

Roma Support Group

Roma Mental Health Advocacy Project Evaluation Report

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Prepared by

The Roma Support Group

Authors

Gabriela Smolinska-Poffley
Sylvia Ingmire

Contributors

Maria Marais
Marta Sosnowska

Contact for information

Roma Support Group
P.O. Box 23610
London E7 0XB

Email: info@romasupportgroup.org.uk
Website: www.romasupportgroup.org.uk

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Contents

Acknowledgments	2
Contents	3
Executive Summary	5
1. Background	8
1.1 Context	8
1.1.1 The Roma Community	10
1.1.2 The Roma Support Group	10
1.2 Purpose of the report	12
1.2.1 Research Questions	12
1.3 Needs for the project	12
1.3.1 Characteristics of the Users	12
1.3.2 Barriers in Accessing Mental Health Services	13
1.4 Mental Health in the context of marginalisation and exclusion of the Roma community	13
2. Original project assumptions	13
2.1 Aims and objectives of the Roma Mental Health Advocacy project	15
2.2 Meeting the identified needs	16
2.3 Intended outcomes	16
2.4 Originally predicted barriers and enablers	18
2.4.1 Barriers	18
2.4.2 Enablers	18
3. The Project	18
3.1 Involvement of other RSG projects and other voluntary and statutory organisations	18
3.1.1 Project staff and volunteers	19
3.1.2 Other RSG projects and staff involved in the Roma Mental Health Advocacy Project	19
3.1.3 Involvement of other voluntary and statutory organisations	20
3.1.4 Other RSG projects and staff involved in the Roma mental health advocacy project	20
3.1.5 Chief Executive	20
3.1.6 The role of other RSG projects	20
3.1.7 Involvement of other voluntary and statutory organisations	22
3.2 Service Users – numbers and characteristics	24
3.2.1 Profile of the Roma mental health advocacy project's service user	24
3.3 Project Activities	25
3.3.1 Direct and indirect support for the project's service users	25
3.3.2 Dissemination of the cultural information	26
3.3.3 Roma Mental Health Pacesetters Project	27
3.3.4 Roma Women's Self-help Group	28
3.4 Number and sources of referrals to the Roma Mental Health Advocacy Project	29
3.5 Number of sessions	30
4. Data Collection/Method	33
4.1 Purpose and methodology of evaluation	33
4.1.1 Data review of existing evidence and statistical data sources	34
4.1.2 Participatory evaluation and insider's perspective	35
4.1.3 External evaluation	36
4.1.4 Study phases	37
4.1.5 Data review of existing evidence and statistical data sources	38

4.2 Research questions	39
4.2.1 Clarifying terms and outcomes	40
4.3 Methods of data collection	41
4.3.1 Focus groups	41
4.3.2 Methods of data analysis	43
4.3.3 Sampling	43
4.3.4 Analysis of data, template analysis	43
4.4 Research ethics and limitations	44
4.4.1 Research ethics	44
4.4.2 Research limitations	44
4.5 Methods of analysing data	44
4.6 Problems with data collection	44
5. Results	46
5.1 What is the socio-cultural profile of the Roma service user wishing to access mental health services?	46
5.1.1 Gender	46
5.1.2 Countries of origin and immigration status	47
5.1.3 Tribal affiliation	47
5.1.4 Age	47
5.1.5 Education	47
5.1.6 Religion	48
5.1.7 Geographical location	48
5.1.8 Employment status	49
5.1.9 Martial status and family life	49
5.1.10 Social life	49
5.1.11 Mental health problems	50
5.1.12 Other health and non-health-related problems	50
5.2 How does the relationship between client and mental health advocate and its dynamics effect empowerment of the client?	51
5.2.1 Empowerment as understood in this research	51
5.2.2 Empowerment as an individual's journey	52
5.2.3 Advocacy	52
5.2.4 Relationship between service users and advocates	54
5.2.5 Distance-travelled form	55
5.2.6 Service users' feedback	57
5.2.7 Reoccurring themes	58
5.3 What type of cultural information is given to mental health professionals by the advocates in the process of their mental health advocacy support and how does it change their knowledge?	63
6. Discussion	66
References	73
Appendices	81
Appendix 1 User Pathway Professionals	82
Appendix 2a Focus Group Questions	83
Appendix 2b Content of the Information Leaflet for the Health Professionals	84
Appendix 2c Letter from West London Mental Health Trust asking for permission to use extracts from the RSG Information Leaflet for Health Professionals in the Revised Cultural Competency Tool-kit	87
Appendix 3 Full break down of the data collected for the socio-cultural profile of the Roma Mental Health Advocacy project's service users	88
Appendix 4 Clients' feedback – summary	105
Appendix 5 Distance-Travelled Forms Summary and Analysis	106

