



Roma Seminar Series Theme **Two**

CHALLENGING BARRIERS AND MISCONCEPTIONS ROMA MATERNAL HEALTH IN IRELAND

Pavee Point Traveller and Roma Centre is a

non-governmental organisation committed to the attainment of human rights for Irish Travellers and Roma. The organisation is comprised of Travellers, Roma and members of the majority population, working in partnership to address human rights issues faced by Travellers and Roma as minority groups experiencing exclusion and marginalisation. Pavee Point has been running a Roma Project since the year 2000. The Roma project is working for Roma in Ireland to have their full human rights and to be actively involved in decisions affecting their lives.

This report was produced by Pavee Point Traveller and Roma Centre as part of a series of seminars exploring Roma rights in Ireland. It is based on the outcomes of a thematic seminar on maternal health and Roma in Ireland. The Health Service Executive (HSE) has funded this work and the position of a Community Development Worker, working on health issues in Pavee Point. HSE staff actively participated in the seminar on maternal health. The HSE have stated a commitment to be informed by the findings and respond appropriately to any recommendations.

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EXECUTIVE SUMMARY

"ADOPTING A RIGHTS-BASED APPROACH TO WOMEN'S HEALTH DEMANDS OPENING SPACES FOR WOMEN TO EXERCISE CHOICES AND SUBVERTING THE SOCIAL AND POWER RELATIONS THAT DENY THEM THEIR FULL HUMANITY."

- Alicia Ely Yamin, Center for Health and Human Rights at Harvard University

Maternal health is a human right. This means access to family planning, information, pre and postnatal care, and resources. States are obligated to implement strategies and policies to ensure this and are also obligated to prioritise the needs of marginalised groups.⁰¹ Women have the right to non-discriminatory and equal access to maternal health care services and adequate nutrition during pregnancy and lactation.⁰²

However, the experiences of Roma women outlined in this report stand in stark contrast to their human rights. This report highlights experiences of poverty and poor living conditions which impact negatively on Roma women's health. The Habitual Residence Condition acts as a major barrier to women accessing basic GP services, due to a lack of resources and a lack of access to medical cards. Women report being afraid to engage with health services in case they receive bills for treatment. Women report receiving conflicting reports in relation to payment for maternal services, often receiving large bills from maternity hospitals and a lack of knowledge of the Maternity and Infant Care Scheme. Women also report fears of children being taken away from them if they engage with health practitioners, particularly if they are living in poverty and overcrowded accommodation. The removal of two blonde Roma children from their families in October 2013 has further exacerbated fears within the community. As a result, public health nurses often experience difficulties tracking mothers of new born babies when mothers make themselves inaccessible upon visits. This can mean children do not get vaccinations. This affects women's health, children's health and public health more widely.

Interviews with Roma women unveil experiences of overt and covert racism, prejudice and inappropriate treatment by health care practitioners. Negative and differential treatment is especially reported in cases where Roma have insufficient or no English language skills or with women whose appearance is more 'traditional'. This builds on a legacy of negative past experiences for many women who have come from countries where racist treatment, segregated or inferior services, and outright denial of services is a common experience.

As women living in poverty struggle to meet basic needs and to survive, it can be impossible to have the financial resources to even pay for transport to access services. In the absence of a medical card, the ability to pay for a GP or hospital services becomes impossible. Indeed accessing nutritious food and buying clothes and nappies for a new baby can be extremely challenging. This, combined with a lack of clear accessible information, and a lack of trust in maternal and broader health services all impact on engagement with pre and post-natal services. Some Roma women in Ireland are reported to opt out of seeking medical attention during pregnancy in instances where they have been bleeding and experiencing abdominal pain. Many women delay accessing care to a late stage of pregnancy. The first point of contact for Roma women with a health service can be in the A&E ward of a maternity hospital when already in labour.

This report reveals that the maternal health among many Roma women appears to be comparatively poorer than among the general population. A lack of access to preventative care can increase the risk of maternal mortality, infant mortality, premature birth and low birth weight. All of this points to an urgent need to gain more data on Roma women's experiences of maternal health, the impact of these experiences and urgent action to increase access to maternal health services for Roma in Ireland.

Realising the right to maternal health and the broader right to health requires more than access to health services. All rights are interdependent and indivisible and the right to health is closely linked to the rights to food, housing, work, education, life, nondiscrimination and equality among others.⁰³ Across Europe, Roma are subjected to racism, discrimination, forced evictions, collective expulsions, policy brutality, hate crime and discrimination in education, accommodation and employment. This level of discrimination and social exclusion results in higher mortality rates and lower life expectancy compared

Committee on Economic, <u>Social and Cultural Rights (CESCR). General</u> <u>Comment 14 on the Right to Health</u> UN Doc. E/C.12/2000/4.

⁰² UN General Assembly, <u>Convention on the Elimination of All Forms of</u> <u>Discrimination Against Women</u>, 18 December 1979, United Nations, Treaty Series, vol. 1249.

⁰³ Committee on Economic, Social and Cultural Rights (CESCR). General Comment 14, 2000.

⁰⁴ European Commission, Communication from the Commission to the European Parliament, the Council, the European Economic and Social Committee and the Committee of the Regions - The social and economic integration of the Roma in Europe, Brussels: European Commission, 2010.

with non-Roma.⁰⁴ In some countries Roma child mortality rates are two to six times higher than among the general population.⁰⁵ In Ireland, the life expectancy for Traveller women is 11.5 years less than the general population and the infant mortality rate for Travellers is 3.6 times the rate of the general population.⁰⁶ A rightsbased approach requires challenging the structural discrimination women face in health systems, as well as in other spheres of public and private life.⁰⁷ It involves opening spaces for women to subvert the social and power relations that deny them their full humanity.⁰⁸ In this context this report outlines some priority actions that need to be taken to address maternal health.

Firstly, the lack of a comprehensive and progressive strategy for Roma inclusion in Ireland needs to be addressed in order to make a plan for realising Roma rights and supporting practitioners in their work. Ireland has been obligated to develop a National Traveller Roma Integration Strategy under the European Commission's EU Framework for National Roma Integration Strategies up to 2020.⁰⁹ However, Pavee Point has highlighted that the current strategy lacks goals, targets, indicators, timeframes, funding mechanisms and monitoring and evaluation mechanisms; and was developed without the involvement of Traveller and Roma.¹⁰ The Commission has also noted dissatisfaction with Ireland's strategy, giving it a score of 4 out 22 in its 2013 assessment.¹¹ The current strategy needs to be revised with the full involvement of Roma and Travellers and part of this strategy should address maternal health.

The Habitual Residence Condition acts as a serious barrier to the attainment of Roma rights to primary care services. This has direct human rights implications for Roma, and also uses valuable resources within the HSE as practitioners try to address issues facing Roma in crisis situations on a case-by-case basis. This needs to be addressed so that Roma can access basic services in a systematic way.

Practitioners report a lack of data in relation to the experiences of Roma women within the health care system. In order to develop evidence-based policies and to identify discrimination, ethnic data is needed. Collection of data disaggregated on the basis of ethnicity across services within a human rights framework is needed. In the meantime further research on the maternal health situation of Roma is required. Roma need to be actively involved in policy-making and decisions that impact their lives. Participation is a central element of a human rights-based approach to health and widely recognised by EU institutions. The model of the

- 05 See statistics on Romania, Slovakia, Hungary, Bulgaria and the Czech Republic, in UNDP, The Roma in Central and Eastern Europe: Avoiding the Dependency Trap, Bratislava: UNDP, 2003.
- 06 Pavee Point, <u>Selected Key Findings and Recommendations from the All-Ireland</u> Traveller Health Study - Our Geels, Pavee Point, 2010.
- 07 Alicia Ely Yamin 'Toward Transformative Accountability: Applying a Rights-Based Approach to Fulfill Maternal Health Obligations', in SUR - International Journal On Human Rights, Volume 7:12 (2010): pp. 95 - 122.

Pavee Point Primary Health Care Project for Travellers is a model that could be developed to promote Roma participation and build relations and trust between Roma and health practitioners.

Considering the reports of negative experiences among Roma women in health services in Ireland, human rights and intercultural training to address prejudice and stereotypes are required. Roma also need to be provided with clear and accessible information on the Irish health care system. This report is intended as a resource for policy-makers, health care practitioners and other relevant parties to assist in developing responsive and inclusive polices and practice. It is seen as a starting point for further work in the area. Ireland has signed up to international treaties protecting the right to health and so has an obligation to ensure that Roma women's rights are respected, protected and fulfilled. The findings of this report indicate urgent action is required for Ireland to meet its human rights obligations.

THE REPORT IS ORGANISED INTO SIX SECTIONS:

SECTION 1 Outlines the rationale for the report. This includes outlining aims and objectives and methodology.

SECTION 2 Gives an overview of the historical and contemporary situation of Roma people in Europe and Ireland. This provides a context for understanding the socio-economic, cultural, political and legal situation of Roma living in Ireland.

SECTION 3 Outlines the human rights context to the right to health and maternal health as set out in international, regional and national instruments. This is followed by looking at policy and practice in health care services across Europe.

SECTION 4 Introduces key findings of the seminar and supplementary research. It outlines barriers and issues experienced by Roma women in accessing maternal health services. It also identifies issues faced by health care practitioners in Ireland in the provision of services. **SECTION 5** Outlines preliminary recommendations in the form of action points to guide policy makers and practitioners in the development and implementation of policies and services.

SECTION 6 Provides a framework to assist policy makers and practitioners with identifying and developing good practice to fulfil the right to maternal health for Roma in Ireland.

¹¹ European Commission, Steps Forward in Implementing National Roma Integration Strategies, Brussels, 26 June 2013, COM(2013) 454 final,

SECTION 01: RATIONALE AND BACKGROUND



"EUROPE HAS A SHAMEFUL HISTORY OF DISCRIMINATION AND SEVERE REPRESSION OF THE ROMA. THERE ARE STILL WIDESPREAD PREJUDICES AGAINST THEM IN COUNTRY AFTER COUNTRY ON OUR CONTINENT."

-Thomas Hammarberg, Former Commissioner for Human Rights of Council of Europe

⁰⁹ European Commission, <u>An EU Framework for National Roma Integration</u> Strategies up to 2020, Brussels, 05April 2011 COM (2011) 173.

¹⁰ Pavee Point, <u>Briefing Note on the National Traveller Roma Integration Strategy</u> (NTRIS), 2013, http://www.paveepoint.je/resources/roma/

This report was produced in response to concerns over Roma maternal health in Ireland. A series of seminars were held in 2012 as part of collaborative work between Pavee Point and the Health Service Executive (HSE) to address Roma health issues. The seminars focused on topical issues identified by Pavee Point and the HSE, and included inputs from a range of participants from statutory and non-statutory organisations and Roma representatives. The report on Roma Maternal Health is the second report in the seminar series.¹²

The need for a forum to explore Roma maternal health concerns in Ireland emerged from previous seminars on Roma and Child Protection considerations. The seminar participants reported that Roma are an atrisk group in terms of health, and concerns were raised specifically in relation to maternal health.

The seminar was attended by a range of participants from the HSE, maternity hospitals, Roma communities and wider civil society. The purpose was to share information in relation to Roma maternal health, and identify needs, challenges and examples of good practice experienced by Roma and health care practitioners.

In Ireland, data on Roma health is largely absent due to the lack of official data being aggregated by ethnicity. There is a specific need to include ethnicity as a category in data collection in order to generate accurate and reliable data and develop responsive and effective policies and services. In the absence of such data, this report can be seen as an exploratory report and a starting point for understanding Roma and maternal health in Ireland.

AIM AND OBJECTIVES

The report is intended as a resource for policy makers, health care practitioners and other relevant parties to assist in understanding the complex and inter-sectoral background of the issues affecting Roma access to health care services.

