7-2011-0032\&language=EN.}$

Commission Staff Working Document 'Investing in Health' accompanying the document 'Towards Social Investment for Growth and Cohesion- including implementing the European Social Fund 2014-2020' (SWD(2013)43 final), available at: http://ec.europa.eu/health/strategy/docs/swd investing in health.pdf.

Communication from the Commission to the European Parliament, the Council, the European Economic and Social Committee and the Committee of the Regions 'Towards Social Investment for Growth and Cohesion-including implementing the European Social Fund 2014-2020' (COM(2013) 083 final), available at: http://eur-lex.europa.eu/LexUriServ/LexUriServ.do?uri=CELEX:52013DC0083:EN:NOT.

The Health for Growth Programme 2014-2020 is currently subject to negotiations and is expected to be adopted in Spring 2014. More information on the proposed programme is available at: http://ec.europa.eu/health/programme/policy/2014-2020/state of play en.htm.

White Paper, Together for Health- A Strategic Approach for the EU 2008-2013, COM (2007) 630 final, available at: http://ec.europa.eu/health-eu/doc/whitepaper en.pdf.

Proposal for a Council Directive on implementing the principle of equal treatment between persons irrespective of religion or belief, disability, age or sexual orientation, COM (2008) 0426 final, available at: http://eur-lex.europa.eu/LexUriServ/LexUriServ.do?uri=COM:2008:0426:FIN:EN:PDF.

¹⁵ Treaty on European Union, OJ C 326, 26.10.2012, available at:

http://eur-lex.europa.eu/en/treaties/new-2-48.htm.

Article 14 of the European Convention on Human Rights, available at: http://www.echr.coe.int/Documents/Convention ENG.pdf.

The European Social Charter is available at: http://conventions.coe.int/Treaty/en/Treaties/Html/035.htm.

The United Nations Convention on the Rights of Persons with Disabilities is available at: http://www.un.org/disabilities/convention/conventionfull.shtml.

2. PROCEEDINGS OF THE WORKSHOP

2.1 Introduction

2.1.1 Welcome and opening – Glenis WILLMOTT (MEP) and Alojz PETERLE (MEP)

In her opening remarks Ms Willmott emphasised that despite being a basic right, access to healthcare is hindered by various factors in the EU, one of which is discrimination. Discrimination has many forms and may target many groups of people, including LGBT, Roma, migrants and people living with mental health problems. Ms Willmott commented that the speakers in this workshop represented many of the most vulnerable groups.

To illustrate the scale of the problem, Ms Willmott referred to a recent report of the European Union's Fundamental Rights Agency (FRA)¹⁹, which found that, in the EU, an average of 42% of LGBT patients are not open with their healthcare professionals about their sexual orientation or gender identity, and 10% of the total of LGBT patients feel that they have been discriminated against by healthcare personnel in the past 12 months.

Regarding discrimination against minority groups, a FRA report stated that, in the Czech Republic, 18% of the Roma population have experienced discrimination in healthcare²⁰. Ms Willmott also referred to a recent UK report²¹, which found that 51% of older people feel that healthcare providers dismiss symptoms and treat them as those linked to old age, instead of looking for the real cause behind their diseases. Before handing over to Mr Peterle, Ms Willmott called on the speakers of this workshop to describe the scale of the problem in a more detailed manner and she expressed her hopes for an interesting discussion.

Mr Peterle approached the topic from the citizens' perspective by saying that 'no one likes discrimination'. Regarding the definition of discrimination, he clarified that not all differentiated treatment is actually discrimination. Nevertheless, even those cases are unpleasant when one experiences differentiated treatment. To illustrate this, he referred to the higher life expectancy of those citizens who live in countries with stronger healthcare systems, as opposed to those who are from countries with less developed healthcare systems.

He also said that information on specialised care, such as cancer treatment, is not always shared across the Member States. The European Union plays a key role in addressing these issues. One of the steps taken to tackle the problem, is the adoption of the European Health Strategy, in which the EU has put forward two very important principles, which are 'Health for All' and 'Health in all Policies'. Discrimination can be eliminated through the implementation of these principles. Mr Peterle finished by welcoming the speakers who represented many groups that are discriminated against in the EU. He emphasised, however, that there are many other groups, such as cancer patients, who also experience discrimination in the sector of health.

¹⁹ FRA 'EU LGBT survey- European Union lesbian, gay, bisexual and transgender survey- Results at a glance', available at: http://fra.europa.eu/sites/default/files/eu-lgbt-survey-results-at-a-glance_en.pdf.

FRA 'Inequalities and multiple discrimination in access to and quality of healthcare', available at: http://fra.europa.eu/sites/default/files/inequalities-discrimination-healthcare_en.pdf.

Department of Health 'Ageism and age discrimination in secondary healthcare in the United Kingdom', available at: http://www.cpa.org.uk/information/reviews/CPA-ageism and age discrimination in secondary health care-report.pdf.

2.2 How does discrimination affect people? Who is affected?

2.2.1 Evidence to decrease mental health related stigma and discrimination

Prof. Graham THORNICROFT, Head of Health Service Research Department at the Institute of Psychiatry, Professor of Community Psychiatry King's College of London (UK)

Prof. Thornicroft's presentation was structured around three main ideas, notably the concept of a mental health gap, the link between mental diseases and premature mortality, and the overview of existing policy actions and practices.

Prior to describing the meaning of 'mental health gap', Prof. Thornicroft illustrated the scale of the problem of mental health related stigma and discrimination by saying that each year about a quarter of the total world population develops a mental disease. Across the globe, about 600 million people live with mental illnesses and, every year, about 900 thousand people kill themselves, i.e. around 3,000 people committing suicide each day. Prof. Thornicroft said that, in Europe, only 25% of people with mental illnesses receive medical treatment, whereas the other 75% remain without treatment.

Prof. Thornicroft defined this situation as a 'mental health gap'²². He continued by discussing the World's Mental Health Survey²³, which compared the treatment of patients with mental and physical disorders in both low and high-income countries. The data suggested that more than 50% of patients with physical disorders are receiving treatment even in the poorest countries, compared to only 10% of patients with mental disorders receiving treatment. These numbers illustrate the scale of the stigmatisation and discrimination that people with mental illnesses face in both low and high income countries.

According to Prof. Thornicroft an important manifestation of stigmatisation and discrimination is the premature mortality of people with mental disorders. Despite counter opinion of certain policy makers, mental diseases actually kill people each year. To prove this, Prof. Thornicroft quoted from a recent research paper²⁴ analysing the life-expectancy of patients with mental disorders in three Scandinavian countries. The research showed that in Finland, Denmark and Sweden, 15-year old women with mental illnesses are expected to live 15 years less on average than those without such diseases. For men from the same age group, the life-expectancy difference was 20 years. He also emphasised that disparities between the life-expectancy of healthy and mentally ill people are not narrowing over time; and interestingly, there are many articles with almost identical conclusions to the Scandinavian research paper that are published across the globe, including in Australia²⁵. To conclude this part of the presentation Prof. Thornicroft said that, in his view, lack of treatment was responsible for the premature death of many mentally ill patients and that this was the 'worst form of lethal discrimination'.

Robert Kohn, Shekhar Saxena, Itzhak Levav, & Benedetto Saraceno 'The treatment gap in mental health care', available at: http://www.who.int/bulletin/volumes/82/11/en/858.pdf; Wang, P. S., et al (2007) Lancet, 370, 841-850 'Delay and failure in treatment seeking after first onset of mental disorders in the World Health Organisation's World Mental Health Survey Initiative', available at: http://www.ncbi.nlm.nih.gov/pmc/articles/PMC2174579/; Thornicroft, G. (2007) Lancet, 370, 807-808 'Most people with mental illness are not treated', available at: http://www.thelancet.com/journals/lancet/article/PIIS0140-6736(07)61392-0/fulltext#article_upsell.

Ormel J. et al (2008) British Journal of Psychiatry, 192, 368-375 'Disability and treatment of specific mental and physical disorders across the world', available at: http://bjp.rcpsych.org/content/192/5/368.full.pdf+html.

physical disorders across the world', available at: http://bjp.rcpsych.org/content/192/5/368.full.pdf+html.

Wahlbeck K, Westman J, Nordentoft M, Gissler M, Laursen TM. 'Outcomes of Nordic mental health systems: life expectancy of patients with mental disorders', available at: http://www.ncbi.nlm.nih.gov/pubmed/21593516.

Before describing the possible actions that could be taken to address mental health discrimination, Prof. Thornicroft referred to one of his recent books²⁶ dedicated to the discrimination of people with mental illness. He said that his original intention was to write only about stigmatisation, but whilst discovering the scale of the problem he realised that stigmatisation and discrimination were interlinked. Prof. Thornicroft said that stigmatisation results from three different elements, namely lack of knowledge, misinformation and ignorance; emotional motives, such as fear, prejudice and anxiety, towards people with mental illnesses; and behavioural aspects, which he referred to as discrimination.

Discrimination in the sector of healthcare can be addressed at both local and national levels. At the local level, there is room for applying the so-called 'social contact theory'. According to the theory that dates back to 1924, direct and personal social contact with individuals of stigmatised groups is effective in reducing stigma. To test the theory, many intervention studies have been conducted, showing that active contact between health professionals and patients, increases knowledge, improves attitudes and behaviours, and reduces stigma. Other means of effective social contact include filming interviews with mental health patients, or live consumer talks. At national level, effective means of interventions include programmes similar to 'Time to Change'27, which aims to improve public attitudes towards people with mental health problems through, for example, campaigns. The evaluation of the first four years progress led by Prof. Thornicroft, shows that discrimination has dropped by about 11% over time. 'Time to Change' has recently formed the so-called Global Alliance of Stigma, comprising mainly of countries with national level intervention programmes. The Alliance is a platform for knowledge sharing, and for the exchange of good practices. The support of prominent celebrities is also a helpful measure, as celebrities can motivate people to fight against stigmatisation and discrimination. For example, Glenn Close addresses major conferences about confronting stigma in mental health.

Amongst the policy and legal measures, Prof. Thornicroft referred to the necessity of implementing the provisions of the UN Convention on the Rights of Persons with Disabilities. Prof. Thornicroft said that this Convention, which has been ratified by most of the countries across the globe, is a powerful tool to fight against the discrimination of people with any type of disability. Finally, Prof. Thornicroft mentioned the so-called 'ITHACA toolkit'²⁸ which could be used to monitor respect for human rights and general healthcare in psychiatric and social care institutions.

BMJ 2013;346:f2539 'The gap in life expectancy from preventable physical illness in psychiatric patients in Western Australia: retrospective analysis of population based registers', available at: http://www.bmj.com/content/346/bmj.f2539.

Prof. Thornicroft 'Shunned: Discrimination against People with Mental Illness', available at: http://www.globalmentalhealth.org/resources/shunned-graham-thornicroft.

Time to Change' is England's biggest programme to challenge mental health stigma and discrimination. It has been running since 2007 with a total budget of about 20 million pounds. More information on the 'Time to Change' programme is available at: http://www.time-to-change.org.uk/.

More information is available at: http://www.mdac.info/sites/mdac.info/files/ithaca_toolkit_english.pdf.

2.2.2 Discrimination in healthcare based on sexual orientation

Mr Anthony BABAJEE, LGBT activist

Mr Babajee started his presentation by describing the 'It starts with me' campaign²⁹, which is a national campaign in England of the Terrence Higgins Trust³⁰. The campaign aims to stop the spread of HIV by communicating messages about the importance of protection by means of HIV testing, the use of condoms and HIV treatment as prevention³¹ (TasP). As part of the campaign National HIV Testing Week takes place in the last week of November each year – the week before World Aids Day. Mr Babajee, while referring to the importance of testing, stated that gay men and people with African origins are disproportionally affected by HIV in the UK. His presentation mainly focused on the types of discrimination and health inequalities that gay men with HIV living in London face, but he stated that these examples can be used by analogy to the sorts of discrimination and inequalities that other groups within the broader LGBT community face.