EXECUTIVE SUMMARY

INTRODUCTION

This report contains the evaluation of a three-year Roma mental health advocacy project. The project was funded by the King's Fund and delivered by the Roma Support Group from August 2008 – July 2011. The project employed one part-time project co-ordinator and two part-time bilingual mental health advocates and supported Roma community members in accessing Mental Health services. Over one hundred community members who expressed a wish to access mental health services were supported by the project advocates and a further fifty Roma individuals were informed about the project, its aims and the support offered.

The Roma Support Group (RSG) is a registered charity and a community-led organisation which has been working with East European Roma asylum seekers, refugees and migrants since 1998. The RSG was well placed to conduct this research, having over ten years of experience in the development and implementation of a wide range of projects and services, focusing on advice and advocacy, engagement and empowerment of Roma communities and individuals.

The King's Fund is a charity that seeks to understand how the health system in England can be improved. Using that insight, The King's Fund works with individuals and organisations to shape policy, transform services and bring about behaviour change.

AIMS

The aims of the project were:

- Improved access to mental health services for Roma community members, as well as an increase in the level of their satisfaction with mental health services.
- Improved well-being and empowerment of Roma service users with mental health needs.
- Raised awareness of Roma culture and Roma patients' specific needs amongst mental health service providers.

RESEARCH QUESTIONS

The following three research questions were agreed with The King's Fund at the beginning of the project:

1. What is the socio-cultural profile of the Roma service user wishing to access mental health services?
2. How does the relationship between client (Roma service user) and mental health advocate and its dynamics effect empowerment of the client?

3. What type of cultural information is given to mental health professionals by the advocates in the process of their mental health advocacy support and how does it change their knowledge?

METHODS

We have combined the Realist Evaluation and Participatory Evaluation approaches using a range of data collection methods consistent with such approaches and the different research questions asked. We used a combination of quantitative and qualitative methods to collect and analyse information. The main methods used were documentary review of relevant statistical data gathered through entry forms, feedback questionnaires and verbal feedback from the service users and mental health professionals, distance-travelled forms, individual service users' action plans, advocates' observation notes, case records, focus group meetings, one-to-one interviews and minutes of meetings.

The realist evaluation methodology concentrates on the relationship between three key elements: the context in which the changes measured take place, the mechanisms used to produce the changes and the outcomes which may be measured which fitted well with the framework of the project.

The participatory approach focuses on co-design and community engagement. This approach is closely related to the ethos of the RSG methods of work which is not only relevant to the process of empowerment of our individual service users but also addresses the historical social exclusion and marginalisation of Roma individuals and communities in Europe.

KEY FINDINGS

1. Most of the Roma community members who were supported by the mental health advocacy project were female (66%), came to the UK from Poland (88%) before 2004 and were asylum seekers (77.5%). The majority (63%) were Catholic, over 60% did not acquire education at a level higher than secondary school and 72% were unemployed. Over 90% stated that they suffer not only from mental health problems but also from physical health problems and again 90% stated that they struggle with non-health related problems such as housing, low income and debts and other family members suffering from long term illnesses.
2. Most of the service users, who received support from the project's advocates, reported increased satisfaction with mental health services and their ability to access general and mental health services was improved.
3. Roma service users with mental health needs reported changes indicating improved well-being and empowerment.
4. We identified the main reoccurring themes; these were the lack of trust towards mental health professionals and the lack of knowledge about mental health and services available, communication difficulties and

isolation, which were closely interrelated and impacted negatively on the service users' state of mind and contributed hugely towards their feeling of disempowerment.

5. The health advocates were able to effectively support the service users in the process of self-development and empowerment. It was made possible by the development of a trust-based relationship between the service users and the health advocates. Crucial in this process was a holistic and individualised approach to service users' needs.
6. Following the health advocates' intervention, service users became more confident in accessing health services and talking about their mental health however we also noticed that in some cases it also led to increased dependency on contact with and the support provided by "their" advocate.
7. Health professionals reported raised awareness of Roma culture and Roma patients' specific needs and service users reported increased satisfaction with the help received from those professionals.
8. Increased knowledge amongst the health professionals of some aspects of Roma culture led directly to better understanding of Roma patients and improved communication. It also enabled the health professionals to tailor interventions better to meet the needs of Roma patients and ensure greater effectiveness and progress towards recovery. Roma patients reported an increase in confidence in health professionals, ability to access mental health services and feeling of being empowered. Additionally, the health professionals reported improved satisfaction in their work with Roma patients.
9. The effectiveness of the cultural information provided to health professionals and the change achieved was greatest in the cases where health professionals approached us of their own accord in relation to their work with individual Roma patients.