The concept of maternity includes distinct stages of motherhood including conception, pregnancy, childbirth and post-natal to end of first year of motherhood.¹³ In this report, the focus is drawn away from the health of the new born child as a result of the emphasis placed in the seminar on the first stages of maternity. The purpose of this report is threefold:

- Outline key barriers and issues experienced by Roma women in relation to maternal health.
- Outline issues raised by practitioners in relation to the provision of inclusive maternal health services for Roma.
- Provide policy-makers and practitioners with information, principles and approaches to inclusive work with Roma.

METHODOLOGY

Due to the lack of quantitative data aggregated by ethnicity, this report is based on qualitative findings from the Roma Maternal and Child Health seminar. A combination of methods is used to map out Roma maternal health considerations. The report is based on contributions by seminar speakers, focus group discussions among seminar participants, and supplementary interviews with practitioners and members of Roma communities. This report is intended to be a starting point for more in-depth and comprehensive research.

SECTION 02: SITUATION OF ROMA IN EUROPE AND IRELAND



"IN MANY EUROPEAN COUNTRIES THE ROMA POPULATION IS STILL DENIED BASIC HUMAN RIGHTS AND MADE VICTIMS OF FLAGRANT RACISM. THEY REMAIN FAR BEHIND OTHERS IN TERMS OF EDUCATIONAL ATTAINMENT, EMPLOYMENT, HOUSING AND HEALTH STANDARDS AND THEY HAVE VIRTUALLY NO POLITICAL REPRESENTATION. THEIR EXCLUSION FROM SOCIETY FEEDS ISOLATIONISM, WHICH IN TURN ENCOURAGES PREJUDICE AGAINST THE ROMA AMONG XENOPHOBES. MORE EFFORT IS NEEDED TO BREAK THIS VICIOUS CYCLE." Council of Europe

12 The first report of the seminar series focused on Roma and child protection considerations, see Pavee Point and the HSE, <u>Roma Communities and Child Protection Considerations</u>, Dublin: Pavee Point and the Health Service Executive, 2012.

13 Patricia Kennedy, <u>Maternity in Ireland: A Woman-Centred Perspective</u>, Dublin: The Liffey Press, 2002.

This section provides an overview of the historical and contemporary situation of Roma in Europe and Ireland. It focuses on the socio-economic, cultural, political and legal context of Roma, including persistent experiences of anti-Roma racism, discrimination, violence and hate crime across Europe.

FACTS AND FIGURES ABOUT ROMA

People who identify as Roma are part of a minority ethnic group that originated in Northwest India. EU institutions use 'Roma' as an umbrella term for people who self-identify as belonging to Roma, Sinti, Travellers, Ashkali, Manush and other groups - this includes Irish Travellers.¹⁴

Irish Travellers are an indigenous minority ethnic group who have been part of Irish society for centuries. Although Irish Travellers are a distinct ethnic group from other Roma, there are parallels in terms of history of nomadism, distinct culture and strong identity associated with family networks. These distinguish Roma and Irish Travellers from majority populations. They also share the experiences of racism and discrimination based on their ethnic background. The nomadic identity of Irish Travellers has been devalued and criminalised through legislation, such as the Housing (Miscellaneous Provisions) Act, 2002. While Roma also have a history of nomadism many were forced to become sedentary under communist regimes. This contrasts with the experience of many Roma now, who have been forced to move and migrate in the face of discrimination and/or violent attacks.¹⁵

Immediate and extended family is a core part of personal identity and Roma culture. It is quite usual for three or four generations of the same family to live together, and Roma who migrate tend to do so with their extended family. The family structure plays a strong role in education about culture, history, and traditions.¹⁶ Roma means 'people' in Romani and is the preferred term used to describe members of Roma communities.¹⁷ Because of the way in which the term 'Gypsy' has been used in some countries, this can be considered derogatory. Although Roma communities can be said to share similar cultural practices, language, history and experiences, Roma are an extremely diverse group and cannot be seen as a homogenous group.

Roma have been European citizens for centuries and constitute the largest minority group in the EU. The Council of Europe estimates that there are 10-12 million Roma living in Europe. Roma live mainly in Eastern and Central Europe, with the largest Roma communities in Romania (est. 2 million) and Slovakia (est. 600,000). Demographically, the Roma population in these countries is approximately 10% of each of the countries' overall population.

Roma speak a Sanskrit-based language called Romani that now exists in similar forms across European countries. Romani is the most extensively spoken language with an estimated 60 variants. Generally, Roma speak the language of the country where they reside. However, Roma who have moved and migrated to another country can often experience language barriers. The use of interpreters and translators in services can be common. However, due to experiences of racism and discrimination in country of origin, a non-Roma interpreter from their country of origin may be unsuitable.

It is important not to over-generalise or stereotype in relation to Roma communities. In fact, stereotypes and prejudices against the Roma are so deeply rooted in European culture that they are often not perceived as such and accepted as fact. The negative behaviour of one individual tends to be automatically applied to all – with no distinction either between different groups of Roma – and is attributed to Romani culture instead of to the individual.¹⁸

ROMA EXCLUSION

HISTORY AND CONTEMPORARY SITUATION

Roma are united by experiences of racism and discrimination. The former Commissioner for Human Rights of the Council of Europe Thomas Hammarberg notes that "Europe has a shameful history of discrimination and severe repression of the Roma. There are still widespread prejudices against them in country after country on our continent".¹⁹

Roma have fled violence and persecution for centuries, and this continues to this day. From the sixteenth to eighteenth centuries, Roma were subjected to anti-Gypsy laws in Western and Central Europe. In Romania, Roma were enslaved. Efforts to expel Roma were gradually replaced in many countries with forced assimilation policies. For example, Roma were banned from wearing distinctive clothing, speaking Romani, or marrying other Roma. During the Holocaust, the Porajmos, it is estimated that between 500,000 and 1.5 million Roma were killed.²⁰ Roma were also targeted and exterminated under fascist regimes in Italy and Romania. Roma have since struggled to be acknowledged for their persecution during the Second World War.

The experiences and situation of Roma differ from country to country. However, Roma continue to be subjected to discrimination and racism across Europe. Openly racist attitudes against Roma are widely tolerated and even extreme racism takes place without condemnation. The European Union Fundamental Rights Agency (FRA) documented in 2011 that 46% of Roma felt discriminated against in the previous year.²¹

Roma have been subjected to house raids, repeated forced evictions, forced sterilisations and police brutality. Anti-Roma rhetoric across Europe is common. In France, the Government has used anti-Roma sentiment to legitimise the policy of expulsion of Roma, by using force if necessary.²² The Commissioner for Human Rights for the Council of Europe has noted that anti-Gypsyism is being exploited by extremist groups in several European countries. For example, the Commissioner

14 European Union Agency for Fundamental Rights, <u>The Fundamental Rights</u> <u>Position of Roma and Travellers in the European Union</u>, http://fra.europa.eu/ sites/default/files/fra_uploads/1012-roma-travellers-factsheet_en.pdf.

- ¹⁵ For more information see Pavee Point, <u>Roma in Ireland an Initial Needs</u> <u>Analysis</u>, Pavee Point Traveller Centre, 2002.
- 16 Louise Lesovitch, <u>Roma Educational Needs in Ireland: Context and Challenges</u>, Dublin: City of Dublin VEC in association with Pavee Point Travellers Centre and the Roma Support Group, 2005.
- 17 This was agreed at the World Romani Congress in 1971, in Council of Europe, <u>Making Human Rights for Roma a Reality</u>, http://www.coe.int/web/coe-portal/ roma.
- 18 European Network Against Racism and European Roma Information Office, <u>Debunking Myths & Revealing Truths about the Roma, http://cms.horus.be/</u> files/99935/MediaArchive/publications/roma%20final%20pdf.pdf.
- 19 Thomas, Hammarberg <u>Forced Evictions of Roma Families Must Stop.</u> Council of Europe, 2006, http://www.coe.int/t/commissioner/Viewpoints/060904_ en.asp.
- 20 Porajmos means 'Roma Holocaust' in Romani, see Huttenbach, H.R., 'The Romani Porajmos: The Nazi Genocide of Europe's Gypsies', in <u>Nationalities</u> <u>Papers</u>, Volume 9:3 (1991): pp. 373-394.

21 European Union Fundamental Rights Agency, <u>The Situation of Roma in 11 EU</u> <u>Member States: Survey Results at a Glance</u>, Luxembourg: Publications Office of the European Union, 2012.

22 ibid.

- 23 See Council of Europe, <u>Czech Republic: Nis Muižnieks says urgent action</u> <u>needed to protect Roma from racist extremism</u>, 2014, http://www. humanrightseurope.org/2014/03/czech-republic-nis-muiznieks-says-urgentaction-needed-to-protect-roma-from-racist-extremism/.
- 24 ERRC, <u>Roma under Attack: Violence Against Roma Surges in Central and</u> <u>Eastern Europe</u>, 2012, http://www.errc.org/.

has stated deep concerns about patterns of anti-Roma events in the Czech Republic and stated the need for urgent action to protect Roma from racist extremism.²³ The European Roma Rights Centre reports that violence against Roma communities is rising across Europe. The attacks they have documented include police violence, arson attacks, mob violence and anti-Roma demonstrations, including an attack in Hungary where six Roma were murdered by vigilantes in 2010.²⁴

Roma continue to experience discrimination in housing, education, employment, health, access to goods and services, and decision-making. A survey by the FRA covering 11 EU countries shows that one in three Roma is unemployed and 90% live below national poverty lines.²⁵ The European Commission notes that

"THE DISCRIMINATION, SOCIAL EXCLUSION AND SEGREGATION WHICH ROMA FACE ARE MUTUALLY REINFORCING. THEY FACE LIMITED ACCESS TO HIGH QUALITY EDUCATION, IN INTEGRATION INTO THE LABOUR MARKET, CORRESPONDINGLY LOW INCOME LEVELS, AND POOR HEALTH WHICH IN TURN RESULTS IN HIGHER MORTALITY RATES AND LOWER LIFE EXPECTANCY COMPARED WITH NON-ROMA." ²⁶

Throughout Europe, the average life expectancy of Roma and Travellers is shorter than that of non-Roma and non-Travellers. Roma and Traveller infant mortality rates are also higher. The Council of Europe states that Roma and Travellers face significant barriers in accessing health care. These include lack of resources to pay for insurance or treatment, discrimination in health care provision and lack of trust in services. Very few Roma or Travellers work in health care provision.²⁷

Roma experience repeated forced evictions and expulsions.²⁸ In many cases where people have been evicted, they have not been given notice, their accommodation has been demolished and they have not been provided with alternative accommodation. In some cases, families have been moved to places unfit for human habitation, such as toxic rubbish dumps. Such actions breach international human rights law. In Italy, a 'nomad emergency' led to the forced eviction of Roma without the provision of alternative accommodation or

²⁵ European Union Fundamental Rights Agency, <u>The Situation of Roma in 11 EU</u> <u>Member States</u>, 2012.

²⁶ European Commission, <u>The social and economic integration of the Roma in</u> <u>Europe</u>, 2010.

²⁷ Council of Europe, <u>Human Rights of Roma and Travellers in Europe</u>, Council of Europe Publications, Strasbourg: 2012.