Mr Babajee said that knowledge-sharing and awareness-raising play a key role in improving the situation of LGBT people in the UK. Sources, similar to FS magazine³², provide particularly valuable information to gay people. Mr Babajee was recently featured in an article in FS magazine about gay community role models, where he tells his own story of living openly with HIV and campaigning for better awareness. He emphasised that articles published in the FS magazine are non-judgmental, thus they meet gay men where they are in their lives rather than telling them where they should be. The stories are also relevant and real, and manage to talk about sex and sexual heath in appropriate and everyday language. Another positive element he mentioned was that the magazine tackles hot topics, such as unprotected sex, or sexualised drug-taking and sexual racism, that health professionals are often reluctant to talk about or do not know how to address effectively. Moreover, stories in the magazine are thought-provoking and informative, thus encourage gay men to consider their own actions.

Mr Babajee then continued by giving an overview of the situation of HIV-positive people in the UK. In 2012, about 98,400 people were living with HIV in the UK, of these about 22% were unaware of their HIV infection. Considering this, it is of particular importance to get HIV testing rates up. Regarding this point, Mr Babajee talked about a recent legislative change in England (the Health and Social Care Act 2012³³), as a result of which since April 2013 the competence of commissioning HIV testing and prevention services, has been transferred to local authorities. Prior to this change, testing was commissioned by National Health Service (NHS) according to the needs of each local area with particular regard to HIV prevalence rates. The challenge after this shift of control over commissioning is to make sure that the local authorities do commission the most effective campaign and testing work.

²⁹ More information on the 'It starts with me' campaign, is available at: https://www.tht.org.uk/itstartswithme.

Terrence Higgins Trust is an NGO which aims at maximising sexual health in the UK and minimising the spread of HIV. More information on the NGO is available at: http://www.tht.org.uk/our-charity/About-us/Our-mission.

Treatment as prevention (TasP) is a HIV prevention method that uses antiretrovial therapy in HIV-positive persons to decrease the chance of HIV transmission. More information is available at: http://whqlibdoc.who.int/hq/2012/WHO_HIV_2012.12 eng.pdf.

FS is a bi-monthly magazine containing information on gay men's health and HIV related issues. More information on the magazine is available at: http://www.gmfa.org.uk/Sites/fsmagazine/pages/about-fs.

Health and Social Care Act 2012 is available at: http://services.parliament.uk/bills/2010-11/healthandsocialcare.html.

This is a challenge, as many local councillors have only limited understanding of the scale of the problem, and HIV and sexual health can often be nearer to the bottom of a politician's list of political priorities. Civic organisations, such as the Terrence Higgins Trust, play a key role in sharing the knowledge with the local authorities.

As an example of the actions at the local level, Mr Babajee referred to the 'HIV needs assessment' commissioned by London Councils³⁴ in 2013. The needs assessment found that there is a need for more targeted work, aiming at the most affected communities, such as gay and black African men. To increase effectiveness, it was decided to involve members of such communities in the work. Moreover, the assessment found that target groups find the currently available information irrelevant and often too medicalised, thus there is a need for the use of more effective and rather conversational language. Mr Babajee found it regrettable that FS magazine had not been commissioned by London Councils.

To conclude, Mr Babajee provided some examples about the types of discrimination that he has experienced while accessing health services. First he referred to a case, when he, after disclosing his HIV-positive status to a dentist, suddenly and inexplicably disappeared from the list of patients³⁵. In another anecdote, Mr Babajee illustrated the ignorance that many gay men face when accessing primary healthcare services. He developed depression around the time when he was diagnosed with HIV. His general practitioner could not provide any sort of advice to him and was seemingly unable to make a referral for him to competent specialists. Through this example Mr Babajee also aimed to illustrate that health professionals often forget about the fact that LGBT people are, first and foremost, people. To tackle these issues there is a need for improved communication between healthcare professionals and minority groups, such as LGBT people. Communication with LGBT people will help them understand the needs of this community and allow them to better support them. Another area in which healthcare professionals can improve their skills is the use of and understanding of new technologies, such as smartphone applications. LGBT people use these applications extensively, especially gay men, in their everyday life, e.g. to find information and to meet each other.

To wrap up Mr Babajee emphasised the need for right, non-judgemental services tailored to the type of people they are caring for.

2.2.3 Racial and ethnic factors as determinants of healthcare

Mr Marian MANDACHE, Executive Director Romani CRISS

Mr Mandache opened his presentation with a brief description of the Roma community and the main issues that they face. The Roma are an ethnic group originating from India. They are widely dispersed, with the majority living in Europe. Over the centuries, The Roma have repeatedly been subject to persecution, in particular during the five centuries of the Romanian Principalities³⁶, and the Holocaust during the Second World War. Nowadays, the Roma are often socially marginalised and face challenges whilst exercising their rights, including the right to free movement. Mr Mandache remarked that in Europe, the Roma community is the most impoverished and discriminated against.

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London Councils is an umbrella organisation working for each of the London borough councils. More information on the London Councils is available at: http://www.londoncouncils.gov.uk/aboutus/default.htm.

Discrimination by dentists based on HIV status is illegal in the UK. More information is available at: http://www.tht.org.uk/myhiv/HIV-and-you/Your-healthcare/Dental-care.

Roma people were subject to slavery during the period of the Romanian Principalities. This era started in the 13th and 14th century, until it was abolished in the 19th century.

Amongst the main health challenges that the Roma face, Mr Mandache referred to their poor health conditions developed as a result of their living conditions – often in polluted environments. The public authorities often place Roma communities close to garbage pits or waste treatment plants, which according to Mr Mandache, constitutes environmental discrimination. Other health issues are linked to malnutrition in Roma communities where they often lack the financial means to eat healthy food and to maintain a minimum level of hygiene. Mr Mandache also referred to the lack of awareness by the health professionals of Roma culture and living conditions.

He went on to explain the causes and consequences of the Roma not being able to have social insurance. The Roma often do not have papers, such as IDs or birth certificates, therefore making it impossible to obtain social insurance for themselves and their families. In Romania, social insurance is granted to those with legal work contracts or those who are granted social welfare. However, due to the current financial crisis, the Government aims to cut costs which might change the criteria used to grant social insurance and health coverage. These changes are likely to affect Roma communities, but to overcome this issue Romania might introduce basic insurance packages specifically for the Roma. These are likely to cover only some life-saving treatments and the treatment of epidemic diseases. Mr Mandache emphasised that health services often have cost implications which the Roma people cannot cover. These costs can be both direct, e.g. medical insurance and medication, and/or indirect, e.g. transportation costs.

Mr Mandache continued by referring to the major forms of discrimination that the Roma face. The most urgent forms include the forced sterilisation of Roma women, the segregation of Roma women and children in hospitals, the discrimination of Roma patients by medical staff, and the 'state-sponsored' discrimination of the Roma. Mr Mandache provided examples of these types of discrimination.

Regarding the sterilisation of Roma women, he referred to the practices followed in Czechoslovakia between 1971 and 1991, which were conducted to reduce the size of the Roma population. Sterilisations were often carried out without the consent of Roma women during Caesarean sections or abortions.

Mr Mandache stated that the segregation of Roma patients in hospitals is common practice in many Central and Eastern European countries, e.g. in Hungary, Slovakia and Romania. In 2011 Romani CRISS, together with ECPI reported a case of segregation in the Marie Curie Hospital in Bucharest³⁷ where Romani patients were being placed in rooms different to those for other citizens. The report followed a prosecution and the case is currently pending before a court.

Regarding the discrimination of the Roma by health professionals, Mr Mandache referred to various discriminatory practices, including the examination of Roma patients after the examination of all non-Roma patients, the use of derogatory language, the redirection of Roma patients to health providers that were located far from their homes, and the failure to provide health information about the health risks associated with certain conditions or health interventions.

More information on the case is available at: http://www.romanicriss.org/PDF/Press%20release%20children%20segregation%20in%20hospital%20Marie%20Curie%20dec%202011.pdf.

As a wider issue of concern, Mr Mandache described the concept of 'systematic state-sponsored racism'. He suggested that many European Governments, e.g. the French Government, put in place racist measures by which they undermine the living conditions of the Roma. As an example, he referred to measures ordering the destruction of their homes. He also suggested that in some countries, such as in Romania, the Governments turn a blind eye to the racist actions of local authorities against the Roma – which is equally destructive.

Mr Mandache continued by stating that even the Fundamental Agency of the European Union has found the situation of the Roma 'shocking'. A recent FRA survey found that over 20% of Roma people are not covered by health insurance and that 90% of them live below the national poverty lines³⁸.

Against this context, Mr Mandache suggested some actions. He emphasised the importance of training health professionals on diversity and anti-discrimination. There is a need to train health professionals in a similar manner to the health mediators³⁹ who have been operating in Romania since 2002. He commented that priorities need to be reconsidered whilst distributing resources since there is less need to invest in research and more need to take real actions with direct positive impact on the Roma communities.

Mr Mandache emphasised the possibility of legal remedies, e.g. litigating on the ground that discrimination has occurred, and called on the European Commission to start infringement actions against certain Member States, and to provide funding for litigation on the ground of discrimination. As a final remark, Mr Mandache referred to the necessity of exploring the possibility of suspending EU funding to those Member States that breach fundamental rights by engaging in systematic discrimination, or fail to implement national Roma strategies.

2.2.4 First round of questions and answers

This section started with the observations of Michael CASHMAN, a Member of the European Parliament and Co-Founder of Stonewall⁴⁰, who opened with the statement that the common elements of the situations that the speakers have already talked about are ignorance and prejudice. To illustrate the situation of the LGBT community in Europe, he quoted the singer Madonna, who once said that coming out as an LGBT is a heroic thing to do, and those who declare themselves as HIV positive are warriors. Mr CASHMAN clarified that it takes courage to declare either of them, and that both groups face stigmatisation and discrimination. Regarding the other groups, he referred to the difficult situation of the Roma and mentally ill people, who also face prejudice and ignorance in their everyday lives.

FRA 'The situation of Roma in 11 EU Member States - Survey results at a glance', available at: http://fra.europa.eu/en/publication/2012/situation-roma-11-eu-member-states-survey-results-glance.

³⁹ Health mediators are professionals who support Roma people in their access to healthcare services with the aim of improving the health status of Roma. Source: World Health Organization, 'Roma health mediation in Romania', available at: http://www.euro.who.int/ data/assets/pdf file/0016/235141/e96931.pdf.

Stonewall is a UK based lesbian, gay and bisexual rights charity formed in 1989 by political activists and others lobbying against section 28 of the Local Government Act. More information on Stonewall is available at: https://www.stonewall.org.uk/.

According to Mr CASHMAN, these people should be supported in the form of education and training, since this is the only way to empower them with the necessary knowledge of their rights. All groups that are discriminated against should uphold their rights, e.g. Roma people should be educated so that they can fight for their right to be registered.

Mr CASHMAN said that funds could be sought from the EU; however he warned that it is easier to gain funding for specific projects and plans than for individual proposals. He advised all of the groups to team up and launch a joint programme against discrimination. Regarding this possible joint programme, he suggested simple banner headings, such as 'Discrimination Kills', which represents the issue that ultimately affects everyone, regardless of the discriminated group.

To conclude, Mr CASHMAN called on the European Institutions to start actions against the Member States where discrimination is the most prevalent. He reminded the audience of the legal possibilities of infringement proceedings and petitions.

The second round of observations was made by Angelika WERTHMANN, a Member of the European Parliament, who expressed her support for a joint programme similar to that suggested by Mr CASHMAN. She highlighted the need for a programme that represents all discriminated groups, addresses all forms of discrimination and is cross-sectoral.

Ms WERTHMANN then described the type of activities that the European Parliament's Petition Committee might do for people who experience discrimination. She referred to a recent petition filed with the Committee by the World Blind Union⁴¹. The petition was filed on the ground that visually impaired people face discrimination in their everyday lives. For example, visually impaired people have only a few books available on the market that they can read, as opposed to the millions of books to which healthy citizens have access. Discrimination breaches European values and laws, including the Charter of Fundamental Rights of the European Union.

The third question was posed by Ann Isabelle VON LINGEN, representing the European AIDS Treatment Group⁴². She referred to the complexity of discrimination and, in particular, to the fact that discrimination often occurs as a result of numerous and varied factors. As an example, she referred to the lack of testing of LGBT people. She said that doctors often fail to prescribe HIV tests to their patients, as they are unaware of their sexual orientation or sexual practices.

This situation could be overcome by enhancing dialogue at the local level and, regarding this point, she referred to a recent project in Berlin which aims to intensify dialogue between patients and their doctors. She warned, however, that projects similar to this are time-consuming and, thus, there is a need to develop other actions, e.g. the improvement of community-based services which can provide tailored-made services, e.g. counselling and specific tests for HIV and syphilis which are spreading amongst the gay community.