RECOMMENDATIONS

On the basis of our three years' work and the findings from our evaluation we would recommend a model of work which would focus on:

- Improving communication strategies with Roma mental health service users
- Person-centred care
- A holistic approach that combines individual and social empowerment
- A holistic approach that supports individuals to improve other aspects of their lives that improve mental health such as housing, welfare etc.
- Research to explore the impact of racism and discrimination on the mental health of the Roma

1. BACKGROUND

1.1 CONTEXT

The Roma Support Group has been offering assistance and support to the Roma refugee and migrant community in London since 1998, which corresponded in time with the arrival in the UK of significant numbers of Roma asylum seekers from Eastern European countries.

1.1.1 THE ROMA COMMUNITY

1.1.1.1 BASIC HISTORICAL INFORMATION

The Roma migrated from India approximately 1000 years ago. For unknown reasons they travelled through Asia, North Africa and Eastern Europe into Western Europe and the Americas. Their presence in Europe dates back to the end of thirteenth century.¹

There are different Roma groups and tribes and they all speak their own dialect. For example there are: Calé of Spain, Finland, and Wales; the Sinti of Germany and central Europe; the Manouche of France; the Romanichals of the United Kingdom; the Boyash and Khalderas of Romania.

Throughout the centuries Roma have faced a high level of discrimination and persecution. For example, Roma were kept as slaves in the Balkans until 1851. Approximately 250,000 – 500,000 Roma were killed in the holocaust². In the late 1950s in Eastern Europe Roma were forced to abandon their traditional travelling lifestyle and were forced to settle. Since the fall in 1989 of socialism in Eastern Europe Roma became victims of attacks by neo-Nazi groups. In Eastern Europe Roma, who originated from India, are the only ethnic minority which can be easily recognised and targeted (in schools, health services, employment and social settings).

1.1.1.2 UK CONTEXT

In the UK there are different groups which are often put in the same context but have different cultural identities and lifestyles: Gypsies (British Roma), Eastern European Roma, Irish Travellers and New Age Travellers. (Irish Travellers and New Age Travellers are not the same ethnic group as Roma and Gypsies).

It was following the latest migration of Eastern European Roma and heavy press coverage that issues related to Travellers and British Roma started to be debated again. They share a lot of problems in common. For example welfare problems, access to health services, low achievement in education and discrimination.

¹ Ian Hancock, *We are the Romani People*, University of Hertfordshire Press, 2002

² Fraser, A., *Dzieje Cyganow*, original title *The Gypsies*, PIW, Warszawa 2001, chapter 8, Page 198

The Roma in the UK come mainly from Poland, the Czech Republic, Slovakia, Romania, Lithuania and the former Yugoslavia. There is very little data available which provides a reliable estimate of the number of Roma refugees and migrants living in the UK. A Mapping Survey undertaken by European Dialogue for the Department for Children, Schools and Families in 2009 estimated the minimum number of Roma in the UK to be 50,000 according to official records; however, community estimates range from 400,000 to 1 million³.

Table 1 UK context of the Roma migration from 1989 up until the present.

Waves of East European Roma migration to the UK

<p><u>Post 1989 migration - asylum</u></p>	<p>Prior to 1989, there were heavy restrictions on movement for all East European citizens. This is one of the reasons why there was a bigger migration movement following the fall of socialism.</p> <p>After 1989 many Roma came to the UK to claim asylum. Only a small proportion of Roma from Eastern Europe were granted Indefinite Leave to Remain (ILR) through the regular asylum procedures. More families were granted ILR under the Amnesty Exercise in 2003.</p>
<p><u>2004 EU accession</u></p>	<p>The European Union was enlarged by the accession of the so called A8 countries including: Poland, the Czech Republic, Slovakia, Slovenia, Estonia, Latvia, Lithuania, Hungary plus Malta, Cyprus.</p> <p>People from A8 countries until May 2011 were allowed to work in the UK and were obliged to register with the Home Office under the Workers Registration Scheme (WRS). Following one year of continuous employment they were able apply for residency in the UK. If people were self-employed they were not required to register under the WRS.</p> <p>Since May 2011 there are no restrictions on work for people from A8 countries and they do not have to register with Home Office under the WRS. Whilst working they have access to secondary health provision and in-work benefits (Tax Credits, Child Benefit and help with housing costs).</p>