²⁸ Amnesty International, <u>Mind the Legal Gap: Roma and the Right to Housing in</u> <u>Romania</u>, Amnesty International Publications, 2011.

prior notice of the eviction.²⁹ A mass forced eviction of Roma took place in Serbia in April 2012. Authorities failed to consult with the Roma communities affected, and denied them adequate information, notice and legal remedies.³⁰ French authorities forcibly evicted more than 21,537 Romani migrants in 2013, this was double the figure from 2012.³¹

Roma children in many European countries remain excluded from quality education. Roma can be segregated in Roma-only classes or schools, and placed in schools for children with intellectual disabilities. The conditions in these schools and classrooms are crowded and inadequate, and there are low teacher expectations of Roma. Roma children face serious challenges to completing a basic standard of education. In 2007 the European Court of Human Rights ruled the Czech Government to have discriminated against Roma in education by denying Roma children access to mainstream education through national policy.³²

ROMA IN IRELAND

It is estimated that there are 5,000 Roma currently living in Ireland. Roma in Ireland mostly come from Romania, the Czech Republic, Slovakia, Hungary, Poland and Bulgaria.

There is very little accurate and reliable data available about Roma in Ireland as ethnicity is not included as a category in official data collection, including in the Census. The lack of accurate information on Roma communities makes it difficult to develop and implement effective and appropriate policies and services.

It is important to note that Roma in Ireland constitute a very diverse community. However, many Roma in Ireland experience disadvantages in accessing education, health, employment and adequate housing, and are subjected to experiences of racism, exclusion and poverty. Roma have been portrayed in a negative light in the Irish media and are often associated with criminal activities and 'organised begging'. Roma also experience a high level of racism in Ireland. Racist incidents against Roma include attacks on houses and verbal abuse. Roma women in particular report not being let in to shops or other services and being subjected to racist comments by service providers. Roma are also subject to racist comments by high ranking public officials and elected representatives. For instance, in 2013, a Judge was reported as saying,

"I ASSUME FROM HIS APPEARANCE THAT HE'S FROM THE ROMA COMMUNITY WHO CAME HERE TO DO WHAT ALL OF THEM TEND TO DO, TO USE THE STREETS TO BEG" ³³

ROMA AND THE RIGHT TO WORK AND SOCIAL PROTECTION IN IRELAND

Many Roma working in Ireland are employed in lowskilled, low-paid areas of employment. Many find it difficult to gain employment due to factors including racism, discrimination and lack of training and formal education. There is a lack of vocational training options for Roma in Ireland and no clear strategy to facilitate Roma participation in mainstream training programmes.

Many Roma are not meeting the Habitual Residence Condition (HRC) which is a set of criteria that social welfare claimants need to meet to show a connection with the Irish state.

Five factors are considered to determine applicants' eligibility for the HRC;

- 1. Main centre of interest
- 2. Length and continuity of presence
- 3. Length and reason for any absence
- 4. Nature and pattern of employment
- 5. Future intention

Roma can face difficulties proving a place of residence in cases where they live with an extended family and do not have a tenant's agreement. Endemic discrimination in education and employment makes it difficult to prove a strong pattern of employment. Low literacy levels and language barriers create difficulties in responding to the Department of Social Protection in a timely manner, and may mean that some do not have all the documentation needed. As a result, many Roma are unable to meet the criteria of the HRC.

There is no safety net for people waiting on a decision with regard to the HRC. Although an urgent needs payment may be issued, this is a discretionary payment. This is unsustainable for people waiting significant periods of time for decisions in relation to their applications. This places Roma in Ireland in very vulnerable positions.

The implementation of this policy has a hugely negative and disproportionate impact on Roma and is a major cause of poverty and subsequent lack of access to adequate accommodation, access to education and healthcare. This is causing huge suffering within the Roma community. It is a cause of hunger, homelessness and poverty.³⁴

Concerns about the HRC have been raised by the Special Rapporteur on extreme poverty and human rights. She states that,

"THIS REQUIREMENT CAN POSE A SIGNIFICANT THREAT TO THE ACCESS TO ESSENTIAL SERVICES AND THUS ENJOYMENT OF HUMAN RIGHTS BY MEMBERS OF VULNERABLE GROUPS, PARTICULARLY PEOPLE EXPERIENCING HOMELESSNESS, TRAVELLERS, ASYLUM-SEEKERS, MIGRANT WORKERS AND RETURNING IRISH MIGRANTS. THE SPECIAL RAPPORTEUR ENCOURAGES THE GOVERNMENT TO REVIEW THE IMPACT OF THE CONDITION AS A MATTER OF PRIORITY." ³⁵

Ultimately, there is a lack of research and initiatives developed to support Roma inclusion in Ireland. For those who are unable to find employment or access supports, options include reliance on charities or 'voluntary repatriation' to country of origin.

30 Amnesty International, <u>Serbia: Hundreds of Families Face Uncertainty after</u> <u>Belvil Eviction</u>, 2012, http://www.amnesty.org/en/news/serbia-hundredsfamilies-face-uncertainty-after-belvil-eviction-2012-04-26#.T5I6aGxXjTA. facebook.. 12-13

²⁹ Amnesty International, Italy: <u>Zero Tolerance for Roma</u>, London: Amnesty International Publications, 2011.

³¹ European Roma Rights Centre, Forced Evictions of Roma double in France, as <u>Authorities Pursue Failed, Expensive Policy</u>, 2014, http://www.errc.org/article/ forced-evictions-of-roma-double-in-france-as-authorities-pursue-failedexpensive-policy/424.

³² European Union Agency for Fundamental Rights, <u>The Situation of Roma</u> <u>EU Citizens Moving to and Settling in Other EU Member States</u>, 2009, Luxembourg: European Communities.

Justice Patrick McCartan, Dublin Circuit Criminal Court, March 2013.

³⁴ Pavee Point, <u>Position Paper: The Impact of the HRC on Travellers and Roma</u>, September 2011.

³⁵ UN General Assembley, <u>Report of the Special Rapporteur on extreme poverty</u> and human rights, Magdalena Sepúlveda Carmona, 2012, A/HRC/20/25.

SECTION 03: ROMA AND THE RIGHT TO MATERNAL HEALTH



"THE RIGHT TO HEALTH IS CLOSELY RELATED TO AND DEPENDENT UPON THE REALIZATION OF OTHER HUMAN RIGHTS, AS CONTAINED IN THE INTERNATIONAL BILL OF RIGHTS, INCLUDING THE RIGHTS TO FOOD, HOUSING, WORK, EDUCATION, HUMAN DIGNITY, LIFE, NON-DISCRIMINATION, EQUALITY, THE PROHIBITION AGAINST TORTURE, PRIVACY, ACCESS TO INFORMATION, AND THE FREEDOMS OF ASSOCIATION, ASSEMBLY AND MOVEMENT. THESE AND OTHER RIGHTS AND FREEDOMS ADDRESS INTEGRAL COMPONENTS OF THE RIGHT TO HEALTH."

UN Committee on Economic, Social and Cultural Rights

INTRODUCTION

Realisation of the right to health is a multi-dimensional issue and interdependent with a broad range of human rights. The right to health is the enjoyment of a range of services, goods, facilities and conditions necessary to ensure that people can reach the highest attainable standard of physical and mental health.³⁶ This section outlines the human rights context to the right to health. Ratified by the Irish State, these set the parameters for Roma rights to maternal health in Ireland and the nature of obligations by the Irish State to respect, protect and fulfil that right. Finally, the realisation of the Roma right to maternal health is examined in the context of practices and policies associated with Roma women in health services in Europe.

INTERNATIONAL HUMAN RIGHTS FRAMEWORK FOR THE PROTECTION OF HEALTH

The right to health and medical care has been recognised in numerous international human rights instruments since 1948. Article 25 of the Universal Declaration of Human Rights states that "everyone has the right to a standard of living adequate for the health and well-being of himself and of his family".³⁷ The Article specifically recognises the right to special care and assistance during motherhood and childhood. These commitments were later reaffirmed by the Vienna Declaration and Programme of Action by recognising civil, political, economic, social and cultural rights to be universal, indivisible, interrelated and interdependent. It asserted that extreme poverty and social exclusion inhibit the full enjoyment of human rights.

Article 12 of the International Covenant on Economic, Social and Cultural Rights (ICESCR) recognises the "right of everyone to the enjoyment of the highest attainable standard of physical and mental health".³⁸ It provides a comprehensive basis for protecting the right to health and outlines a number of non-exhaustive steps for State Parties to take to fulfil this right. The General Comment No.14 by the Committee on Economic, Social and Cultural Rights (CESCR) recognises a number of underlying socio-economic determinants of health, including housing, food, nutrition, safe water and sanitation, and access to health related information and education. It affirms that elements to ensure the right to health include the availability, accessibility, acceptability and quality of health care. These elements recognise that health services, facilities and goods must be accessible without discrimination, particularly for the most marginalised groups in society, such as women and ethnic minorities.

The General Comment acknowledges the role of socio-cultural and biological determinants which influence the health of women and men. It specifically addresses the right to maternal, sexual and reproductive health, and notes that measures to improve services must focus on access to family planning, information, antenatal and postnatal care, and resources to act on information. It urges States to develop and implement strategies and policies from a gender-balanced approach taking into account the needs of marginalised groups. This includes the provision of culturally appropriate healthcare services.

The principles of non-discrimination and equality are recognised throughout ICESCR. Adherence to non-discrimination is an immediate obligation under Article 2 (2), defining discrimination as either direct or indirect. Accordingly the Committee notes the need to address formal discrimination as well as substantive discrimination. This "requires paying sufficient attention to groups of individuals which suffer historical or persistent prejudice instead of merely comparing the formal treatment of individuals in similar situations." ³⁹ CESCR also notes the need to tackle systemic discrimination and points to the need to prioritise marginalised groups through allocation of greater resources to such groups and ensuring the implementation of law and policy.⁴⁰

40 ibid.

³⁶ UN General Assembly, <u>International Covenant on Economic, Social and Cultural Rights</u>, 16 December 1966, United Nations, Treaty Series, vol. 993, p. 3, Article 12.

³⁷ The United Nations, <u>Universal Declaration of Human Rights - Preamble</u>, 1948, adopted 10 December 1948 UNGA Res 217 A(III) (UDHR).

³⁸ UN General Assembly, <u>International Covenant on Economic, Social and Cultural</u> <u>Rights</u>, 16 December 1966, United Nations, Treaty Series, vol. 993, p. 3, Article 12.

³⁹ Committee on Economic, Social and Cultural Rights (CESCR). General Comment 14, 2000.

The right to health is also recognised in other international instruments including the International Convention on the Elimination of All Forms of Racial Discrimination, the Convention on the Elimination of All Forms of Discrimination against Women, the Convention on the Rights of the Child and the Convention on the Protection of the Rights of all Migrant Workers and their Families.

The Convention on the Rights of the Child outlines specific measures for State Parties to undertake, including lowering the rates of infant and child mortality, ensuring suitable antenatal and postnatal health care, and access to information and education on maternal health related concerns. Article 12 of the Convention on the Elimination of all Forms of Discrimination against Women specifically affirms that states should take appropriate measures to eliminate discrimination against women in the field of health care. This includes ensuring equal access to maternal health care services and adequate nutrition during pregnancy and lactation. These should be provided for free where necessary.

EUROPEAN HUMAN RIGHTS FRAMEWORK FOR THE PROTECTION OF HEALTH

Under the European Convention on Human Rights, the European Court of Human Rights has developed indirect protection for social and economic rights by recognising that political and civil rights often intersect with them.⁴¹ The Revised European Social Charter guarantees the protection of social rights.⁴² Together with the Charter, the European Committee on Social Rights make a specific note of the right to the protection of maternity and recognises health care as "a prerequisite for the preservation of human dignity".⁴³ The Charter of Fundamental Rights of the European Union makes these fundamental rights more visible and clear, and applies directly to Member States when implementing EU legislation.⁴⁴

There are several EU proposals that directly relate to the inclusion of Roma, such as Directive 2000/43/ EC which obliges Member States to ensure nondiscriminatory access to healthcare, social protection, housing, employment, education and training.⁴⁵ More specific to the situation of Roma, the EU Framework for

42 Council of Europe, *European Social Charter (Revised)*, 3 May 1996, ETS 163.

44 European Union, <u>Charter of Fundamental Rights of the European Union</u>, 7 December 2000, Official Journal of the European Communities, 18 December 2000 (OJ C 364/01).