Regarding the role of the EU, she referred to the need of training activists and lawyers who can enforce the right for protection against discrimination. She also called on the EU to establish recommendations or guidelines for administrative authorities dealing with the most vulnerable groups, e.g. undocumented migrants. Undocumented migrants often face administrative burdens and have no access to social or healthcare services.

More information on the petition is available at: http://www.europarl.europa.eu/news/en/news-room/content/20120216IPR38346/html/Binding-rules-to-ensure-blind-people's-access-to-books.

More information on the European AIDS Treatment Group is available at: http://www.eatg.org/aboutus.

Amongst the speakers, Prof. THORNICROFT commented on the difficulty of disclosing mental problems in Europe. He argued that people often feel ashamed to declare themselves as mentally ill. In the UK, some politicians have recently disclosed their own mental problems. He was not aware of any such case at the European Parliament. Prof. THORNICROFT welcomed the idea of launching a joint programme against discrimination that addresses all forms of discrimination and represents all groups that are discriminated against.

Mr BABAJEE welcomed the banner head line 'Discrimination Kills'. Based on what he had heard from previous speakers he realised that, regardless of the group, the forms of discrimination are the same, e.g. disclosure of a certain state seems to be difficult for all groups.

Regarding non-disclosure, Mr MANDACHE described the situation of the Roma in Romania. In 2011 there was a survey conducted in Romania where people were asked about their ethnicity. The results show that many people with Roma origins did not declare themselves as Roma. Mr MANDACHE explained that Romani CRISS conducted a study to understand the reasons behind the results. They found that many people failed to make such a declaration for fear of marginalisation and discrimination. Another reason was the lack of knowledge, as many Roma were unaware of the meaning of the term 'ethnicity' which was used in the survey. Mr MANDACHE also stated that highly educated Roma often hide their ethnic origin because they fear that, as Roma persons, they would not be as successful.

The second part of the workshop, dedicated to the topic 'Developing Policies' was introduced by Mr PETERLE. This part was presented by representatives of the European Union's Fundamental Agency and a medical doctor representing the Italian Institute for Health, Migration and Poverty. He stressed that the second part of the workshop focused on the types of measures that are available to address discrimination. Prior to handing over to the speakers, he commented that problems in the healthcare sector often arise from the lack of respect towards each other, and amongst the potential measures, he referred to the important role played by education.

2.3 Developing policies

2.3.1 Multiple discrimination in healthcare

Mr Ioannis N. DIMITRAKOPOULOS, Head of Department Equality and Citizens' Rights, EU Agency for Fundamental Rights (FRA)

Access to healthcare is a fundamental right, and is recognised by many international and European legal instruments as well as by Member States' legislation. Article 21 of the Charter of Fundamental Rights of the EU recognises the right to be free from discrimination, including on the grounds of sex, racial or ethnic origin, religion or belief. Article 35 quarantees the right of access to preventive healthcare and the right to benefit from medical treatment under the conditions established by national laws and practices. These principles should be safeguarded by the EU Member States. Despite the legal obligations in place, practices differ across the EU. Research shows that persons belonging to ethnic minorities and, in particular, Roma people, migrants (especially irregular migrants), pregnant women and children, often experience inequalities while accessing healthcare services⁴³. To overcome this situation the EU Health Strategy⁴⁴ aims to remove and reduce all health inequalities. Removing such inequalities becomes more important today as European healthcare systems are struggling to balance conflicting considerations of cost and public health concerns. The economic crisis and an ageing population present considerable challenges to Member States trying to reduce public spending, including healthcare and, at the same time, fulfilling their duty to protect the right to health. This is particularly important in the context of the EU 2020 Strategy for growth⁴⁵ which is underpinned by commitment to high-quality healthy lives and the removal of healthcare inequalities in order to ensure that everybody can benefit from growth. Regarding this point, Mr Dimitrakopoulos stated that it is a Member State competence to define the appropriate health policies and legislation, to manage health expenditure, to allocate resources in line with the obligation arising from EU law - which is to ensure that no one is directly or indirectly discriminated against when accessing healthcare. FRA has recently published an opinion⁴⁶ on the implementation of the Equality Directives⁴⁷, and concluded that barriers and inequalities still exist. According to Mr Dimitrakopoulos the adoption of the Horizontal Directive⁴⁸ on discrimination might resolve some of the problems by extending protection against discrimination to all grounds and all sectors, including health.

E.g. Results of EU-MIDIS provide examples to health inequalities, which is available at: http://fra.europa.eu/en/project/2011/eu-midis-european-union-minorities-and-discrimination-survey.

White Paper, Together for Health: A Strategic Approach for the EU 2008-2013, COM (2007) 630 final, available at: http://ec.europa.eu/health-eu/doc/whitepaper_en.pdf.

Communication from the Commission, Europe 2020- A Strategy for smart, sustainable and inclusive growth, COM(2010) 2020 final, available at: http://eur-lex.europa.eu/LexUriServ/LexUriServ.do?uri=COM:2010:2020:FIN:EN:PDF.

FRA Opinion on the situation of equality in the European Union 10 years on from initial implementation of the equality directives, available at: http://fra.europa.eu/en/opinion/2013/fra-opinion-situation-equality-european-union-10-years-initial-implementation-equality.

⁴⁷ Racial Equality Directive 2000/43/EC and Employment Equality Directive 2000/78/EC.

Proposal for a Council Directive on implementing the principle of equal treatment between persons irrespective of religion of belied, disability, age or sexual orientation, COM/2008/0426 final, available at: http://eur-lex.europa.eu/Notice.do?checktexts=checkbox&val=473800.

Mr Dimitrakopoulos explained that the fulfilment of the fundamental right to health concerns three important interrelated issues, the first of which is health inequalities. Health inequalities mainly concern people with lower educational levels, job status or income, as they often live and work in less favourable conditions, face more diseases, receive poor quality healthcare and often die young. To illustrate the poor health conditions of the most vulnerable groups, Mr Dimitrakopoulos said that there is abundance of evidence highlighting the very poor living and working conditions of many migrants and ethnic minorities, including the Roma. A recent FRA survey⁴⁹, targeting the Roma in 11 Member States, revealed that one out of three respondents aged 35 to 54 felt that their health problems limited their daily activities. Another survey found that twice as many Roma women aged 50 and above, declare their health conditions as 'poor' or 'very poor' compared to non-Roma women of the same age group⁵⁰. Situations similar to these are considered as manifestations of health inequalities.

As a second issue limiting the right of access to healthcare, Mr Dimitrakopoulos referred to the lack of universal health coverage, which according to the World Health Organization is necessary to ensure that all people obtain health services⁵¹. To scale the problem, Mr Dimitrakopoulos mentioned a recent FRA briefing⁵², which found that almost 20% of the Roma do not have medical insurance, or they do not know if they are covered by any medical insurance. Mr Dimitrakopoulos also illustrated the vulnerable situation of irregular migrants by stating that, in 19 EU Member States, irregular migrants are entitled to receive only emergency healthcare services⁵³; moreover in 11 out of 19 Member States, irregular migrants are asked to pay for emergency healthcare. In Mr Dimitrakopoulos's view, despite the fact that it is a human rights obligation for the Member States to allow access to their healthcare services, they are reluctant to do so, due to its possible financial implications. FRA finds that a lack of evidence on the financial implications of delaying treatment of irregular migrants is blocking policy makers from promoting access to healthcare for this group. Moreover, cost-effectiveness is one of the discussion topics of the current debates on access to necessary healthcare for irregular migrants. To provide evidence of the financial benefits of providing access to healthcare services, FRA has recently conducted a study comparing the costs of emergency treatments and timely interventions⁵⁴. The results showed that costs linked to early intervention were lower than those linked to emergency treatment. Thus, Mr Dimitrakopoulos concluded that the promotion of access to healthcare should be seen as a cost-effective measure.

⁴⁹ FRA, 'The situation of Roma in 11 EU Member States', available at: http://fra.europa.eu/sites/default/files/fra_uploads/2099-FRA-2012-Roma-at-a-glance_EN.pdf.

FRA, 'Analysis of FRA Roma survey results by gender', available at: http://fra.europa.eu/sites/default/files/ep-request-roma-women.pdf.

Universal health coverage is a goal to ensure that all people obtain the health services they need without suffering financial hardship when paying for them. More information is available at: http://www.who.int/features/ga/universal health coverage/en/index.html.

FRA Brief: Data on discrimination of Roma and anti-Roma crime, available at:

http://www.statewatch.org/news/2013/mar/eu-roma-fra-briefing.pdf.

FRA 'Migrants in an irregular situation: Access to healthcare in 10 European Union Member States', available at: http://fra.europa.eu/sites/default/files/fra_uploads/1771-FRA-2011-fundamental-rights-for-irregular-migrants-healthcare_EN.pdf.

More information is available at: http://fra.europa.eu/en/call-for-tender/2012/negotiated-procedure-case-study-cost-exclusion-healthcare.

The third aspect of access to healthcare was linked to barriers and discrimination. Mr Dimitrakopoulos first clarified that the notions of 'barriers' and 'discrimination' were distinct. 'Discrimination' was defined as the unequal treatment of a person because of one or more personal characteristics, such as age, disability, sexual orientation, religion or belief. 'Barriers' include mechanisms or structures that impede or delay access to health services, or which reduce their quality or effectiveness. To illustrate the difference, Mr Dimitrakopoulos referred to service costs applied in a uniform manner, which could be seen as barriers - but not as manifestations of discrimination. Some barriers, however, constitute instances of indirect discrimination⁵⁵. Mr Dimitrakopoulos said that 'one-size-fitsall' measures often result in indirect discrimination. For example, a person with intellectual disability cannot receive the same treatment as a healthy patient, as they cannot communicate with the healthcare providers in the same way as others. Therefore, the universalistic approaches of many healthcare systems should be reviewed and adapted to the special needs.

EU law currently protects against direct and indirect forms of discrimination only on the grounds of racial or ethnic origin and gender, and provides no protection against the combination of these grounds. FRA's research has shown that, in the healthcare sector, people face unequal treatment often because of a combination of their characteristics. This type of discrimination, i.e. where two or more grounds interact in an articulated way, is commonly called multiple or intersectional discrimination⁵⁶. Mr Dimitrakopoulos stated that a combination of grounds make certain groups particularly vulnerable, e.g. older migrants, i.e. on the grounds of their age and ethnic origin, young female workers, i.e. on the grounds of gender and age, or Muslim women, on the grounds of gender, religion and ethnicity. A FRA report⁵⁷ also found that groups defined by more than one characteristic often faced both barriers and health inequalities. Moreover, healthcare providers are often not prepared to meet the needs of specific groups and are therefore unable to treat them equally. FRA also found that some healthcare users who believe that they have been treated unequally may react in ways that can affect their health, if, for example, they were to avoid using healthcare services. As an additional difficulty, Mr Dimitrakopoulos referred to the unreported forms of discrimination, which often occur as patients are unaware of their rights, or due to the complex redress systems are unable to enforce their rights. The research also revealed that lawyers are reluctant to litigate on the ground of discrimination, as the compensation awarded to their clients is rather low. Considering this, Mr Dimitrakopoulos said, that in order to improve access to redress, compensation should be proportionate and dissuasive, redress mechanisms should be enhanced and healthcare users should be informed of the existence and function of available legal remedies.

Ibid.

Indirect discrimination refers to a neutral provision that has a disproportionate effect on certain people, because of one of their characteristics.

FRA 'Inequalities and multiple discrimination in access to and quality of healthcare', available at: http://fra.europa.eu/en/publication/2013/inequalities-discrimination-healthcare.

To conclude, Mr Dimitrakopoulos called on the EU to provide increased legal protection against discrimination and, in particular, to extend the scope of application of EU law to all sectors – including the sector of health, and to all grounds. Mr Dimitrakopoulos also said that the promotion of positive measures, such as the increase of free language assistance by translators and interpreters, was equally important. Finally, a recent FRA research⁵⁸ was presented which concluded that discrimination in clinical practice is rare.