National Roma Integration Strategies up to 2020 aims to target the marginalisation and poor socio-economic conditions experienced by Roma in Europe.⁴⁶ This European Commission initiative provides a European structure to guide the development of national Roma inclusion policies in every member state; and to mobilise funds to support this work. The European Commission states that: "[National Strategies should] be designed, implemented and monitored in close cooperation and continuous dialogue with Roma civil society, regional and local authorities." The framework develops a targeted approach to Roma inclusion by setting goals in health, education, employment and housing. The target for health is to decrease the gap in health status between Roma and the rest of the population. In December 2013, the European Council adopted a Recommendation on Effective Roma Integration Measures in the Member States, which is the first EU legal instrument to hold Member States to account for Roma inclusion.

Member States are expected to address inequalities in health care by addressing issues of access to quality healthcare, poor living conditions, high infant mortality, and the significantly lower life expectancy among Roma. The strategy specifically asserts that Member States should ensure access to preventative and quality healthcare for Roma women and children in line with the principle of non-discrimination. Members of Roma communities should be directly involved in the development and implementation of healthcare programmes.⁴⁷

As part of the EU Framework for National Roma Integration Strategies, Ireland has submitted a National Traveller and Roma Integration Strategy to the European Commission. Pavee Point has identified significant shortcomings with this document. It contains no goals, timeframes, funding or monitoring mechanism, Roma are largely excluded from the document, and there was no consultation or active participation of Roma, Travellers and wider civil society in the development of the strategy. Pavee Point has urged the Government to review the existing strategy and address these shortcomings.⁴⁸ The European Commission has specifically noted that "the specific situation and challenges met by Roma regarding health should be better described."⁴⁹ The most recent assessment (2013) of Ireland's National Traveller Roma Integration Strategy by the European Commission has been very critical. Out of 22 criteria set by the Commission Ireland is deemed to have met just 4.50

LEGISLATIVE AND POLICY FRAMEWORK FOR ROMA MATERNAL HEALTH IN IRELAND

As a party to the international and regional human rights treaties, the Irish State is obliged to protect and deliver the right to health. However, there are significant health inequalities among the Irish population. For instance, the mortality rate among Irish Traveller women is 3 times higher and infant mortality is 3.5 times higher than among the general population.⁵¹

The Irish Constitution does not explicitly recognise the right to the promotion and protection of health, although the Irish Courts have later interpreted Article 40.3.1 of the constitution to guarantee this right in the case of Heeney v Dublin Corporation.

Healthy Ireland - A framework for improved health and wellbeing, 2013 - 2025, is the national framework for action to improve health in Ireland. This document states the link between women's socio-economic circumstances and their health, and thus the health of their children. It identifies early intervention before birth as critical to children's health. It identifies a government commitment to reducing the gap in low birth rates between children from the lowest and highest socioeconomic groups through the National Anti-Poverty Strategy 2002. It also sets a target for reducing the percentage of people at risk of poverty and in consistent poverty. It states that indicators will need to be disaggregated by key equality characteristics including ethnicity and migrant status.

The Department of Health and the Minister for Health carry the main responsibility for the development and evaluation of health policy, legislation and strategic planning. The Health Act of 1970 assigned the cost of health care to be the responsibility of each individual, with the exception of cases where the cost would cause 'undue hardship' for an individual. It introduced the medical card system which entitles free access to public health services and acute hospital care if deemed eligible through means test, discretionary assessment and EU entitlement. With the Health Act 2004 the provision of health services became the responsibility of the Health Service Executive.

- 49 European Commission, <u>Comission Staff Working Document: Accompanying</u> <u>the document National Roma Integration Strategies: a first step in the</u> <u>implementation of the EU Framework</u>, Brussels, 21.5.2012, SWD(2012) 133 final.
- 50 European Commission, <u>Steps Forward in Implementing National Roma</u> Integration Strategies, 2013.
- 51 Pavee Point, <u>Selected Key Findings and Recommendations from the All-Ireland</u> <u>Traveller Health Study</u> 2010.

Health services in Ireland are undergoing significant changes at present. The Health Service Executive (HSE) Directorate was established in 2013. Future Health - A Strategic Framework for Reform of the Health Service 2012 - 2015 outlines the proposed steps for reform of the health services. The Child and Family Agency (Tusla) has also been established. It is imperative that these changes present an opportunity to address Roma health rights and result in positive outcomes for Roma.

Under the HSE's Maternity and Infant Care Scheme, every pregnant woman who is ordinarily resident in Ireland is entitled to free maternity care even without a medical card. 'Ordinarily resident' refers to women who are living or intend to remain living in Ireland for at least one year. The service is provided by a GP and a hospital obstetrician, and includes a number of antenatal and postnatal services. Mothers are also entitled to free in-patient and out-patient public hospital services in instances that relate to pregnancy and birth. As a scheme, mothers are required to apply in order to qualify for free maternity health care.⁵²

The National Action Plan for Social Inclusion 2007-2016 identifies Travellers and other minority ethnic groups as among the most vulnerable groups in Ireland. It emphasises the importance of the HSE National Intercultural Health Strategy in addressing health needs of minority groups.⁵³

The HSE National Intercultural Health Strategy 2007 - 2012 aims to tackle issues of access, inequality and quality of services for people with diverse ethnic backgrounds. It provides a framework through which to plan, deliver and support health care services in order to provide accessible, effective and quality services. The strategy explicitly mentions Roma as being among the most disadvantaged groups in Ireland, and recognises poor living conditions to be an increasing concern among Roma communities. The strategy raises particular concerns in relation to vulnerable women and maternal and reproductive health. It sets out recommendations to address issues of access, follow-up care, and practical and emotional support particularly for young and first-time mothers. It also recognises the importance of including an ethnic identifier in data collection to produce evidence based data.

The HRC has a significant effect on the realisation of Roma right to health due to the difficulty experienced by many Roma to qualify. The impact of the HRC on Roma maternal health is further outlined in section four of this report.

⁴¹ Council of Europe, <u>European Convention on the Protection of Human Rights</u> <u>as amended by Protocols Nos. 11 and 14</u>, supplemented by Protocols Nos. 1, 4, 6, 7, 12 and 13, http://www.echr.coe.int/NR/rdonlyres/D5CC24A7-DC13-4318-B457-5C9014916D7A/0/Convention_ENG.pdf.

⁴³ Council of Europea Committee of Social Rights, <u>Digest of the Case</u> Law of the European Committee of Social Rights, 1 September 2008.

⁴⁵ Council of the European Union, 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, 19.7.2009).

⁴⁶ European Commission, <u>An EU Framework for National Roma Integration</u> <u>Strategies up to 2020</u>, 2011.

⁴⁷ ibid.

⁴⁸ Pavee Point, <u>Briefing Note on the National Traveller Roma Integration Strategy</u>, 2013.

⁵² Health Service Executive, <u>Maternity and Infant Care Scheme</u>, 14 July 2010, http://www.hse.ie/eng/services/Find_a_Service/maternity/combinedcare.ht

⁵³ Government of Ireland, <u>National Action Plan for Social Inclusion 2007-2016</u>, Dublin: Stationery Office, 2007.

ROMA RIGHT TO HEALTH IN EUROPE POLICY AND PRACTICE

"PUT YOUR WIFE INTO A WHEEL-BARROW AND WHEEL HER TO THE MEDICAL CENTRE". Emergency medical official to a Roma person in Croatia

There is a serious gap in the standard of health between Roma and non-Roma in Europe. Statistically, Roma health scores significantly lower in both Western and Eastern Europe, the average life expectancy is estimated to be approximately 10 years shorter than among the general population in countries such as the UK, Hungary and Spain.⁵⁴ There is also evidence of higher infant and child mortality rates - in some countries Roma child mortality rates are two to six times higher than among the general population.⁵⁵ In Ireland, the life expectancy for Traveller women is 11.5 years less than the general population and the infant mortality rate for Travellers is 3.6 times the rate of the general population.⁵⁶

Direct and/or indirect discrimination, racism, social exclusion and poverty create economic, physical and information barriers to accessing health care. Barriers to formal employment and social protection create financial difficulties to access treatment and health insurance. Research by the FRA found less than one out of three Roma respondents to be in paid employment, and approximately 20% to have no medical insurance or be unaware whether they are covered by insurance.⁵⁷ In some areas in Bulgaria up to 90% of Roma have no health insurance. Roma EU migrants in France are reported to experience more difficulties with accessing universal health insurance in comparison to other non-Roma EU migrants.⁵⁸

Geographic isolation from healthcare services creates physical barriers to access. For instance, in Bulgaria an estimated 55% of Roma experience difficulties with physical access as a result of isolation from areas with healthcare provision and lack of means of transportation.⁵⁹ Inadequate housing conditions, insecure tenure, forced evictions, overcrowding, toxic living environment, homelessness, and a lack of public infrastructure in areas with high residence of Roma people, further contribute to serious obstacles to the attainment of health.⁶⁰

Lack of access to education and information about rights and entitlements, health services and health related issues, also impede access and engagement in health care services. Poor levels of literacy and language skills further complicate accessing vital information. Some Roma can lack proof of identity or official documentation regarding their legal status, which generally act as gateways to accessing public services.⁶¹ Reports on discrimination against Roma across Europe, show that Roma are persistently denied access to health care and treatment. Direct discrimination, the differential and unfavourable treatment of a person on grounds of racial or ethnic origin, is evident in instances of denial of emergency aid, refusals to respond to calls from Roma settlements, segregation in health facilities, refusal to treat Roma patients, poor and degrading treatment, and verbal abuse.⁶² Roma are also subjected to indirect discrimination, which occurs when an apparently neutral provision, practice or criterion places a person from a distinct racial or ethnic origin at a particular disadvantage.63

The FRA reports discrimination against Roma by health care personnel to be a particular problem, with 17% of respondents reporting to have had experienced discrimination in the previous 12 months.⁶⁴ There are reports about refusals to treat Roma patients on grounds of Roma being 'noisy' and 'dirty'.⁶⁵ In countries where GPs have the right to choose patients, some have refused to register Roma on the grounds of their ethnicity or assumptions about their inability to pay for treatment.⁶⁶ Traveller specific data in the UK shows that 17% of Travellers have experienced discrimination when trying to register with a GP.⁶⁷

Human rights violations against Roma in healthcare have been highlighted in several European countries. Bulgaria was found to be in violation of the European Social Charter in 2008 on the grounds of imposing restrictions that had a disproportionate effect on Roma to access medical assistance and insurance, discrimination by healthcare providers, and remoteness of medical facilities.⁶⁸ In Slovakia, Bulgaria and Moldova violations include long delays in the arrival of emergency medical assistance and refusals to respond to calls from Roma settlements.⁶⁹

In September 2011, the ERRC raised concerns about child marriage to the UN Committee on the Rights of the Child (CRC) and the Committee on the Elimination of Discrimination Against Women (CEDAW), which raises health concerns among others.⁷⁰ Early marriage has been historically linked to the slavery of Roma in Romania as a way of protecting Roma girls from rape by their "owners" or "owners" sons.⁷¹ It is important to note the diversity of views within Roma communities in relation to early marriage and to avoid simple equations between Roma culture and early marriage.⁷² Where early marriage does occur this can impact on Roma girls' access to education and wider human rights, including health.

54 Council of Europe, *Human Rights of Roma and Travellers in Europe*, 2012.

- 55 See statistics on Romania, Slovakia, Hungary, Bulgaria and the Czech Republic, in UNDP, <u>The Roma in Central and Eastern Europe</u>, 2003.
- 56 Pavee Point, <u>Selected Key Findings and Recommendations from the All-Ireland</u> <u>Traveller Health Study</u>, 2010.
- 57 European Union Fundamental Rights Agency, <u>The Situation of Roma in 11 EU</u> <u>Member States</u>, 2012.
- 58 Since 2007 EU citizens have been required to provide proof of sufficient resources in order to access universal health insurance in France. This is difficult for the most marginalised and impoverished Roma to provide. For more information, see Council of Europe, <u>Human Rights of Roma and Travellers</u> <u>in Europe</u>, 2012.

59 ibid.

60 European Communities, <u>Breaking the Barriers - Romani Women and Access to</u> <u>Public Health Care</u>, Luxembourg: European Communities Publications, 2003.

61 ibid.

- 62 ibid.
- 63 European Commission, <u>An EU Framework for National Roma Integration</u> <u>Strategies up to 2020</u>, 2011.
- 64 European Union Fundamental Rights Agency, <u>The Situation of Roma in 11 EU</u> <u>Member States</u>, 2012.

- 65 Emergency medical official to a Roma person in Croatia, ERRC, <u>Ambulance not</u> on the Way: The Disgrace of Health Care for Roma in Europe, ERRC, 2006.
- 66 European Communities, <u>Breaking the Barriers</u>, 2003.
- 67 Council of Europe, <u>Human Rights of Roma and Travellers in Europe</u>, 2012.

68 ibid.

- 69 Emergency medical official to a Roma person in Croatia, in ERRC, <u>Ambulance</u> <u>not on the Way</u>, 2006.
- 70 ERRC, <u>Submission to the Joint CEDAW-CRC General Recommendation</u> Comment on Harmful Practices: Child Marriages among Roma, 2011.

ROMA MATERNAL HEALTH

IN EUROPE

"YOU GYPSIES HAVE TOO MANY CHILDREN AND YOUR BREATH SMELLS FROM HUNGER."

Statement by a medical professional in Macedonia while Roma woman was giving birth.

The poor health outcomes among Roma generate specific gender related concerns. Roma women are subjected to multiple discrimination based on their gender, ethnicity, socio-economic status and other factors. In this context, numerous reports have raised particular concerns about the sexual, reproductive and maternal health of Roma women.

There are a number of issues that Roma women face in accessing maternal health care services. The issues result in low rates of engagement in antenatal and postnatal care, high rates of sickness, infant mortality, miscarriage, death, serious damage to woman's health after childbirth, and lower life expectancy. For instance, miscarriage and infant mortality among Roma in Moldova are almost twice as high among the general population.⁷³

The limited access to healthcare during maternity is often directly related to unequal opportunities to access employment, education, adequate housing, social protection and legal status. These issues are compounded by experiences of racism and discrimination in services, abuse by practitioners during pregnancy and childbirth, and lack of physical access to healthcare.⁷⁴

According to the FRA, the unemployment rate among Roma women is higher than among non-Roma women and Roma men. In comparison to Roma men, the unemployment rate is approximately one third higher among Roma women.⁷⁵ As a result, women are less likely to have access to health insurance and funds to pay for treatments.

Roma women are also less likely to have access to information on preventative and reproductive care due to past and persistent experiences of discrimination in education and health. Inclusion in education is particularly important for Roma girls, as schools are often a key source of information on health related issues.

72 ibid.

73 ERRC, Ambulance not on the Way, 2006.

74 European Communities, <u>Breaking the Barriers</u>, 2003.

⁷¹ Oprea, Alexandra, <u>Child Marriage a Cultural Problem, Educational Access</u> <u>a Race Issue? Deconstructing Uni-Dimensional Understanding of Romani</u> <u>Oppression.</u> 2005, http://www.errc.org/cikk.php?cikk=2295

⁷⁵ European Union Fundamental Rights Agency, <u>The Situation of Roma in 11 EU</u> <u>Member States</u>, 2012.

Inadequate housing and living conditions and lack of access to public infrastructure, compound the effects for pregnant women and place them and their children's health at risk. Women are often forced to neglect their own needs in terms of accessing health, education or other public services in an effort to ensure basic needs for their children.⁷⁶

Discrimination against Roma women in health care is particularly evident in maternity wards and emergency care. There are various reports by the ERRC about human rights violations against Roma women in healthcare services. For instance, in Bulgaria a Roma woman bled to death as a result of being left without medical attention for several hours after giving birth. In another case, a pregnant Roma women who was bleeding and experiencing abdominal pain was denied care by emergency aid and her GP. Two days later she found out that the foetus was no longer alive, but after filing a complaint she received no compensation or information about her complaint. In Macedonia a Roma woman miscarried in a hospital as a result of being left unattended, she was also refused pain relief by a nurse on duty who thought that the woman was 'complaining too much'. The absence of trained medical professionals in assisting delivery is also reported in several countries. There is evidence of cases where medical students are used to assist in deliveries with Roma more often than with non-Roma women.⁷⁷ Cases of coercive sterilisation of Roma women without their knowledge or consent have been documented across Europe. Between the 1970's until the 1990's it was state policy in Czechoslovkia to sterilise Roma women so as to reduce their 'high and unhealthy' birth rate.⁷⁸ This was part of a policy to assimilate Roma into wider society and to stop the 'social risk' that Roma posed. The Czech ombudsman estimates that as many as 90,000 women from the former Czechoslovakia became infertile due to coercive sterilisation.⁷⁹ The ERRC has documented cases of coercive sterilisation as recently as 2007.⁸⁰ Women affected by this practice have not received adequate acknowledgement of this human rights violation or reparations.

Segregation of Roma in health facilities occurs regularly in some hospitals, particularly in maternity wards.⁸¹ The practice of allocating segregated wards, bathroom or eating facilities for pregnant Roma women has been reported in various countries. In Bulgaria Roma-only wards have been found to be visited less frequently by staff and have poorer sanitary conditions. In a hospital in Hungary, Roma-only wards have been left unattended by janitorial services with women required to clean the wards themselves. In the same hospital doctors have been reported to refuse to touch Roma patients.⁸²

Discrimination and negative experiences contribute to short and long term effects for women, including mistrust in health services and professionals, unattended health problems, and ultimately increased social exclusion. Several initiatives in Europe have tried to overcome these effects by introducing Roma health mediators and combatting prejudiced and racist attitudes among health care professionals. Although some of these initiatives have been successful, culturally sensitive services remain restricted and there are very few Roma in Europe working in the health sector.83

SECTION 04: EXPERIENCES AND PRACTICES



M50

"WOMEN SHOULD NOT HAVE TO FACE RACISM; WOMEN SHOULDN'T BE AFRAID TO GO IN HOSPITAL." Interview with a Roma participant

76 European Communities, <u>Breaking the Barriers,</u> 2003.

- 77 Emergency medical official to a Roma person in Croatia, in ERRC, Ambulance not on the Way, 2006.
- 78 Helsinki Watch, <u>Struggling for Ethnic Identity</u> Czechoslovakia's Endangered Gypsies, New York:Human Rights Watch, 1992.
- 79 Beth Walker (Ed), State of the World's Minorities and Indigenous People, Minority Rights Group International, 2013
- 80 ERRC, NGOs Welcome Czech Republic Recommendation on Forced Sterilisations, March 2012, http://www.errc.org/article/ngos-welcome-czechrepublic-recommendation-on-forced-sterilisations/3971
- 81 European Communities, <u>Breaking the Barriers</u>, 2003.
- 82 Council of Europe, *Human Rights of Roma and Travellers in Europe*, 2012.
- 83 Council of Europe, Human Rights of Roma and Travellers in Europe, 2012.

The following section outlines the key discussion points of the seminar on maternal health and supplementary interviews with Roma and health care practitioners. It is important to highlight that the experiences of Roma in Ireland must be seen in the context of wider experiences of Roma in Europe. It is also important to note that Roma as an ethnic group is heterogeneous in the same way as any other group is. Therefore, the findings presented do not reflect the experiences of all Roma living in Ireland.

Overall, it is evident that past and/or current experiences of discrimination and racism influence access to antenatal and postnatal health care in Ireland. Poor living conditions, poverty, barriers to employment, social protection and medical cards, lack of access to information and lack of trust in service providers act as major obstacles for the fulfilment of Roma maternal health in Ireland. As a result, the maternal health among many Roma women appears to be comparatively poorer than among the general population. There is a lack of access to preventative care, which can increase the risk of infant mortality, premature birth and low birth weight.

The key findings are discussed thematically by first outlining the issues and barriers experienced by Roma women, followed by highlighting the challenges faced by practitioners.

The findings are divided into the following themes;

- Financial barriers: poverty and lack of social protection
- Fears over child protection concerns
- Negative experiences in health care services
- Lack of clear and accessible information
- Translation and interpretation services
- Inadequate housing conditions and homelessness
- Lack of data
- Engagement in health services

EXPERIENCES OF ROMA WOMEN

FINANCIAL BARRIERS: POVERTY AND LACK OF SOCIAL PROTECTION

"COULD YOU IMAGINE A WOMAN GOING TO HOSPITAL TO GIVE BIRTH AND HAVE NO MONEY OR MEDICAL CARD-WHAT IS SHE GOING TO DO?"

Interview with a Roma participant, Dublin, March 2013

Barriers to accessing employment and social protection, and resulting poverty and poor living conditions strongly shape the maternal health of Roma women in Ireland. Roma participants emphasised that the current restrictions imposed by the Habitual Residence Condition constitutes one of the main obstacles to access health care for women who are unable to qualify as habitually resident. With limited or no access to income and social protection, they are unable to pay for appointments and treatments and access medical cards.

Health practitioners reported that the health concerns Roma generally present with at hospitals would be more suitable and effective to deal with through primary healthcare. However, many Roma have limited access to primary care services due to lack of access to medical cards, obstacles registering with GP services, and the cost of primary care. As a result, many women delay accessing care to a late stage of pregnancy. The first point of contact for Roma women with a health service can be an A&E ward of a maternity hospital when already in labour.

The high cost of hospital care means that many Roma struggle to pay for fees and are unable to pay and engage in follow-up visits. Without a medical card or a referral from a GP, public out-patients, A&E patients, daily in-patients and long-stay patients are liable for statutory charges. These services can be provided free of charge at the discretion of the HSE in selected cases, where people have difficulty paying.⁸⁴ However, it appears that some Roma have been subjected to high hospital fees, some reporting to have received bills up to €1,200. It is also unclear how many Roma living in Ireland are aware or informed about the HSE's Maternity and Infant Care Scheme, under which every pregnant woman who is ordinarily resident in Ireland is entitled to free maternity care. It appears that women are given conflicting information at hospitals in terms of fees, and are not always informed about the scheme. The application form for the scheme is filled in together with a GP of a woman's choice. However, lack of GP access and language and literacy barriers, can prevent access to this information and the scheme.

Lack of finances also curtails the ability to access nutritious food during pregnancy, prepare for the birth of the child, and purchase necessary supplies such as clothing and nappies. Transportation and additional costs such as medication and medical equipment put an additional financial pressure on women. Roma participants reported that women who live in extreme poverty are often forced to generate income through begging in an effort to provide for basic needs for themselves and their children. It was strongly emphasised that begging for women is the last resort and not a cultural practice.

Many Roma women who experience poverty and destitution live in poor housing conditions or are homeless. Insecure tenure and overcrowding are common issues. Due to unsuitable and unsustainable living conditions, many Roma are forced to move from accommodation to accommodation. The need to satisfy more immediate needs, such as shelter and food, take centre stage for Roma women in these situations. This also impacts negatively on women's health status. In this context it becomes very difficult for a woman to have her right to health realised.