According to Mr Dimitrakopoulos it shows that health professionals are generally reluctant to acknowledge that unequal treatment can be present in healthcare. The general obligation of treating each patient equally and with respect is embedded in their key ethnical codes, such as the Hippocratic Oath. Despite this, health professionals may not easily recognise that their own working practices, or their deeply-ingrained stereotyping of certain groups of patients can inadvertently affect the rights of particular groups of healthcare users. Therefore the FRA calls on health professionals to better reflect on how equalities are ensured in practices across all levels of healthcare.

2.3.2 Daily tackling and resolving discrimination in healthcare

Dr Gianfranco COSTANZO - Head of Unit for International relations, National Institute for Health, Migration and Poverty (IT)

Dr Costanzo provided a practical insight into the way the National Institute for Health, Migration and Poverty (the National Institute)⁵⁹ tackles discrimination on a daily basis. Article 32 of the Italian Constitution⁶⁰ states that the Republic safeguards health as a fundamental right of each individual and as a collective interest, and guarantees free medical care for the poor. In addition, under the Italian Unique Text on Immigration⁶¹, certain health services are provided by the National Institute free-of-charge for undocumented migrants. These services include healthcare for children, maternal care, compulsory vaccination, urgent outpatient and hospital care.

Dr Costanzo described an algorithm showing that general access to the healthcare services is quite complex for non-EU national migrants. Despite the initial complexities, the Italian system allows a number of exemptions for migrants, including exemption from co-paying the costs of these healthcare services.

Dr Costanzo emphasised that the Italian system aims to eliminate health inequalities, since this might lead to discrimination and in particular to discrimination against non-EU migrants. Furthermore, discrimination may increase and generate more poverty, social exclusion, and also increase the occurrence of diseases. Thus discrimination should be eliminated. To address health inequalities and discrimination against migrants in the sector of health, the National Parliament decided to launch a public policy with the aim of helping the national health services understand the needs of these vulnerable groups, including migrants. This needs assessment contributed to the development of tailor-made measures.

FRA 'Inequalities and multiple discrimination in access to and quality of healthcare', available at: http://fra.europa.eu/sites/default/files/inequalities-discrimination-healthcare_en.pdf.

More information on the National Institute for Health, Migration and Poverty is available at:
http://www.inmp.it/index.php/eng/About-Us/About-Us/NIHMP-National-Institute-for-Health-Migration-and-Poverty.

⁶⁰ The English text of the Italian Constitution is available at:

http://legislationline.org/download/action/download/id/1613/file/b4371e43dc8cf675b67904284951.htm/preview.

Legislative Decree 25 July 1998, n. 286, available at:
<a href="http://www.interno.gov.it/mininterno/site/it/sezioni/servizi/legislazione/legisl

Therefore, as part of this public policy, the Ministry of Health established the National Institute for Health, Migration and Poverty, which is a public body based in Rome. The remit of the Institute covers the development of approaches for dealing with the most vulnerable groups, research activities, and the organisation and operation of training.

Amongst the most vulnerable groups, the Institute's work mainly focuses on migrants and poor people. Dr Costanzo said that whilst developing the approaches to be followed by the healthcare system, the Institute pays particular attention to cost-efficiency. Regarding cost-efficiency, Dr Costanzo stated that allowing migrants' access to larger scale outpatient healthcare services is more cost-efficient than only giving them access to the emergency services since the costs of such services are, as a general rule, much higher than those linked to the costs of preventive healthcare.

Dr Costanzo continued with a description of the types of services that the National Institute provides to the most vulnerable groups, which mainly include specialist services, e.g. laboratory testing, dermatology services, internal medicine, paediatrics, gynaecology, and odontoiatrics. To make the best use of such services the National Institute has mapped potential accessibility issues that the most vulnerable groups may face, i.e. physical accessibility, relational accessibility and economic accessibility.

Physical accessibility is an issue for migrants who might undertake work activities and to address this, Dr Costanzo reported that the National Institute is open seven days per week, has opening hours during the afternoons, has no waiting list, and special care services are accessible without prior referral by the general practitioners.

Dr Costanzo then explained relational accessibility as the relationship between health professionals and their patients. Relational accessibility is typically hampered by linguistic and cultural barriers, i.e. 74% of the patients attending the National Institute are migrants who rarely speak Italian. To overcome the linguistic barriers, the National Institute provides multilingual information in the form of brochures, questionnaires and national language news items on its website. Since cultural barriers hinder the understanding of the needs of the most vulnerable groups, such barriers have been reduced by employing, for instance, transcultural mediators.

The transcultural mediators are trained staff who speak several foreign languages and because of these technical and cultural skills, they serve as a 'bridge' between the health staff and their patients, facilitating easier access to the healthcare services. Furthermore, transcultural mediators are involved throughout the whole duration of the migrant patients' clinical paths, i.e. from registration to the conclusion of the medical treatment.

Dr Costanzo explained that he found the problems and types of economic barriers that migrant patients face too inter-sectorial and complex to expand on them at this point. However he referred to the National Institute's current projects involving the management of projects funded by the Ministry of health to support free-of-charge provision of medical devices.

2.3.3 Second round of questions and answers

Mr Alojz PETERLE took the floor first and asked Dr Gianfranco COSTANZO about the idea behind the establishment of the National Institute. Dr COSTANZO explained that the Institute initially started working as an experimental joint project of three Italian regions, i.e. Lazio, Puglia and Sicily, since these regions were the most affected by migration. After this experimental phase, which lasted about three years, the Government with the support of 20 regions, decided to stabilise the legal status of the project and therefore established the National Institute.

Ms Ann Isabelle VON LINGEN representing the European AIDS Treatment Group, whilst commenting on the work of the National Institute, stated that the set-up of the Institute proves that, sometimes, it is more beneficial to approach target groups directly instead of waiting for them to come and ask for support. The European Institutions, including the working groups of the European Parliament play a crucial role in giving publicity to such cases, and more 'good practice' cases need to be highlighted as NGOs often see the reluctance of the Member States to provide services to the most vulnerable groups. Ms VON LINGEN also emphasised the need to involve the relevant communities in these projects. As a good practice example, she referred to European projects that operate under the supervision of steering groups in which the relevant communities are involved.

Mr PETERLE's second question was also addressed to Dr COSTANZO. He asked if there were volunteers involved in the activities of the National Institute. Dr COSTANZO explained that the Institute was a public body with regular staff members. However, the Institute is currently developing a network which aims to involve all types of stakeholders, including public bodies and volunteer organisations. This network will assist the Institute in defining the needs of the most vulnerable groups.

Ms Glennis WILLMOTT asked Dr COSTANZO if the cost-effectiveness of the Institute's services has ever been assessed. In particular, Ms WILLMOTT asked if the approach towards the types of services provided by the Institute have changed as a result of the current financial crisis. Dr COSTANZO, in his response, said that prior to establishing the Institute, the National Government conducted a feasibility study which compared the costs linked to specialised services and to emergency treatment. The ratio of cost-efficiency was 1:12; in other words the costs of the emergency treatment services were 12 times more than those linked to specialised care.

Mr Marian MANDACHE asked the audience for their thoughts on the link between the right to life and the imposition of taxes on emergency services. In his view, it breaches human rights, that in some countries, only those who have medical insurance or who pay the related costs, can benefit from emergency treatment – including life-saving emergency treatment. According to Mr MANDACHE, such practices breach the European Convention on Human Rights.

Mr Ioannis DIMITRAKOPOULOS responded by stressing that there are more urgent issues in the EU than those linked to access to emergency treatment. Access to emergency treatment is universal in all EU Member States. He acknowledged, however, that despite legal guarantees, discrimination might occur in some Member States. He further stressed that addressing these issues falls under the Member States' competences. To ensure that discrimination cases are adequately addressed, the Member States should ensure that patients are informed of their rights and put in place effective redress mechanisms.

Mr DIMITRAKOPOULOS stressed that, in his view, instead of discrimination, patients often face barriers. He also commented that he had never heard of such a case where a person was thrown out from a hospital on the ground that he belonged to a certain group. He acknowledged, however, that sometimes there are requirements that patients cannot fulfil and are, thus, prevented from accessing healthcare services, e.g. a hospital might forbid the presence of younger relatives (who often speak the local language) during the examination of older patients who do not speak the language of the country and due to this linguistic barrier, these patients might not be able to communicate with the clinical staff and as a result, they do not receive the appropriate treatment. Mr DIMITRAKOPOULOS concluded that looking at barriers similar to those he mentioned is more urgent than addressing the potential issues linked to the provision of emergency services.

Mr DIMITRAKOPOULOS further commented that currently applicable legislation does not allow the EU to legislate in all areas and all grounds, and that the EU has no legislative power to address issues linked to those barriers. He also referred to other legal issues that concern national level legislation. He noted that despite the legislation in place, the number of complaints lodged with the national equality bodies is low. Equality bodies, in his view, should ease the procedures to lodge complaints and to make sure that they keep track of the discrimination cases. Regarding this point, Mr DIMITRAKOPOULOS noted that complaints are not necessarily followed by procedures, e.g. they are dismissed on the ground of lack of evidence of discrimination.

Mr PETERLE then asked Mr DIMITRAKOPOULOS about the type of discrimination they focus on the most. Mr DIMITRAKOPOULOS stressed that the FRA does not follow any sort of hierarchy. Their activities cover a wide-range of discrimination grounds, including discrimination by age, disability, ethnic and racial origin, and sexual orientation.

Regarding the current activities of the FRA, Mr DIMITRAKOPOULOS referred to an on-going survey which serves as an update of the 2008 survey called EU-MIDIS⁶². EU-MIDIS targeted about 25,000 immigrants and persons belonging to ethnic minorities from the 27 EU Member States. Based on the results of the on-going and the 2008 surveys, the EU will be able to assess the effectiveness of applicable legislation in the field of antidiscrimination.

A similar survey was conducted last year for LGBT people⁶³, the result of which showed that there is an issue in the sector of healthcare. The survey also revealed that direct discrimination by health professionals is rare, whereas LGBT people often experience health barriers. According to Mr DIMITRAKOPOULOS, barriers are easier to deal with. This is despite the fact that many health professionals claim that there are no such barriers in Europe. The survey showed that barriers are often linked to the time-constraints faced by health professionals. Due to their schedules, health professionals do not find the time to deal with patients with special needs. Mr DIMITRAKOPOULOS, again, emphasised that addressing issues of this sort is a Member State competence. Nevertheless, he noted that the EU could show good practices to the Member States. Some good practices could be established by EU level legislation, such as the Cross-Border Health Services Directive⁶⁴, which put in place the minimum standards that could influence practices at the national level.

Ms VON LINGEN commented on the discussion of cost-effectiveness by saying that the European AIDS Treatment Group also puts emphasis on the lower costs linked to prevention compared to the costs of emergency treatment. She gave an example of a practice, which she was aware of, and which concerned access to emergency treatment and the costs linked to it. The case quoted an asylum seeker who needed medical treatment.

More information on EU-MIDIS is available at:

http://fra.europa.eu/en/project/2011/eu-midis-european-union-minorities-and-discrimination-survey.

FRA 'EU LGBT survey- European Union lesbian, gay, bisexual and transgender survey- Results at a glance', available at: http://fra.europa.eu/en/publication/2013/eu-lgbt-survey-european-union-lesbian-gay-bisexual-and-transgender-survey-results.

Directive 2011/24/EU of the European Parliament and of the Council of 9 March 2011 on the application of patients' rights in cross-border healthcare, OJ L 88, 4.4.2011, p. 45–65, available at: http://eur-lex.europa.eu/Result.do?T1=V3&T2=2011&T3=24&RechType=RECH_naturel&Submit=Search.

The authorities deported the asylum seeker on the ground that such treatment is costly and should be provided to the asylum-seeker in his country of origin. In her view, such a decision breached the right to life, since the treatment that the asylum-seeker needed was not available in his country of origin. She said that issues similar to this should be taken into account whilst having a discussion on cost-effective measures.

Dr COSTANZO said that asylum-seekers in Italy are registered as Italian nationals, thus the question was irrelevant in the light of the National Institute's activities. He reminded the audience of the special status of stateless persons who are not entitled to any health benefits. These groups are even more disadvantaged than, e.g. migrants. Thus, whilst designing any measures, it is particularly important to map the characteristics and needs of the targeted group.

Ms Sarada DAS from the Standing Committee of European Doctors (CPME) thanked all the speakers for their valuable input which CPME could use in putting forward recommendations for its members. Ms DAS asked Dr COSTANZO if medical doctors are contacted through national or regional medical associations, or if are approached individually. Dr COSTANZO answered that the National Institute has an extensive network, which involves both national and regional medical associations.

2.3.4 Conclusions

In his concluding remarks, Mr Peterle emphasised the importance of the topic and stated that, regardless of the results of the European Parliament elections in 2014, the topic will remain high on the political agenda. He stressed that workshops similar to this could help people become better informed.

Ms Willmott also highlighted the importance of the topic and called on all actors to work together. She finally concluded that projects similar to the one suggested by Mr Cashman should be supported.

ANNEX 1: PROGRAMME

WORKSHOP

Discrimination in Healthcare

Wednesday, 22 January 2014 from 12.30 to 14.45 European Parliament, P7C050, Brussels

Organised by the Policy Department A-Economy & Science for the Committee on the Environment, Public Health and Food Safety (ENVI)

AGENDA

12.30 - 12.35

Welcome and opening by Co-chairs of the Health Working Group, Glenis WILLMOTT and Alojz PETERLE, MEPs

Part 1

How does discrimination affect people? Who is affected?

12.35 - 12.45

Discrimination in health care against people with mental illness

Prof. Graham THORNICROFT, Section of Community Psychiatry, Health Services and Population Research Department, Institute of Psychiatry, King's College London (UK)

12.45 - 12.55

Discrimination based on sexual orientation

Mr Anthony BABAJEE, young LGBT activist (UK)

12.55 - 13.05

Racial and ethnic factors as a determinant of healthcare

Mr Marian MANDACHE, Executive Director, NGO Romani Criss (RO)

13.05 - 13.30

Q&A

Part 2

Developing policies

13.30 - 13.40

Multiple discrimination in healthcare

Mr Ioannis N. DIMITRAKOPOULOS, Head of Department Equality and Citizens' Rights, EU Agency for Fundamental Rights (FRA)

13.40 - 13.50

Daily tackling and resolving discrimination in healthcare

Dr Gianfranco COSTANZO, Head of Unit Relations with National and International Institutions, Project Cycle Management and Corporate Social Responsibility, National Institute for Health, Migration and Poverty (IT)

13.50 - 14.30 Q&A

14.30 - 14.40 Conclusions

14.40 Closing

ANNEX 2: SHORT BIOGRAPHIES OF SPEAKERS

Prof. Graham Thornicroft

Graham Thornicroft is Professor of Community Psychiatry, and Head of the Health Service Research Department at the Institute of Psychiatry, King's College London. He is a Consultant Psychiatrist working in an Early Intervention community mental health team in South London, and is Director of King's Improvement Science.

His areas of expertise include: mental health needs assessment, the development of new outcome scales, cost-effectiveness evaluation of mental health treatments, stigma and discrimination, the development of community-based mental health services, and global mental health.

He has published 29 books and 333 peer-reviewed scientific papers (e.g. Discrimination against People with Mental Illness, Self-stigma, empowerment and perceived discrimination among people with bipolar disorder or depression in 13 European countries: The GAMIAN-Europe study, Global pattern of experienced and anticipated discrimination against people with schizophrenia: a cross-sectional survey, etc.).

Mr Anthony Babajee

Unashamedly positive, Ant Babajee has been living with HIV since 2007. He grew up in south-west England and currently lives in London. Ant came out as gay at the age of 19 during the first year of a German and history degree. Being mixed race (with a father from Mauritius), gay and HIV-positive, Ant jokes that on diversity monitoring forms he has to tick lots of boxes!

Ant currently works as a marketer and graphic designer, but his background is in broadcast journalism, including five years at the BBC. As he regained confidence after his HIV diagnosis, Ant has sought to use his media skills to talk about his experiences of living with the virus. Even though he is open to his wonderfully supportive friends and family, the biggest challenge Ant faces is disclosing his positive status to new people he meets, such is the stigma that still surrounds HIV 30 years after the first cases emerged.

Ant has talked about openly living with HIV as a gay man in numerous interviews on radio, television and the web. He has appeared in the national and local media in the UK – on ITV News, Gaydio and numerous BBC local radio stations. In early 2013, he was featured in FS magazine, published by sexual-health charity GMFA, as a gay community role model.

Ant has been volunteering with Terrence Higgins Trust, Europe's largest HIV and sexual-health charity, since 2010 and became a trustee at the end of 2013. He supports other people living with the virus around Britain as the volunteer moderator on the myHIV web forum. He also volunteers with THT's health improvement team on the London gay scene as well as with GMFA. Ant is also a member of UK-CAB, a network of HIV treatment advocates, and ReShape – a recently formed HIV and hepatitis C thinktank.

Ant is an avid tweeter as @t4rdis – he is a fan of British sci-fi series Doctor Who – and regularly discusses LGBT and HIV issues with his followers. He also posts to his Tumblr blog at t4rdis.me.

Mr Marian Mandache

Marian Mandache was born in an Ursari Roma family in Romania. He became a lawyer in the Bucharest Bar (2005) and got his LL.M. from Columbia University (2010) where he also served as a teaching assistant of Prof. Jack Greenberg. Marian works on Roma rights since 1999 and he is currently the Acting Executive Director of the NGO Romani CRISS. He acquired valuable field experience by conducting numerous fact-finding missions on various human rights violations. He has drafted complaints to the ECtHR on Roma issues. He has litigated landmark cases on hate-speech (against the President of Romania, the Prime-Minister, the Minister of Foreign Affairs), on school segregation (School 19 Craiova) or law enforcement misconduct. Marian was part of expert groups drafting law proposals (e.g. amendments to the Romanian anti-discrimination legislation) and developing international standards (CoE, EC, OSCE). Marian has delivered trainings for judges, police officers and civic activists. He has authored six books on the human rights situation of Roma.

Mr Ioannis N. Dimitrakopoulos

Ioannis Dimitrakopoulos is a Head of the 'Equality and Citizens' Rights' department at the European Union Agency for Fundamental Rights (FRA). His areas of expertise include issues of equality and non-discrimination, as well as child rights. He studied sociology at Manchester and Essex University, UK. Since the mid-1980s he has worked in academic institutions, where he lectured and conducted quantitative and qualitative social research. In parallel, during the 1990s he worked in local and regional governments. Later, he coordinated national and transnational research projects. Since 2003, when he started working for the Agency, he has been responsible for several of its major publications and conributed extensively to a number of policy documents.

Dr Gianfranco Costanzo

Dr Costanzo is the Head of Unit for International relations, relations with regions and project cycle management of the National Institute for Health, Migration and Poverty (NIHMP). Prior to joining the NIHMP, he was a senior medical officer at the Ministry of Health, in charge of overseeing the preparatory works conducted for the meetings of the Council of Health Ministers' Working Party of public health. Between 2002 and 2008, Dr Costanzo's main responsibility at the Ministry of Health was to coordinate health cooperation programmes. From 1999 to 2001, Dr Costanzo was supporting the work of the Ministry of Health from Brussels, where he was in charge of the health dossiers linked to the EU's enlargement process. Prior to this position, Dr Costanzo was a seconded expert at the European Commission's Directorate General for Health and Consumers. Dr Costanzo is a medical doctor by training and he has post-degree diploma in gynaecology and obstetrics.

ANNEX 3: PRESENTATIONS AND FACTSHEET

Presentation by Prof. Graham Thornicroft

Evidence to decrease mental health related stigma and discrimination

Professor Graham Thornicroft

graham.thornicroft@kcl.ac.uk

Institute of Psychiatry

at The Maudsley





University of London

"The issue of stigma against mental illness sometimes feels like the worst part about it." Tom





Plan

- 1. mental health gap
- 2. premature mortality
- 3. what must we do?

Plan

- 1. mental health gap
- 2. premature mortality
- 3. what must we do?

Challenge 1: the 'treatment gap'

- 20-30% of global population has mental illness each year
- > 66% of people with mental illness receive no treatment
- treatment gap occurs in all countries:
 - in Europe 74% and in Nigeria up to 98% untreated
- R. Kohn, et al (2004) Bull. of World Health Org. 82: 858-866
- Wang, P. S., et al (2007) Lancet, 370, 841-850
- Thornicroft, G. (2007) Lancet, 370, 807-808

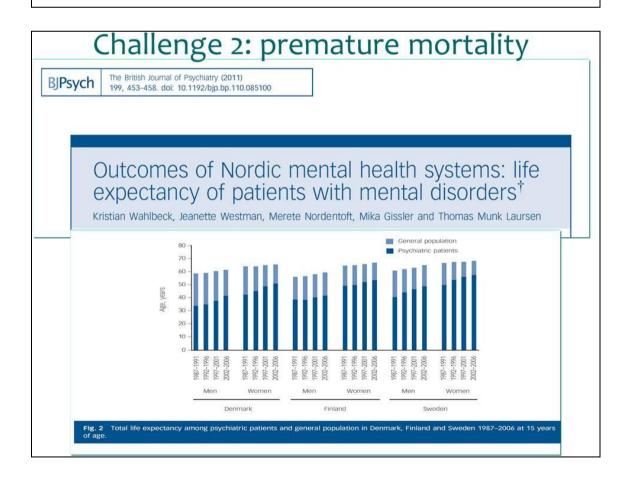
Treatment gap: percent treated in high, medium & low resource settings

	High income % treated	Low & middle income % treated
Physical disorders		
Diabetes	94%	77%
Heart disease	78%	51%
Asthma	65%	44%
Mental disorders		
Depression	29%	8%
Bipolar disorder	29%	13%
Panic disorder	33%	9%

Ormel J. et al (2008) British Journal of Psychiatry, 192, 368-375.

Plan

- 1. mental health gap
- 2. premature mortality
- 3. what must we do?



BJPsych

The British Journal of Psychiatry (2011) 199, 441–442. doi: 10.1192/bjp.bp.111.092718

Editorial

Physical health disparities and mental illness: the scandal of premature mortality[†]



Graham Thornicroft

Summary

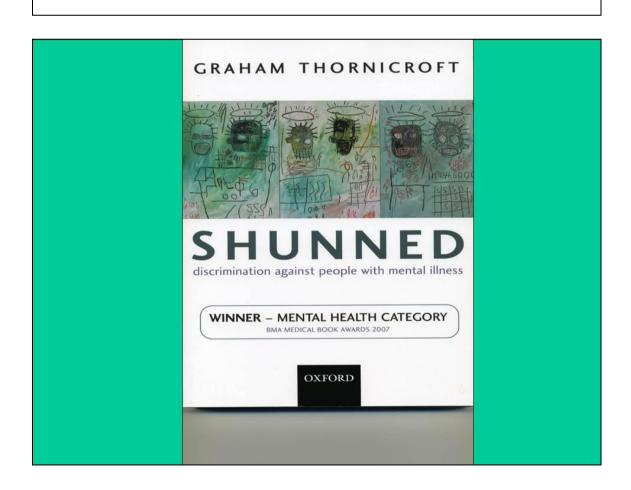
A 20-year mortality gap for men, and 15 years for women, is still experienced by people with mental illness in high-income countries. The combination of lifestyle risk factors, higher rates of unnatural deaths and poorer physical healthcare contribute to this scandal of premature mortality that

contravenes international conventions for the 'right to health.'

Declaration of interest

Plan

- 1. mental health gap
- 2. premature mortality
- 3. what must we do?



What is stigma?