CHILD PROTECTION CONCERNS

It is important to highlight that there are little concerns raised over child protection issues within Roma families in terms of abuse or neglect. The concerns raised are linked to a situation of extreme poverty experienced by families, with parents having no means to provide basic supports for their children. It has become obvious that the HRC is resulting in serious issues of child poverty and destitution. Social workers have expressed great concerns over this situation. They have stated that although taking children into care should be a last resort, it may often seem like the only way to gain access to basic needs and services for Roma children.⁸⁵

Fears over child protection concerns among Roma must be examined in the context of past experiences elsewhere in Europe, where assimilationist policies have led to the disproportionate number of Roma children placed in state care. Young Roma women who have not qualified as habitually resident are particularly afraid of authorities removing their children from families. Underage marriage and childbearing, an issue within some Roma communities, are in conflict with legislation in Ireland and young Roma women in such situations are also afraid of state intervention.⁸⁶ The removal of two blonde Roma children into state care on the basis of their physical appearance in October 2014 has further exacerbated fears of engaging with authorities.⁸⁷ Such fears act as a deterrent for women to access antenatal and postnatal services.

The fear is based on a thinking that the scarce resources available to provide for children, poor housing conditions and poor health status of mothers would be used as reasons by authorities to remove children from families. Fears about the role of public health nurses during maternity also contribute to this situation. Follow-up home visits after birth can be understood as an opportunity for authorities to take Roma children into care or to seek payment for hospital services. As a result, public health nurses often experience difficulties with tracking mothers of new born babies when mothers make themselves inaccessible upon visits. This can mean children do not get vaccinations. This affects mothers' health, children's health and public health more widely. The need to explain the situation and purposes of home visits to women was identified as crucial in order to avoid these situations.

⁸⁴ This excludes long-stay patients whose charges can be altered to avoid hardship. For more information, see Health Service Executive, *Hospital Charges*, 25 Jan 2013. http://www.hse.ie/eng/services/Find_a_Service/hospitals/ Hospitalcharges.html.

⁸⁵ Pavee Point and the HSE, <u>Roma Communities and Child Protection</u> <u>Considerations</u>, 2012.

⁸⁶ See Oprea, Alexandra, <u>Child Marriage a Cultural Problem, Educational Access a</u> <u>Race Issue?</u> 2005.

⁸⁷ For more information on these cases see Irish Times, <u>Roma people now</u> <u>iscared' of having their children taken from them</u>, Oct 26 2013, http://www. irishtimes.com/news/politics/roma-people-now-scared-of-having-theirchildren-taken-from-them-1.1573960 and statement by UN Independent Expert on Minority Issues, Rita Izsák, <u>Roma in Europe: Guilty until proven</u> <u>innocent?</u>, 29 October 2013, http://www.paveepoint.ie/roma-in-europe-guiltyuntil-proven-innocent/

EXPERIENCES IN HEALTH CARE SERVICES

With numerous human rights violations against Roma across Europe, the level of trust and confidence in medical practitioners and other professionals is often low. Roma interviewees pointed out how past experiences in the country of origin act as a major deterrent for accessing healthcare in Ireland. Some Roma women in Ireland are reported to opt out of seeking medical attention during pregnancy in instances where they have been bleeding and experiencing abdominal pain. The fear of negative treatment by Irish practitioners is also linked to one of the reasons why Roma women may leave maternity hospitals soon after giving birth. This subsequently reduces the time of care given in hospitals, and creates barriers for practitioners to reach mothers within the first week of the child's birth.

The findings unveil serious concerns in relation to "institutional racism - the collective failure of an organisation to provide an appropriate and professional service to people because of their colour, culture or ethnic origin".⁸⁸ While many practitioners work in a positive and informed way with Roma, practices by other health care professionals show evidence of institutional racism in attitudes, behaviours and processes. These can be based on unwitting ignorance, prejudice, thoughtlessness and racist stereotyping, which have led to the disadvantage of Roma women.

There are a number of reported instances where Roma women have been unable to secure an appointment with a GP service. This illustrates willingness by Roma to engage in primary health care, but raises serious concerns in terms of practices of institutional racism. A Roma interviewee had witnessed an instance where a Roma woman was questioned about her ability to pay when trying to register with a GP service. She was asked to leave and instead attend the Mater Hospital, before being physically escorted out of the GP service. The reason given to the woman was "sorry the doctor is busy".

The participants highlighted that the refusal of care contributes to wider misconceptions among Roma about the Irish healthcare system. Having had been refused care by one health careprovider or practitioner can contribute to thinking that access to any healthcare in Ireland is exhausted. Ultimately, this results in low level of confidence in being able to secure healthcare in Ireland and women not accessing antenatal or postnatal care. Subjective experiences of Roma women in the healthcare system unveil experiences of overt and/or covert racism, prejudice and inappropriate treatment by healthcare practitioners. Negative and differential treatment is especially reported in cases where Roma have insufficient or no English language skills or with women whose appearance is more 'traditional'. An interviewee who at times accompanies Roma women to hospitals and healthcare centres stated...

..."I FEEL STRANGE, GOING TO THE HOSPITALS. IF I SAY SHE IS A ROMA WOMAN THEY DON'T CARE... BUT IF SHE IS WEARING A LONG SKIRT, LOOKING TRADITIONAL, THEY TREAT THEM DIFFERENTLY".

Racist stereotypes about Roma being 'dirty' and 'smelly' also appear to persist, with an example of a nurse opening a window without any given reason, even though the traditionally dressed Roma woman explained to prefer to have it closed.

The Roma participants raised concerns about being treated with a lack of respect. For instance, women feel that the role of the extended family is not always respected by hospital staff. The formal procedure around hospital visits is often different from the customary practices of those Roma for whom it is common to have their extended family to visit. As a result of hospital wards generally not being able to accommodate a large number of visitors, Roma family members are asked to leave. In some instances, security or the Garda Síochána have been called prior to any requests been made for Roma to leave. The participants highlighted the importance of showing respect towards Roma in these instances, by explaining why the presence of extended family in hospital wards is not appropriate. The consensus was that this can be achieved by open and honest communication about general information, practices and procedures of hospitals. Poor treatment in health services in Ireland has a negative effect on the already low levels of trust in healthcare practitioners and the likelihood of engaging in services in the future. The reported instances of refusals and negative treatment by healthcare practitioners are worrying findings. According to a Roma interviewee, in the context of widespread and persistent anti-Roma discrimination and racism across Europe, these practices need to be critically examined.

ACCESSIBLE INFORMATION

Many Roma women are unfamiliar with the use of antenatal and postnatal health services due to barriers and low use of these services in countries of origin. Maternity related procedures, such as the induction of labour, can be unfamiliar to Roma, and contribute to women feeling disempowered if choices and decision making around maternal healthcare are not articulated and presented in an appropriate, accessible and clear manner.

Roma interviewees highlighted the lack of information and knowledge about health and medically related concerns to be one of the contributors to many women not seeking antenatal and postnatal services. Lack of information about the Irish healthcare system and the cost of care create confusion among Roma, often not knowing where and how to access care. Reports of Roma being provided with conflicting information by hospital administration, further contributes to this confusion.

Limited or no literacy and English language skills further compound this problem by making it difficult for women to access the information and services needed. For instance, some Roma have been asked to email or physically go to a hospital to arrange an appointment for antenatal care. For many Roma this can be difficult to do due to lack of literacy and computer skills or ability to afford the cost of transport.

TRANSLATION AND INTERPRETATION SERVICES

The low levels of English language and literacy skills among some Roma demonstrate the need for access to translation and interpretation services. The availability and quality of these services varies widely. Some hospital staff show an awareness about the potential problems of using non-Roma translators who originate from the same country as Roma patients, given the extent of anti-Roma racism throughout Europe. There are reports of instances where staff seek confirmation from Roma women, whether they feel comfortable with using a translator from the same national background. However, the lack of understanding about the potentially complex relation between non-Roma translators and Roma women appears to be common place.

Anti-Roma sentiments among non-Roma translators have resulted in a failure to provide quality services. For instance, a Roma participant reported an instance where a Romanian translator did not allow a Roma patient to express her level of pain in a hospital she was admitted to, instead the translator engaged in calling her names. The Roma woman was supported with filing a complaint about the incident, but the translator subsequently denied what had happened and the woman never received any feedback about her complaint.

On other occasions, translation services are not necessarily made available for Roma women. Participants report of practices where external translators are not arranged, and instead women are asked to bring a friend or family member who speaks English to accompany them in services. Although this can allow for the exchange of information through a person women can trust, the use of a family member can create other kinds of concerns and barriers to information.

⁸⁸ Michael, Sheaff <u>Sociology and Health Care: an Introduction for Nurses</u>, <u>Midwives and Allied Health Professionals</u>, Berkshire: Open University Press, 2005.

ISSUES ARISING AMONG HEALTH PRACTITIONERS

Many of the barriers outlined above were raised by practitioners. Some expressed frustration with the limited options in providing support and services for Roma women, in the context of a lack of an overall strategy for Roma inclusion and a lack of support in working with women with limited entitlements and lack of access to medical cards and primary care services.

DATA COLLECTION

Practitioners highlighted the absence of data to be a significant barrier when planning and delivering services for Roma women. The participants strongly agreed that an ethnic identifier needs to be implemented across all administrative systems and should include 'Roma' as a category. Without this, practitioners are working in a vacuum, as the lack of accurate and reliable data prohibits the development and implementation of appropriate policies and practices.

ROMA ENGAGEMENT IN HEALTH SERVICES

Key issues experienced by healthcare practitioners working with Roma women are non-attendance and nonengagement. Many struggle to ensure and encourage Roma women to engage in antenatal and postnatal services. The lack of trust and confidence in healthcare professionals among women was identified as being a major contributor to the issue.

In addition to factors already identified, there are other practical, psychological and emotional factors that act as barriers to access and engage in services. Some women, especially young girls, appear shy or embarrassed when they come in contact with practitioners. This can result from not having previous experience in engaging in healthcare services, deprivation or trauma. On the other hand, attending services can be difficult due to inability to afford transport costs and long waiting times at hospitals. Women who have other children often have no access to a crèche or babysitter that would free them to attend services.

Practitioners report to have particular difficulties with engaging with Roma women who are homeless or live in inadequate housing conditions. In these cases women are more likely to opt out of health services and, rather, satisfy some of more immediate needs of their families. The transience of Roma living in these conditions makes it difficult for practitioners to maintain contact and keep track of where Roma women live.

SECTION 05: RECOMMENDATIONS



"IMPROVING HEALTH SYSTEMS CANNOT BE SEEN AS A TECHNOCRATIC EXERCISE; BY BRINGING **HUMAN RIGHTS TO BEAR, TRANSFORMING** HEALTH SYSTEMS CAN AND SHOULD BE UNDERSTOOD AS A MEANS OF CONSTRUCTING SOCIAL CITIZENSHIP FOR WOMEN IN A SOCIETY -AND MOST CRITICALLY FOR POOR, RURAL AND MARGINALIZED WOMEN." Lynn Freedman

The following section outlines the specific and most pressing supports needed for Roma and healthcare practitioners. This allows for the development of a set of preliminary recommendations for policy makers and practitioners in relation to the promotion and protection of Roma maternal health. The identified gaps require urgent attention to be addressed through the Irish National Traveller/Roma Integration Strategy, other relevant policy and legislation, and healthcare practices

NATIONAL TRAVELLER/ROMA INTEGRATION STRATEGY

The importance of having an adequate national framework for the promotion and protection of Roma health was highlighted by seminar participants. There are significant shortcomings in the current Irish National Traveller/Roma Integration strategy. Pavee Point has been strongly critical of the strategy, which almost completely fails to mention Roma and involved no active participation or consultation with Roma or Travellers in its development. A progressive strategy with goals, timeframes, funding mechanisms and monitoring mechanisms is urgently needed.⁸⁹

The strategy needs to address the current situation of lack of access to basic social protection, especially medical cards, as well as access to education, training, employment and adequate housing conditions. Without this, Roma women in particular continue to face significant barriers to the right to maternal health. Such a strategy would also provide a framework within which service providers can work. The strategy should also include measures to target forms of discrimination and racism and specifically address the situation of Roma women.