• Problem of knowledge = Ignorance

• Problem of attitudes = Prejudice

Problem of behaviour = Discrimination

Eg help seeking Eg treatment provision

Local level interventions

Social contact theory

- theory from Bogardus 1924
- direct, personal social contact with individual(s) of stigmatised group is effective to reduce stigma

Target Groups

- Police officers
- Young people √
- Medical students
- Nurse students √
- 1. Pinfold V. et al (2003). Reducing psychiatric stigma and discrimination: Evaluating an educational intervention with the police force in England. Social Psychiatry & Psychiatric Epidemiology, 38, 337-344.
- 2. Pinfold V. et al (2003). Reducing psychiatric stigma and discrimination: Evaluation of educational interventions in UK secondary schools. British Journal of Psychiatry, 182, 342-346.
- 3. Kassam A, Thornicroft G et al (2011) Mental illness: clinicians' attitudes scale. Acta Psyc. Scand.
- Clement S et al (2012) Filmed v. live social contact interventions to reduce stigma: randomised controlled trial BJP



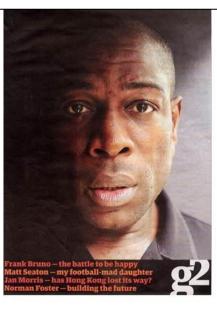




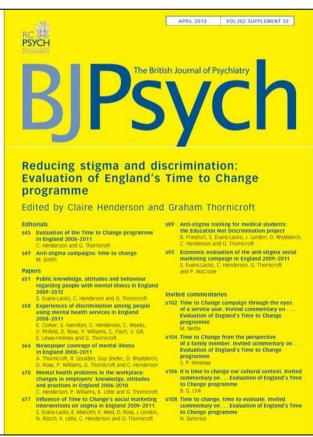
- compared live consumer talks, DVD consumer talks, and boring lecture for nursing students
- attitudes, compassion and behaviour improved for live consumer and dvd groups
- both better than lecture still better 4 months later
- recorded sessions most cost-effective

National level interventions



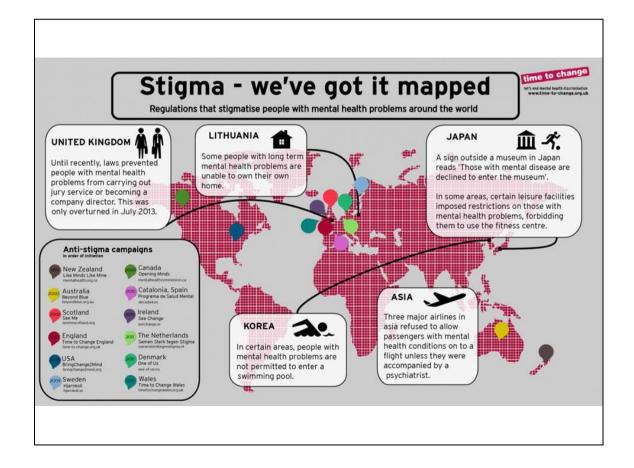


Former World Heavyweight Boxing Champion Frank Bruno supports Time to Change in England by disclosing bipolar disorder



Time to Change: 4 year outcomes

- 8 papers published in British Journal of Psychiatry 2013
- Clear positive changes across England
- Small to moderate sized improvements
- Most positive change in service users reports of experienced discrimination (<11%)





U.N. Convention on the Rights of Persons with Disabilities (CRPD)

- adopted in 2006 by the UN General Assembly
- first comprehensive human rights treaty of the 21st century
- developed by Committee of General Assembly 2002-8
- human rights instrument with clear social development dimension
- affirms that all persons with all types of disabilities are holders of all human rights and fundamental freedoms

Epidemiology and Psychiatric Sciences, page 1 of 14. $\,$ $\,$ $\,$ Cambridge University Press 2012 doi:10.1017/S2045796012000467 $\,$

ORIGINAL ARTICLE

Development of the ITHACA Toolkit for monitoring human rights and general health care in psychiatric and social care institutions

J. Randall^{1†}, G. Thornicroft^{1†*}, L. Burti², H. Katschnig³, O. Lewis⁴, J. Russo⁴, T. Shaw¹, K. Wahlbeck⁵ and D. Rose, for the ITHACA Project Group^{1‡}

www.ithacastudy.eu

Further information

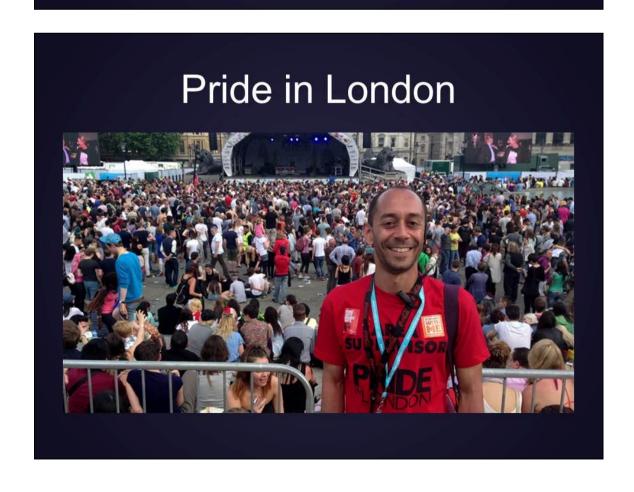
Contact: graham.thornicroft@kcl.ac.uk

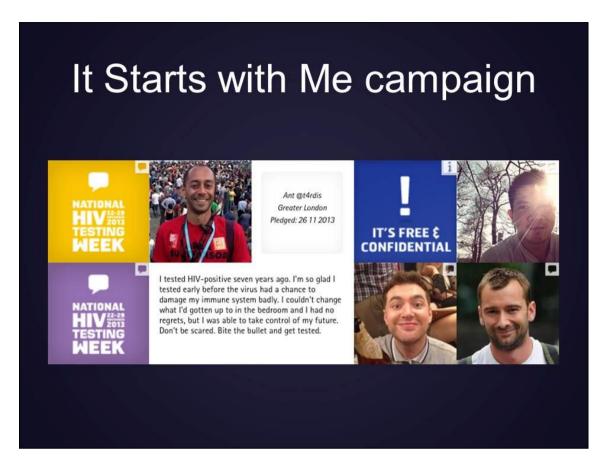
Resources: dropbox for > 50 stigma documents

Presentation by Mr Anthony Babajee

Discrimination in healthcare based on sexual orientation

Ant Babajee







FS magazine

- Non-judgmental meet gay men where they are in their lives rather than telling them where they should be
- Real and relevant talk honestly about sex and sexual health in appropriate language
- Challenging tackles hot topics such as unprotected ('bareback') sex, sexualised drug-taking ('chem sex') and sexual racism – that may make some feel uncomfortable but that demand discussion
- Thought-provoking and informative gay men encouraged to consider their own actions

HIV in the UK

- In 2012, an estimated 98,400 people were living with HIV in the UK
- Of these, 22% were unaware of their HIV infection
- From 1 April 2013, local authorities in England responsible for commissioning of HIV prevention services

London HIV needs assessment

- · Commissioned by London Councils in 2013
- Focus groups found gay men wary of information from statutory sources – lack of relevance
- Need for targeted work involving representatives of target audience in development of work
- Most effective language is non-medicalised and language gay men use conversationally with each other

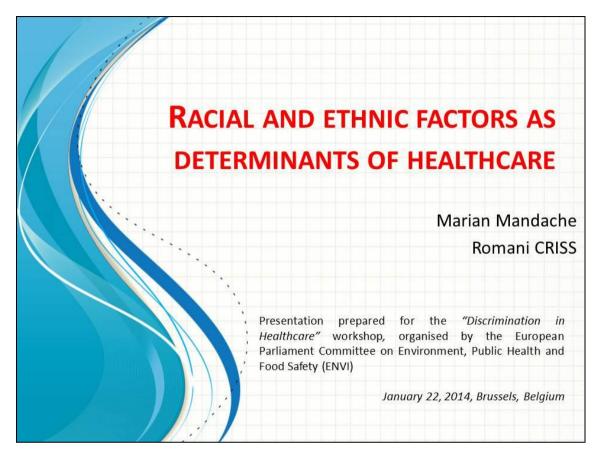
Some thoughts

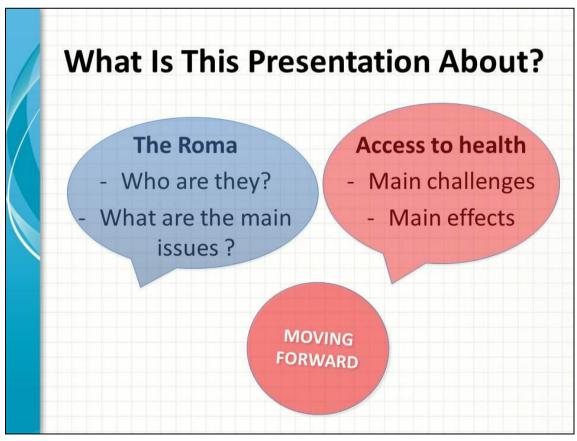
- · Ignorance just talk and ask questions
- LGBT people are, first and foremost, people too
- Don't assume what was true five years ago is still the case cf: rise in popularity of smartphone dating apps
- · Seek to understand and please don't patronise
- "I've been positive for 10 years and you'll be OK" disclosure, peer support and mentoring
- Can the healthcare or support worker relate to me? Can I trust them?
- The 'right' services eg: care services for older LGBT people
- Getting politics out of the bedroom, but the political will to improve and shape services

Sources of information

- · Terrence Higgins Trust: www.tht.org.uk
 - It Starts with Me: www.startswithme.org.uk
- GMFA: www.gmfa.org.uk
 - FS magazine: www.fsmag.org.uk
- National Aids Trust: www.nat.org.uk
- Stonewall: www.healthylives.stonewall.org.uk
- Pride in London: prideinlondon.org
- Public Health England: www.gov.uk/phe
- London Councils: www.londoncouncils.gov.uk/policylobbying

Presentation by Mr Marian Mandache





The Roma in One Slide

- The Roma are a population that migrated out of NW India around year 1000-1050 and spread all over Europe and most of the world;
- Nomadism, Slavery, Holocaust, Free Movement
- The Roma are culturally, economically and socially heterogeneous;
- However, Roma are, probably, the most impoverished and most discriminated against population in Europe (see e.g. ECHR decision in DH v. the Czech Rep.).

Some of the Main Challenges

- the impact of the environment and standard of living upon peoples' health;
- the causes and consequences of the lack of a social insurance;
- formal and informal costs associated to healthcare provision;
- overt and hidden ethnic discrimination.

THE IMPACT OF THE ENVIRONMENT AND STANDARD OF LIVING UPON PEOPLES' HEALTH

- The diseases faced by the communities serviced by health mediators are not diseases specific to the Roma. They are consequences of the reactions of the human body to the conditions of living a poor life in polluted environments;
- These diseases remind us that the communities in question are placed close to garbage pits or treatment plants (environmental racism). And this continues to happen systematically in Europe (e.g. 100 Roma people still leave next to the water-waste plant for 10 years after being "relocated there by the Miercurea Ciuc Mayoralty in Romania");
- Financial problems lead to not being able to eat healthy food and maintain a minimum level of hygiene, which, even if accepted cannot be respected;
- The affiliation to "less fortunate" groups often generates negligent treatment from the part of doctors towards the people belonging to these groups, which may have dramatic consequences;
- The idea is that the Roma are "used to it" and immune to precarious conditions, proves out to be just a myth, being a sort of evading the responsibilities of the institutions and of the medical staff, but not only.

THE CAUSES AND CONSEQUENCES OF THE LACK OF A SOCIAL INSURANCE

- In 2014, in many European countries, many Roma individuals have no birth certificates, no IDs and no property papers, after tens of generations. This does hamper efforts to getting insurance and access to health care;
- The health insurance systems may vary in different EU states.
 Great concern across Europe for cutting state costs due to the "financial crisis";
- In Romania, the main ways to get insured are to have a legal work contract or to register for social welfare. The social welfare may be cut off as a result of changes in the granting criteria (or as a result of the people choosing welfare meals and then being ineligible for social welfare), but also due to the temporary migration abroad;
- New health law is being proposed; it aims at reducing costs.

FORMAL AND INFORMAL COSTS ASSOCIATED TO HEALTHCARE PROVISION

Direct costs

- Medical insurance, copayments, medication;
- Most vulnerable ones are the large families with low income.

Indirect costs

 Transportation to the medical office (particularly, in remote rural areas)

OVERT AND HIDDEN ETHNIC DISCRIMINATION

- Forced sterilisation of Roma, most notably in Slovakia;
- Segregation of Roma women and children in hospitals;
- Discrimination by medical staff;
- Systemic state-sponsored racism.

FORCED STERILIZATION OF ROMA

- Between 1971 and 1991 in Czechoslovakia, the "reduction of the Roma population" through surgical sterilisation, performed without the knowledge of the women themselves, was a widespread governmental practice.
- The sterilisation would be performed on Romani women without their knowledge during Caesarean sections or abortions.
- Some victims claim that they were made to sign documents without understanding their content. By signing these documents, they involuntarily authorised the hospital to sterilise them
- In exchange, they sometimes were offered financial compensation or material benefits like furniture from Social Services — though it was not explicitly stated what this compensation was for.
- The justification for sterilisation practices according to the stakeholders was "high, unhealthy" reproduction (ROMEDIA).