ETHNIC IDENTIFIER

Effective policy making should be based on reliable and comprehensive data informed by the active participation of people directly affected by the policy.⁹⁰ The lack of data aggregated by ethnicity in Ireland results in an absence of accurate and reliable knowledge about the experiences and uptake of healthcare services by Roma women. This leaves service practitioners and policy makers working in a vacuum.

Healthcare practitioners have highlighted the need to change this situation. They emphasise the importance of an ethnic identifier in feeding into responsive and adequate policy development and service delivery. The inclusion of an ethnic identifier would also allow to record instances of discrimination and racism, and ultimately safeguard equal access to healthcare for Roma. Pavee Point notes that the collection of data on the basis of ethnicity must be undertaken within a human rights framework.

This requires:

- A universal question (everyone is asked the question, not just minority ethnic groups);
- Based on principle of self-identification (no one else decides your ethnicity);
- Data collected is aggregated and anonymised (no one can identify specific individuals);
- Data is only used for the purpose for which it was collected;
- It is available in a timely manner and;
- It is analysed in consultation with the organisations representing minority ethnic groups.

ROMA PARTICIPATION

The need to ensure involvement of Roma in the development and implementation of effective healthcare policies, strategies and initiatives is widely recognised by EU institutions. The active participation of Roma women in the elaboration and implementation of policies has been recognised as essential in ensuring Roma attainment to human rights, especially the right to health.⁹¹

Participation of Roma women in improving their own access to healthcare and other public services must be enhanced at international, regional, national and local levels. Their involvement at all stages of policy development affecting their own community should be ensured. This contributes to more responsive and effective policies and practices, which have a positive effect on the whole community. The model of the Pavee Point Primary Healthcare Project for Travellers has been cited as an example of good practice by the European Commission in relation to National Roma Strategies and could also be developed with Roma.

IDENTIFIED SUPPORTS FOR ROMA WOMEN AND PRACTITIONERS

ACCESSIBLE INFORMATION

Participants felt at times that Roma were being criticised about a perceived lack of ability to look after their own health. They emphasised that Roma women want to be educated about health issues. The education of women should include the provision of information about the Irish healthcare system, where and how to access care; rights and entitlements; and language, literacy and computer training. The information should be presented in an appropriate, accessible and clear manner, and ultimately aim to empower women to engage in decision making over their own care. As expressed by a Roma participant.

"ROMA DON'T KNOW HOW THINGS WORK IN SOCIETY. WE NEED TO EDUCATE ROMA WOMEN ABOUT HEALTH ISSUES, ESPECIALLY YOUNG ROMA GIRLS... IF WOMEN ARE EDUCATED THEY WOULD NOT BE AFRAID TO GO IN TO GET HELP, AND THEY WOULD KNOW WHERE TO GO".⁹²

INTERCULTURAL SERVICE PROVISION

It is evident that there is a need for supports and tools for healthcare practitioners to promote and ensure Roma engagement in services. Understanding of the issues affecting the poor levels of health, engagement and trust is low. Awareness-raising about the socioeconomic, political, cultural, and human rights context of Roma across Europe plays a key role in helping to understand these issues. This allows for the development of appropriate, responsive and effective policies and practices, and mitigates policies and practices from being based on cultural assumptions.

The need to ensure access to public services in culturally sensitive and non-discriminatory basis has been recognised in international and regional human rights instruments. Roma participants highlighted that service provision, which is based on non-judgemental, respectful and culturally appropriate practices, is key to overcoming the poor levels of engagement among Roma. Capacity building among both Roma and healthcare practitioners play a key role in raising awareness and enhancing Roma engagement. This should take place through professional training in the form of human rights, intercultural training and cultural competence among healthcare practitioners, and enabling Roma to work as healthcare professionals. Considering the reports of negative experiences among Roma women in health services in Ireland, intercultural training, anti-racism and other initiatives to address prejudice and stereotypes are required. These initiatives also contribute to overcoming mistrust in healthcare professionals and enhance Roma engagement in services.

In conclusion the following recommendations were identified:

- Development of a progressive National Traveller Roma Integration Strategy;
- Address the impact of the Habitual Residence Condition;
- Ensure involvement of Roma in the development and implementation of effective healthcare policies, strategies and initiatives;
- Provide information about the Irish healthcare system - where and how to access care; rights and entitlements; and language, literacy and computer training, to Roma women in a clear, accessible and appropriate way;
- Adopt the model of the Pavee Point Primary Healthcare Project for Travellers with Roma;
- Build up trust between health practitioners and Roma;
- Ensure service provision based on nonjudgemental, respectful and culturally appropriate practices;
- Professional training in the form of human rights, anti-racism and intercultural training among healthcare practitioners;
- Enable Roma women to work as healthcare professionals and;
- Initiatives to tackle racism and stereotypes.

SECTION 06: FRAMEWORK FOR IDENTIFYING AND DEVELOPING GOOD PRACTICES



ma Children in Irelan hoto by James Frahe "ACCOUNTABILITY IN A HUMAN RIGHTS-APPROACH TO MATERNAL HEALTH RELATES TO OBLIGATIONS TO 'RESPECT, PROTECT AND FULFILL' A WIDE ARRAY OF CIVIL AND POLITICAL RIGHTS, AS WELL AS ECONOMIC AND SOCIAL RIGHTS, AND GOES FAR BEYOND THE HEALTH SECTOR." Committee on Economic, Social and Cultural Rights

This section provides a framework to assist policy makers and practitioners to identify and develop good practices to fulfil Roma rights to maternal health.⁹³ The proposed framework is based on principles and examples of good practice identified by participants. It is given further depth by integrating examples within relevant frameworks at international, regional and national levels. These include the guiding principles and quality indicators for policy and service delivery adapted from the European Network for the Promotion of Sexual and Reproductive Health of Refugees and Asylum Seekers (EN-HERA), the Ten Common Basic Principles on Roma Inclusion, and the community development approach exemplified by the Pavee Point Traveller Primary Health Care Project.

The section begins by outlining the principles of the EN-HERA framework for the development and identification of good practices in relation to reproductive and maternal health of marginalised women. The principles are outlined in conjunction with quality indicators for service delivery in maternal health care.

The indicators include;

- Availability, acceptability, affordability and accessibility,
- Evidence-based and in line with international guidelines,
- Information and choice,
- Monitoring and evaluation,
- Continuity of care.

The section then moves onto outlining the Ten Common Basic Principles on Roma Inclusion to provide guiding principles for policy and service delivery more specific to the situation of Roma. Finally, it introduces the community development approach, and its possible contribution to Roma inclusion to health by adapting the Traveller Primary Health Care Project to the specific situation of Roma in Ireland.

The frameworks outlined largely overlap with one another, and are designed to be integrated together to work as a guiding framework for policy development and service delivery. It is important to note that the proposed framework is also relevant to other groups in Ireland experiencing marginalisation and social exclusion.

FRAMEWORK FOR POLICY AND SERVICE DELIVERY FOR MATERNAL HEALTH: EN-HERA ⁹⁴

RIGHTS-BASED APPROACH

Reproductive and maternal health is a basic human right recognised by numerous international, regional and national instruments. The attainment of the right to health is directly related to access to economic, social and cultural resources. States that are party to relevant human rights treaties are obliged to ensure access to those resources in line with the principle of non-discrimination in relation to gender, ethnicity, race, language, religion, national or social origin, and so on.

EMPOWERMENT

"EMPOWERMENT IS A MULTI-DIMENSIONAL SOCIAL PROCESS THAT HELPS PEOPLE GAIN CONTROL AND TRANSFORM THEIR LIVES AND THE ORGANISATION OF SOCIETY IN ORDER TO SHARE POWER AND RESOURCES EQUITABLY"

To empower people means to provide them with the capacity, abilities, access and power to influence their lives.

GENDER-BALANCED APPROACH

This approach acknowledges the equal participation of women and men as a basis for sustainable development. It notes the Vienna Declaration which asserted that the human rights of women are an inalienable, integral and indivisible part of human rights. The approach requires the assessment of implications of any legislation, policy or initiative for both women and men.

MULTIDISCIPLINARY APPROACH

Multidisciplinary approach to reproductive and maternal healthcare service delivery involves the provision of holistic care and services. The approach relies on a perception that increasing the involvement of diverse stakeholders in service delivery ultimately results in efficient and culturally appropriate services. Considering that many Roma women in Ireland experience diverse and complex issues, a multidisciplinary approach could potentially address them, by involving professionals from different disciplines working as a team towards a common goal.

POSITIVE EXAMPLE OF A MULTIDISCIPLINARY APPROACH: ROMA SPECIFIC PRIMARY HEALTH CARE CLINIC IN TALLAGHT, DUBLIN

The Tallaght Roma Integration Project (TRIP)⁹⁵ is a network of local statutory, community and voluntary organisations who have worked alongside members of the Roma community since 2009 to address the needs of the local Roma community in Tallaght.⁹⁶

TRIP have taken the combined theoretical approaches of primary health care, community development and integration to addressing some of the general needs of the local Roma community and have been successful in establishing and managing the first Roma specific primary health care clinic in Ireland.

The TRIP/Safetynet Roma GP service operates two afternoons per week and is located on the site of Tallaght Hospital. The service offers primary healthcare and support services for members of the Roma community.⁹⁷ The service was set up in response to an identified need following a number of consultations with approximately 40 members of the local Roma community in Tallaght which highlighted the situation that many Roma had no access or entitlement to a medical card and therefore no access to a GP. TRIP, in consultation with Tallaght Hospital also identified an over-representation of members of the Roma community

96 Tallaght Roma Integration Project (TRIP) is a network of community based groups dealing with Roma community issues. The purpose of the group is to:

- encourage cross learning;
- identify the different needs of the Roma community and explore how those needs can be met;
- identify gaps in the delivery of services to the Roma community and explore how those gaps can be bridged;
- create awareness, collect case studies and advocate for the delivery of services that meet the needs of the Roma community, encouraging cultural awareness and sensitivity in the delivery of services among service providers;
- influence policies to accommodate the diverse range of needs within the Roma community that now exist in Irish society;
- foster collaborative action between the membership of the group, Roma community and service providers and;
- support to delivery of the services of the Safetynet Roma GP bus to the target group.

93 Definition of good practice as "being effective, transferable and applicable in different contexts", adopted from EN-HERA!, <u>Sexual and Reproductive Health</u> and Rights of Refugees, Asylum Seekers and Undocumented Migrants: A <u>Framework for the Identification of Good Practices</u>, Ghent: ENHERA! Network, 2009.

94 ibid.

95 The clinic has been running since September 2012 and was officially launched in March 2013. in the local A & E Department. The clinic was set up to address this identified need and since its establishment, has provided free primary health care to over 1,000 Roma who otherwise lack access to finances, or medical cards. Integral to addressing issues of language and literacy barriers and lack of trust in health and other services, TRIP has worked in conjunction with members of the Roma community since its establishment. The clinic's operational and support team also consists of Roma and non-Roma volunteers, including a female GP. Roma cultural mediators and interpreters. TRIP members, who are frontline staff, also work on a case management basis with members of the Roma community who present at the clinic needing further complex social support. This further support, combined with a culturally specific primary healthcare clinic, has been invaluable in improving the relationship between the local Roma community in Tallaght and local service providers.