SEGREGATION OF ROMA WOMEN AND CHILDREN IN HOSPITALS

- Cases reported in Romania, Hungary,
 Bulgaria and other countries;
- In 2011, Romani CRISS and ECPI reported the case of segregation of Roma children in the Marie Curie Hospital in Bucharest;
- Roma children patients were being placed in different rooms than the Romanian children patients;
- The trial is still pending at national level.

DISCRIMINATION BY MEDICAL STAFF

Practices that may lead to discriminatory behavior within the health public system include:

- examining Roma patients after the examination of all non-Roma patients, regardless of the time of arrival of the former;
- using of derogatory language;
- redirecting the patients towards suppliers of medical services from the proximity;
- Improper or lack of informing towards the risks associated with some intervention forms.

DISCRIMINATION BY MEDICAL STAFF

"As I stepped outside to wait for my husband, a tall, thin man aged around 40 came to me. "Excuse me, excuse me", he said. I wonder if he observed my dark skin colour and that I am a black- haired woman in order to think that I am a gypsy. Excuse me; did you deliver a baby here? Yes. Please, could you tell my wife to come out? Sure, of course! I noticed he was a gypsy, and whatever he was, he was still human. Of course! Nevertheless, where is she? I do not remember but it is with A or 16A... something with A and B. When I went there, I did not see anything, where could this annex be. I ask a nurse: excuse me, do you know where this annex is? What are you looking for there, who are you looking for? Well, a man asked me to call his wife. All right but there are only gypsies there. All right, I had gotten angry but I did not say anything, I went inside. It was cold, it was winter. January. Winter, not summer. Our children and this is true exactly as I say it, my baby girl and the children in the annex had their head wrapped in a scarf, as they did it there, some sort of bonnet. I entered in that annex, it was bigger than this one, divided in two by a folding screen, like in the gynaecology room, there was only Iris there [neighbourhood populated with Roma persons]. None of the children there, (...), did not have that type of wrapped bonnet, nor any regular bonnet, maybe the mothers could not bring any bonnets from home, the children weren't even wrapped, nothing... and the nurse was inside. I went to the woman I was looking for, I told her that her husband was waiting for her outside and she left. I ask the nurse: "aren't the children cold?" (...) Do not worry Madame, it is not cold she said, these are gypsy people. I felt so bad then, that honestly I tell you, I went out crying... now really, what did that child do wrong because he was born a gypsy and not a Romanian? This is a real and true case...'

(testimony presented in ROMANI CRISS - Roma Health. Perspective Of The Actors Involved In The Health System – Doctors, Health Mediators And Patients report)

SYSTEMIC STATE -SPONSORED RACISM

- Many European Governments, such as France, continuously and overtly hunt down Roma, on the base of their ethnic origin, destroying their homes. These practices impact directly their state of health, as well as their access to healthcare;
- Many European Governments, such as Romania, turn a blind eye to the numerous and grave forced evictions of Roma by local authorities, followed by demolition of their homes and placement in toxic areas (e.g. former chemical laboratory in Baia Mare or garbage pit in Cluj-Napoca). This Mayoralties continue to receive funding from the EU;
- Two decades of democracy in Eastern European countries brought to little in terms of "Roma integration". It did not bring about even the "regularisation" of a population which lives in the respective countries for hundreds of years. The massive lack of property documents is interconnected with the lack of IDs and sometimes birth-certificates. Inaction/poor progress made by Governments in this regards is an indicator on their commitment to address the Roma situation;
- When Mayoralties such as Bucharest spend indecent amounts of money for floral arrangements and only hire one health mediator (for about 150 euros/month) in the entire 2 million inhabitants city, the level of commitment is obvious and so are the results as to increasing access of Roma to healthcare.

Main Effects

The FRA – Fundamental Rights Agency:

"The results are shocking in many respects: of those surveyed in this report, one in three is unemployed, 20 % are not covered by health insurance, and 90 % are living below national poverty lines. Although governments and societies have been aware of Roma exclusion and deprivation, the magnitude and the similarity of exclusion patterns across EU Member States is striking and leaves no excuse for delaying swift, effective action to improve the situation".

The Fundamental Rights Agency,

The situation of Roma in 11 EU Member States. Survey results at glance

Ways Forward?

Time has come to head towards a common sense approach:

- •Training for medical students and staff on diversity and anti-discrimination;
- •Pilot and scale-up available experiences. In Romania, since 2002, when the health mediator programme created by Romani CRISS was taken over by the Ministry of Health, the Government has failed to try doing anything similar. So did most other Governments:
- •Less money into researching the problems Roma face (there seems to be general consensus the situation is bad), more money into actually dealing with problems, such as community health programs for vulnerable groups;
- •EU to make funding available for litigating against discrimination;
- •EU to start using the infringement procedure to fight discrimination against Roma. If millions of Roma face massive, unacceptable discrimination across the members states, and no Government is brought before the EU Court of Justice, then something is wrong;
- •EU to implement mechanisms for suspending European funding for local and national authorities which engage in systemic discrimination or fail to register progress in implementing national strategies for Roma.

(Re)Sources

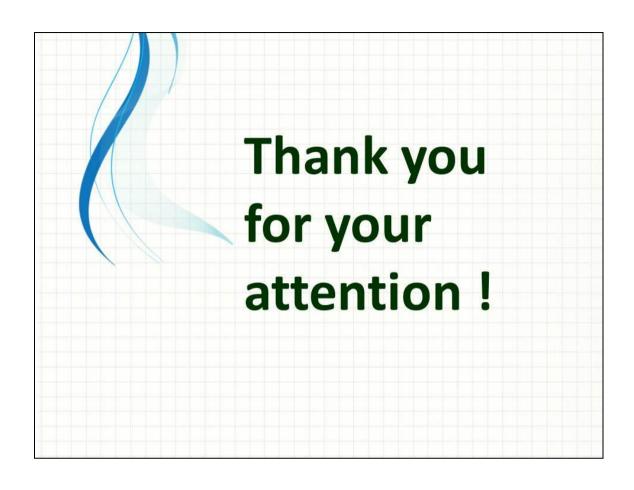
 Romani CRISS - Roma Health. Perspective Of The Actors Involved In The Health System – Doctors, Health Mediators And Patients

http://www.romanicriss.org/PDF/raport%20final%20osi%20health%20_engleza.pdf

 ROMEDIA - Forced Sterilization Of Romani Women – A Persisting Human Rights Violation

http://romediafoundation.wordpress.com/2013/02/07/forced-sterilization-of-romani-women-a-persisting-human-rights-violation/

The Fundamental Rights Agency - The situation of Roma in 11 EU Member States - Survey results at a glance http://fra.europa.eu/en/publication/2012/situation-roma-11-eu-member-states-survey-results-glance



Factsheet by Mr Ioannis Dimitrakopoulos



HELPING TO MAKE FUNDAMENTAL RIGHTS A REALITY FOR EVERYONE IN THE EUROPEAN UNION

EQUALITY

Inequalities and multiple discrimination in access to and quality of healthcare

Article 21 of the Charter of Fundamental Rights of the European Union recognises the right to be free from discrimination, including on the grounds of sex, racial or ethnic origin, and religion or belief. Article 35 guarantees the right of access to preventive healthcare and the right to benefit from medical treatment under the conditions established by national laws and practices.

Policy context

The European Union has laws prohibiting discrimination on six grounds, namely: sex, age, disability, religion or belief, race or ethnic origin, and sexual orientation. All too often, however, people are discriminated against on more than one ground; this is called 'multiple' discrimination. An elderly woman belonging to a minority ethnic group, for example, may be treated unequally because she is old, a woman and belongs to an ethnic minority. A younger male member of that ethnic minority or an elderly woman of a different ethnic group may not face similar treatment.

From a legal perspective, two difficulties exist in addressing multiple discrimination when accessing healthcare:

- EU law protects against discrimination only on grounds of sex and racial or ethnic origin when accessing healthcare.
- EU law and the law of most EU Member States do not specifically recognise or make provisions for dealing with multiple discrimination.

As a result, victims of multiple discrimination may have difficulties in bringing successful claims before a court or any other complaints body. Furthermore, policy makers are not obliged to take multiple discrimination into account when formulating policies to improve equal access to healthcare.

FRA research

The FRA report Inequalities and multiple discrimination in access to and quality of healthcare examines experiences of

unequal treatment on more than one ground in healthcare, providing evidence of discrimination or unfair treatment. The report supplements a 2011 FRA report, EU-MIDIS Data in Focus 5: Multiple Discrimination, which focuses on multiple discrimination experiences by respondents of ethnic or immigrant origin, compared with the general population.

This latest FRA report analyses barriers and individual experiences of multiple discrimination in healthcare and how they can prevent access to healthcare services. It aims to contribute to discussions on the adoption of the proposed EU Horizontal Directive legislation which would extend equal protection against discrimination on age, disability, religion or belief and sexual orientation to all fields, including healthcare. The work also aims to improve understanding of how policy makers and complaints procedures deal with multiple discrimination.

Methodology

This report is based on legal desk research and social fieldwork conducted in: Austria, the Czech Republic, Italy, Sweden and the United Kingdom. In the fieldwork, more than 170 health users at risk of multiple discrimination due to the interplay of their age, sex, ethnicity and disability as well as 140 health professionals, representatives of equality bodies, health complaint bodies and non-governmental organisations (NGOs) were interviewed. The evidence collected though the fieldwork is analysed against existing legal instruments addressing multiple discrimination in healthcare at the national, European and international levels. The report looks at three particular groups at risk of multiple discrimination in access to healthcare:

- women with a migrant/ethnic minority background, including women with disabilities, trying to access reproductive healthcare;
- older people with a migrant/ethnic minority background, including those with disabilities;
- migrant/ethnic minority young people aged 18 to 25 years, with intellectual disabilities.

Key issues

The FRA research findings show that healthcare systems may create barriers in access to healthcare or provide healthcare of a different quality to people who share more than one protected trait, such as sex, disability and ethnicity. Communication and language barriers, for example, affect many groups specifically protected by anti-discrimination law, but individuals who share more than one protected characteristic face additional complex challenges. The report's findings also show that such health users might experience a lack of dignity and respect when meeting, communicating and interacting with healthcare staff.

Evidence-based advice

Given the evidence gathered by the FRA, the EU and its Member States could take several steps to improve the situation as regards multiple discrimination.

European Union law

The EU could:

- provide equal protection against discrimination on all grounds protected by EU law in areas beyond employment – as envisaged in the European Commission's proposed 'Horizontal Directive':
- Introduce stronger measures to prevent, and combat multiple discrimination, ensuring that sex discrimination is also protected.

Institutionalising multi-dimensional equality in the healthcare system

EU Member States could:

- consider more dissuasive and proportionate compensation for discrimination cases in healthcare;
- Increase free language assistance in healthcare settings and when providing health information – including translation and mediation services for those who do not speak or understand the language. This includes 'sigri' language and other forms of support for people with sensory or intellectual impairments;
- encourage more positive actions for those facing a risk of intersectional discrimination: for example, by accommodating the needs of women belonging to

- ethnic minorities who want to be treated by female healthcare professionals; by funding community-based mobile outreach programmes targeting different ethnic communities and equality groups among them; by allocating more time for medical consultations for people belonging to these groups;
- consider providing training for healthcare professionals on discrimination and multiple discrimination, cultural competence and understanding disabilities;
- collect systematically health statistics that can provide a full picture of the intersection of different grounds, including data on ethnicity (recording both migrant status and ethnicity, where legal) and disability (taking into account the human rights framing of disability enshrined in the United Nations Convention on the Rights of Persons with Disability (CRPD), the so-called social model of disability).

Access to justice

The EU and its Member States could:

- Increase healthcare users' awareness of the existence and functioning of available complaint mechanisms, both for healthcare and discrimination issues;
- consider creating one equality body that covers a number of discrimination grounds so that 'multiple' discrimination can be tackled more effectively.
 Furthermore, referral mechanisms between equality bodies and health complaint bodies, and awareness of anti-discrimination legislation among health complaint bodies, should be enhanced.

Further information:

The FRA report on Inequalities and multiple discrimination in access to and quality of healthcare is available at: http://fra.europa.eu/en/publication/2013/inequalitiesdiscrimination-healthcare

For an overview of FRA's work on multiple discrimination, see: http://fra.europa.eu/en/project/2011/ multiple-discrimination-healthcare

FRA – European Union Agency for Fundamental Rights

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Presentation by Dr Gianfranco Costanzo





THE RIGHT TO HEALTH

The Italian Constitution Act, at article 32, states that the Republic safeguards health as a fundamental right of the person and as interest of the community, and provides free cure to poor people.

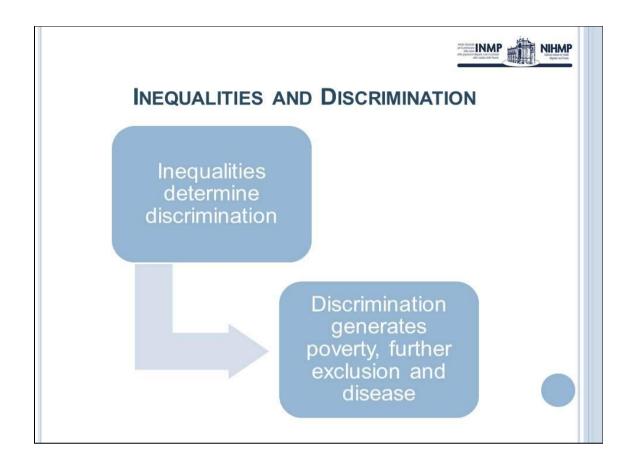
HEALTH ASSISTANCE FOR IRREGULAR MIGRANTS IN ITALY

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di papilaco Nigoria per Cottano
Alle nadari di Brasil

In accordance with Article 35 of the Italian Unique Text on Immigration, the following health services are guaranteed to undocumented migrants:

- * urgent, essential and continuative outpatient and hospital care
- * prevention programmes aimed at protecting individual and public health
- * maternal care
- * minors' health care
- * compulsory vaccination
- * diagnosis, treatment and prevention of infectious diseases
- * international prophylaxis

Algorithm of non-EU migrants access to the Italian National No ¿ Yes Legally residing in Italy? Health Service Yes Has he/she applied for or does he/she own a residence permit If deprived of any means titling to compulsoryation? of subsistence, he/she is (i.e. work, reunification) entitled to access the National Health Service through the Temporarily Resident Foreign National code (STP Code) Yes No Is he/she a reunited Is he/she residing for parent aged over-sixty-five? more than three months? No He/she is entitled Is he/she a student or a to the compulsory No Yes Yes person working au pair? egistration in the NHS Yes No He/she is entitled He/she is not entitled to to the voluntary registration in the NHS the registration in the NHS INMP NIHMP





A PUBLIC POLICY IN ITALY

The Parliament decided to launch a public policy to help the National health service understand the needs of frigile populations, migrant and poor people, in terms of health.

Needs to be declined into operational models of healthcare delivery, tailored upon the specificity of the target.



THE NIHMP

The NIHMP is a public body based in Rome which assures to the NHS health assistance, sectorial research and operational training, with a particular focus on migration and poverty.

Main target groups are:

- o poor people
- documented and undocumented migrants
- o international protection seekers
- o refugees
- o victims of violence



NIHMP SERVICES

Specialist services

- Laboratory Tests (reception from 7.30 to 9.45 am)
- Plastic Surgery (medical examinations, wound dressing, outpatient surgery, chemical skin peeling)
- Dermatology (medical examinations, cryotherapy, wound dressing, diathermocoagulation, epiluminesc removal of minor skin lesions, chemical skin peeling)
- Tropical Dermatology
- · Ethnic Dermocosmetology
- Gynaecology (medical examinations, diagnosticultrasonography, pap-test, colposcopy)
- Infectious and Tropical Diseases (medical examicounselling)
- Travel Medicine (vaccinations and international prophylaxis)
- Internal Medicine (preventive medical examinations, gastroenterology, hepatology)
 Microbiology and Skin Mycology
- Child Neuropsychiatry (medical examinations, interviews, psychotherapy)
- · Social Ophthalmology
- Social Dentistry and Gnathological Rehabilitation Ethnopsychiatry-Oriented Clinical Psychology (medical examinations, psychotherapy, counselling)

Terms of access

The Outpatient Department is in Rome, Via delle Fratte di Trastevere 52. Opening hours:

- from Monday to Friday from 7.30 to 12.00 am
 Tuesday, Wednesday and Thursday also in the afternoon from 2.00 to 5.00 pm
 Saturday and Sunday from 8.00 to 12.00 am

Social and Health Care Services

Social and Health Care Services

Social and Health Care Assistance Service The service
carries out reception and guidance activities and provides
information on health care, social, educational, training,
labour and legal issues, on public and private services and
on the activities of the Service itself, it also achieves actions
aimed at facilitating the encounter of labour supply and
demand

From Monday to Friday from 8.00 am to 1.00 pm

Tuesday, Wednesday and Thursday from 2.00 to 7.00 pm
Tel. 06.58543666

Service for Homeless People An interdisciplinary team provides information, guidance and health care, psychological and anthropological assistance to Italian and foreign fromeless people at risk of social exclusion.

• From Monday to Friday from 8.00 am to 1.00 pm

- Tuesday, Wednesday and Thursday from 2.00 to 7.00 pm Tel. 06.58543687 - psd@inunp.it

"The Street Lawyer" Service About 50 lawyers and apprentices, supported by a cultural mediator, work as volunteers to guarantee free qualified support to those citizens who have legal problems and are deprived of their fundamental rights.

Wednesday and Thursday from 3.00 to 6.00 pm. Tel. 06 58543782 - roma@avvocatodistrada.it

Tel. 0.58543782 - roma@avvocatodistrada.ts
Service for International Protection Seekers, Refugees and
Victims of Torture An interdisciplinary team provides
method, psychological and social support to international
protection seekers, refugees and victims of rorture. Method
examinations, psychological counselling, information and
guidance on how to recreiv legal and social significant
guidance on how to recreiv legal and social significant
erfugee application is issued.

- From Monday to Friday from 8.00 am to 1.00 pm
- Tuesday, Wednesday and Thursday from 2.00 to 7.00 pm
Tel. 06.58543687

Service for Minors The service is open to Italian and foreign minors and their families, unaccompanued minors, asylum seekers and victims of human trafficking. It offers psychodiagnostic, treatment and counselling activities particularly focused on adolescent problems and trauma

- Tuesday from 12.00 am to 6.00 pm
- Wednesday from 12.00 am to 3.00 pm
 Wednesday from 9.00 am to 3.00 pm
 Thursday from 10.00 to 12.00 am
 Tel 06.58543687 06.58543731

Tel 06.5834367 - 06.58343731

Clinical Service for Sexual Health and Emotional Education The service is open to young and adult people, without gender or age distinctions, who are in need for health care assistance for reasons related to sexual health and emotional education. The Service uses a multi and trans-disciplinary approach considering the existence of different social and culture-related conceptions.

From Monday to Friday from 8.00 am to 1.00 pm

Tiesday, Wednesday and Thursday from 2.00 to 5.00 pm Tel 06.58543782

Service for Women's Rights and Health The Service carries on actions against discriminations, social exclusion and unemployment by providing health education, medical assistance, information and prevention activities for women and minors victims of physical and psychological violence.

From Monday to Friday from 8.30 am to 3.00 pm Tel 06.5854368711

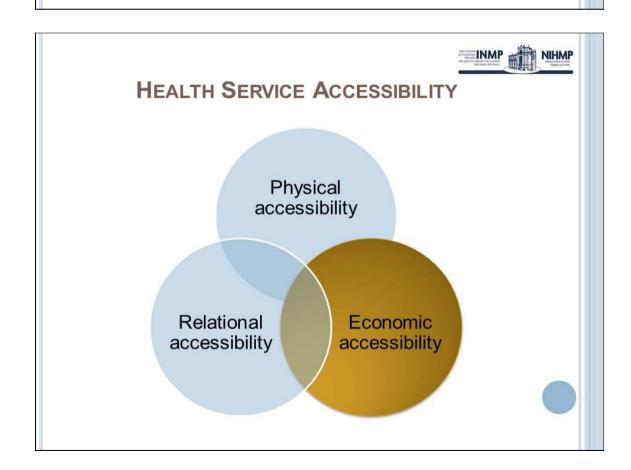
The service provides the entitled persons with the codes STP (Foreigner Temporarily Present) and ENI (European Person not Registered with the National Health Service).



HEALTH SERVICE ACCESSIBILITY

With the aim of improving the health status of weak population groups, the NIHMP is committed to removing access barriers. In this sense, it adopts specific measures for overcoming physical, relational and economic barriers to access.







MODEL OF PHYSICAL ACCESSIBILITY

- o OPD open in the afternoon
- o 7 days a week
- o no waiting lists
- o no GP prescription or GP inside



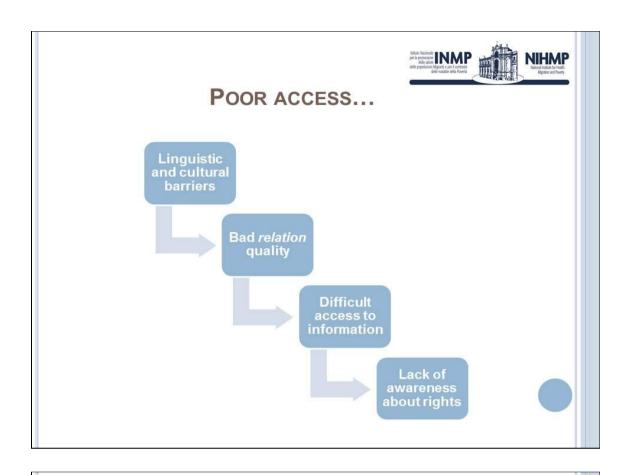
MODEL OF RELATIONAL ACCESSIBILITY

At the NIHMP 74% of patients are migrants. To overcome linguistic barriers is therefore of fundamental importance. Written information is translated into the most encountered languages:

68

- English
- o French
- Spanish
- Arabic
- **Rumanian**
- Albanian
- Chinese
- Russian
- **OUkrainian**







OVERCOMING LINGUISTIC BARRIERS

Multilingual information provided includes:

- o information brochures
- o notices
- o directions
- o informed consents
- questionnaires for assessing patients' needs and satisfaction
- o news on the NIHMP's website



OVERCOMING CULTURAL BARRIERS

People cared at the NIHMP's premises convey through the language their entire cultures. And each culture has got its own codes to conceive and express suffering.

Health operators can therefore fully understand the suffer and needs only by using a linguistic-cultural approach.



NIHMP APPROACH

The NIHMP developed a specific model aimed at understanding and meeting the needs of vulnerable groups.





NIHMP APPROACH

Transcultural and interdisciplinary model in use provides the participation of different professionals in the reception and care of migrants, including:

- doctors
- psychologists
- anthropologists
- transcultural mediators



TRANSCULTURAL MEDIATION

The transcultural mediation staff is composed of 30 persons from different areas of the world, speaking about **36 languages**





WHAT IS IT?

It goes far beyond translation and interpretation. Transcultural mediators are able to:

- o favour mutual knowledge
- o actively ease integration
- o actively participate to interaction
- o act and produce change



WHAT THEY DO

Mediators are involved throughout the whole health care path of migrants and follow them in the different clinical and social steps.





WHAT THEY DO

Reception

registration, needs assessment, referral to the different services and guidance





WHAT THEY DO

Medical examinations

> they take part to the medical examination setting, facilitate interaction and make cultural backgrounds meet and find common points





WHAT THEY DO

- Psychological counselling
 with psychologists and anthropologists
- * psychological counselling for international protection seekers is also aimed at creating the *dossier* required by the relevant Commission, thus trying to overcome linguistic and cultural barriers to access international protection status





WHAT THEY DO



Social and health care guidance

At the Institute, a specific service managed by transcultural mediators offers information and guidance on social and health care issues.





WHERE WE ARE

www.inmp.it

Thank you!



NOTES



DIRECTORATE-GENERAL FOR INTERNAL POLICIES



Role

Policy departments are research units that provide specialised advice to committees, inter-parliamentary delegations and other parliamentary bodies.

Policy Areas

- Economic and Monetary Affairs
- Employment and Social Affairs
- Environment, Public Health and Food Safety
- Industry, Research and Energy
- Internal Market and Consumer Protection

Documents

Visit the European Parliament website: http://www.europarl.europa.eu/studies