Prior to the clinic being established, many Roma were accessing the Tallaght A&E department for health concerns that would have been more appropriate to deal with through primary health care services. This was seen as placing an unnecessary burden on the busy A&E ward, and the high cost of hospital care meant that many Roma were unable to engage in follow-up visits. This situation was identical to the one experienced by maternity hospitals which are often the first point of contact for Roma women to access healthcare during maternity.

The health status of Roma patients at the clinic are beginning to paint a more accurate picture of Roma health and this is raising serious concerns. TRIP acknowledge that barriers to primary healthcare experienced by many Roma are contributing to this situation. The multidisciplinary approach has shown to be an effective model to address some of the complex issues experienced by Roma. The clinic has made significant improvements in ensuring Roma engagement in the service. One of the GPs noted that the lack of trust that appeared to be present at the beginning with many of the patients has diminished, and the patients now engage in on-going follow-up visits.

97 The clinic has been running since September 2012 and was officially launched in March 2013. As a multidisciplinary approach, TRIP provides an example of how service delivery from this perspective can begin to address some of the issues of access, make services more appropriate, and contribute to increased levels of engagement. In this way, the lessons and insights of TRIP are a valuable resource that could guide service delivery at all levels and areas of healthcare.

It is, however, important to note that the clinic, since its inception, was never perceived as a long term solution to the serious barriers Roma in Ireland experience with accessing and engaging in healthcare services. The clinic has filled and continues to fill a significant and serious gap in Roma attainment to the right to health. However, TRIP agree that segregated services are not a sustainable solution for long term and effective change. Rather, what is needed is wider sociopolitical change which enables Roma in Ireland to access healthcare services, facilities and goods on an effective, equitable basis.

CROSS-SECTORAL APPROACH

Issues of access to healthcare by Roma must be considered in the context of enjoyment of other human rights. A cross-sectoral approach to maternal healthcare acknowledges that access to health is inseparable from access to education, adequate housing, social protection and employment. The cross-sectoral approach emphasises an integrated approach to maternal health promotion for marginalised and vulnerable women, where inclusion in healthcare and services are dealt with in conjunction with inclusion in housing, education, employment, and political and administrative sectors. The cross-sectoral approach should be adopted at international, regional, national and local levels.

"A CROSS-SECTORAL APPROACH REQUIRES A BROAD PERSPECTIVE AND PARTNERSHIP WITH OTHER SECTORS THAN HEALTH. THESE SECTORS CAN INCLUDE, BUT ARE NOT LIMITED TO: THE PSYCHO-SOCIAL, THE POLITICAL AND ADMINISTRATIVE, THE LEGAL AND JUDICIAL, THE EDUCATIONAL AND COMMUNITY DEVELOPMENT, THE SAFETY AND SECURITY SECTORS." ⁹⁸

TEN COMMON BASIC PRINCIPLES ON ROMA INCLUSION⁹⁹

Endorsed by the Council of Ministers and adopted by the European Commission, the Ten Common Basic Principles on Roma Inclusion provide guidelines for policy makers and practitioners in EU Institutions and Member States when developing and implementing policies and services for Roma inclusion. The Principles are drawn from the experience of successful policies throughout Europe. Any work with Roma communities should be underpinned by these Principles.

1. CONSTRUCTIVE, PRAGMATIC AND NON-DISCRIMINATORY POLICIES

The first Principle focuses on 'constructive and pragmatic' policies: policies that are appropriate to the situation on the ground. The design, implementation and evaluation of policies and projects should not be based on preconceptions, but on the actual situation of the Roma. How can this be achieved in practice?

- Do not base policies on pre-conceptions but on the actual situation.
- For this purpose, make use of studies, surveys, visits, and the involvement of Roma people or experts, etc.
- Promote such an approach to all actors.
- Make sure that EU values (human rights, dignity, non-discrimination, etc.) are respected.
- Take into account the socio-economic inequalities experienced by the Roma and support equal opportunities/equal access of Roma people.

2. EXPLICIT BUT NOT EXCLUSIVE TARGETING

There is an ongoing debate on how to best address the needs of minority ethnic groups which includes two contrasting approaches: a specific approach (targeted at a specific minority) or a general approach (concerning everybody). The second Principle allows us to go beyond this debate with the introduction of the 'explicit but not exclusive approach'. This approach is particularly relevant for policies or projects taking place in areas populated by the Roma together with other minority ethnic groups or marginalised members of society.

3. INTER-CULTURAL APPROACH

The inter-cultural approach asserts that policies and services should focus on effective communication and inter-cultural skills and learning. The 'inter-cultural approach' stresses that both the Roma and mainstream society have much to learn from each other and that inter-cultural learning and skills deserve to be promoted alongside combating prejudices and stereotypes.

4. AIMING FOR THE MAINSTREAM

The fourth Principle draws attention to the longterm impact of policies and projects as sometimes, despite aiming to support Roma inclusion, they can result in strengthening segregation. The fourth Principle emphasises that promoting the inclusion of the Roma in mainstream society should be the ultimate aim of all policies. Accordingly, all actions should be assessed to see if they risk causing segregation and adapted if necessary.

Roma segregation may also be exacerbated by measures that are apparently neutral but that ultimately create additional barriers for the Roma because of their situation: this is known as 'indirect discrimination.' How can this be achieved in practice?

- Support de-segregation by promoting integrated approaches.
- Avoid measures that risk strengthening segregation or even creating new forms of segregation and pay attention to the longterm impact of policies and projects.
- Be aware of the risk of indirect discrimination (when apparently neutral measures ultimately create additional barriers for the Roma).
- Involve Roma communities.

5. AWARENESS OF GENDER DIMENSION

Roma women are more likely to experience social exclusion than both Roma men and women in the majority community. Roma women are particularly vulnerable and suffer disadvantages such as limited access to employment, education, health and social services. They are often victims of multiplediscrimination: discrimination on the grounds of gender and ethnic origin. Roma women also have a crucial role to play in promoting inclusion How can this be achieved in practice?

- Address the specific needs of Roma women in the design, implementation and evaluation of policies and activities.
- Pay attention to related issues (e.g. multiple discrimination, domestic violence, exploitation, access to health/childcare).
- Ensure that Roma women participate and play a leading role in consultative bodies or monitoring committees.

⁹⁸ EN-HERA!, <u>Sexual and Reproductive Health and Rights of Refugees, Asylum</u> <u>Seekers and Undocumented Migrants</u>, 2009.

⁹⁹ Council of the European Union, <u>10 Common Principles on Roma Inclusion</u>, Brussels, 28 May 2009, http://register.consilium.europa.eu/pdf/en/09/st10/ st10394.en09.pdf.

6. TRANSFER OF EVIDENCE-BASED POLICIES

The sixth Principle stresses the need to learn from your own experiences, as well as exchange experiences with other stakeholders or practitioners with the aim of drawing lessons from their work. In order to benefit from experience, good practices should be highlighted and disseminated to others. It is recognised that the development, implementation and monitoring of Roma inclusion policies requires a good base of regularly collected socio-economic data. How can this be achieved in practice?

- Use and combine existing information and, where appropriate, collect data (in line with regulations protecting personal data) in order to monitor project and policy developments.
- Take into account the results achieved by various processes initiated (e.g. EU Roma Network, European Platform for Roma Inclusion, Roma Decade, etc.)
- Where relevant, get inspiration from and build on examples and experiences of work with other vulnerable groups.
- Use information from outside the EU.
- Promote information sharing and exchange of experience among Member States.

7. USE OF EU INSTRUMENTS

There are a number of European Union instruments for Member States to use in the promotion of Roma inclusion. These consist of legal, financial and coordination instruments, including Racial Equality Directive, Framework Decision on Racism and Xenophobia, European Social Fund, and European Regional Development Fund.

8. INVOLVEMENT OF REGIONAL AND LOCAL AUTHORITIES

Regional and local authorities play a key role in the implementation of Roma inclusion policies. Member States need to design, implement and evaluate policy initiatives in close cooperation with the authorities.

9. INVOLVEMENT OF CIVIL SOCIETY

Member States also need to design, develop, implement and evaluate Roma inclusion policy initiatives in close cooperation with civil society actors such as non-governmental organisations, social partners and academics/researchers. The involvement of civil society is recognised as vital both for the mobilisation of expertise and the dissemination of knowledge required to develop public debate and accountability throughout the policy process.

10. ACTIVE PARTICIPATION OF ROMA

The effectiveness of policies is enhanced with the involvement of Roma people at every stage of the process. Roma involvement must take place at both national and European levels through the input of expertise from Roma experts and civil servants, as well as by consultation with a range of Roma stakeholders in the design, implementation and evaluation of policy initiatives. Support for the full participation of Roma people in public life, stimulation of their active citizenship and development of their human resources are also essential. How can this be achieved in practice?

- Consult and involve NGOs, academics and Roma representatives in all stages of policy development.
- Benefit from the expertise of civil society.
- Organise public debates throughout the policy process.
- Reflect on measures concerning positive action to encourage Roma participation in public life and active citizenship.
- Promote employment opportunities for the Roma by including positive actions in human resources strategies, such as organising training courses, traineeships etc.

COMMUNITY DEVELOPMENT

APPROACH

The community development approach entails a process during which members of a community work together to identify needs, exert influence on decision making over matters that affect their lives, and ultimately aim to create societal change. The collective takes centre stage over the individual in the process of aiming to create a more equitable society. This means working with one's community rather than for a community. Practical application of the approach has shown that community development can produce sustainable and successful results.

The principles that underpin the approach include;

- Equality
- Participation
- Empowerment
- Social Justice
- Collective Action

101 The Primary Health Care approach was formally established in 1978 at the Joint World Health Organisation and United Nations Children's Fund conference in Alma-Ata.

EXAMPLE OF GOOD PRACTICE: PRIMARY HEALTH CARE FOR TRAVELLERS PROJECT¹⁰⁰

Based on the Primary Health Care approach, the Pavee Point Primary Health Care for Travellers Project (PHCTP) has approached Traveller inclusion from a community development approach.¹⁰¹ The project integrates cross-sectoral and multi-disciplinary approaches to eradicate economic, social, cultural and political determinants of the poor health status of Travellers. The approach applied in the project has proved to be successful over the years in developing strong leaders and advocates within the Traveller community and working with young Travellers.

The PHCTP was established in partnership with the Eastern Health Board in 1994. It included a training course for Travellers to develop their capacity, skills and confidence to work as Community Health Workers (CHWs) and conduct research to identify Traveller health needs. Travellers work in partnership with the Health Service Executive personnel through Traveller Health Units, which provide health services for Travellers. In this way, the project has allowed Traveller women in particular to gain access to the labour market.

The Community Health Workers engage in the development of a healthcare model based on the community's own values. They follow a social determinants approach to addressing health issues, whereby the impact of socio-economic conditions and experiences of racism and discrimination are acknowledged as key factors in determining health status. As a result, the PHCTP allows for the community to prioritise their health needs.

The PHCTP is credited with bringing real and substantial benefits to the Traveller communities where they are located. Monitoring of the PHCTP showed improvements in levels of satisfaction, uptake and utilisation of health services by Travellers in the area. The project won a World Health Organisation Award in May 2000. As a result of the success of the original Pavee Point PHCTP, this has been widely replicated and there are projects throughout the country.

Although Roma and Travellers are not a homogenous group and their situation in Ireland differs from one another, there are significant similarities in the experiences and health determinants of the groups. As a result, the lessons and insights from the PHCTP provide a valuable resource to guide the promotion and attainment of Roma maternal health in Ireland. Adapted to the specific needs and circumstances of Roma women in Ireland the approach can be seen as a viable option for the development of policy and service delivery for Roma women.

¹⁰⁰ See Pavee Point, A Review of <u>Travellers' Health using Primary Care as a Model</u> of <u>Good Practice</u>, Pavee Point, 2005.

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