³ *Mapping Survey: Patterns of settlement and current situation of New Roma communities in England*, European Dialogue, Department for Children, Schools and Families (DCSF), August 2009, pp 81-82

<p><u>2007 EU accession</u></p>	<p>The European Union was enlarged by the accession of the so called A2 countries of Bulgaria and Romania.</p> <p>People from A2 countries have heavy restrictions on work (only self-employment and Work Permits allowed).</p>

1.1.2 THE ROMA SUPPORT GROUP

The Roma Support Group, which is the only Roma-led organisation in London and in the UK focusing on working with and for the Roma community, offers support to over 870 families (approx. 4,350 individuals), assisting them in the process of integrating with the mainstream society through a wide range of projects. These projects and services address different groups (age or gender focused) within the Roma community and different issues and problems, which they are confronted with.

1.1.2.1 RESOURCES - INTERNAL CAPACITY

The history of the Roma Support Group (RSG) portrays its ability to develop, grow and change under adverse circumstances, which included existing without any funding for the first 2 years while developing our main projects and activities. Ensuring geographical mobility of our venues in order to follow the London-based dispersal of asylum seekers implemented by central and local governments, while continuing to best serve our community and a successful challenge of a contentious Home Office practice to remove and cause destitution of thousands of Roma asylum seekers in the context of the EU Accession in May 2004.

Despite of the above obstacles, the organisation successfully evolved from an informal voluntary/community network to a more established structure through acquiring a registered Charity and a Company Limited by Guarantee status and strengthening its internal infrastructure through building a strong Management Committee with Roma and non-Roma Trustees, who are top experts in their respective fields of work. The organisation has been awarded

a Quality Mark for our Advice/Advocacy services, which enabled us to develop and implement policies and working procedures. We employ 12 members of staff and over 20 volunteers at any given time and have attracted many high profile funders, who support us in our work for the Roma refugee/migrant communities in London.

During the past decade, we have rigorously applied monitoring and evaluation of our various projects in order to learn and develop models of good practice, which we are invited to share at national and local conferences, seminars and cross-sector networking meetings. On many occasions we have acted as consultants to local and central governments, statutory agencies, such as: Jobcentres, Primary Care Trusts, education departments, schools, academic institutions and many others, influencing some of the policies, which directly affect Roma refugees and migrants. We have adopted the most effective methods of consulting with our service users utilising ways, which are culturally acceptable in the Roma community in order to understand their needs, opinions and aspirations. In our work we have learnt to acknowledge that the Roma community should not be perceived as monolithic but rather as a dynamic entity diversified on the basis of nationality, country of origin, tribal/clan affiliation, language, gender and age. We have developed ways of incorporating these differences into the ways we consult and outreach our service users, as well as deliver our services.

A very important aspect of the RSG's work is the way Roma service users are engaged in our activities. The Roma who access our services have a strong sense of ownership of the organisation and individual projects. They are not only service users but also co-owners of the organisation and activities run by the RSG. Community members often support RSG staff in consultancy roles. Most of our referrals come from community members who already access our services. New/prospective service users check our reputation with members of their extended families and tribes or if that is not possible other Roma who already access our services. In the first stages of their involvement with the RSG projects new service users scrutinise and assess our work and engagement. Once trust is gained it is extended to all RSG projects and staff members. That factor helps all the new projects and project workers to engage with service users in a more meaningful and effective way.

According to academics and experts on Gypsy/Travellers and Roma in the UK, during the past decade the RSG has initiated a process of cultural mobilisation not only amongst Roma refugee/migrant communities but also by example throughout Gypsy and Traveller communities in England. This has been achieved by organising high profile and large scale cultural/heritage events, which attract significant numbers of non-Roma while at the same time relying on the involvement of Roma people at a grassroots level. These events have led to the mobilisation of Roma and non-Roma communities by giving them a shared goal and vision and enabling them to learn from each other in a friendly, mutually respectful and non-confrontational environment.

1.2 PURPOSE OF THE REPORT

This report contains the evaluation of a three-year Roma Mental Health Advocacy Project. It is intended for anyone interested in the Roma community and particularly those working in the health and mental health setting. The report aims to analyse the data and findings related to the original research questions (1.2.1), over the life of the project (2008-2011). The research questions were set at the beginning of the project by the Roma Support Group and The King's Fund in order to further our understanding of profile of the Roma suffering from mental health problems, the role of advocacy in their empowerment and to increase the awareness of the Roma community amongst mental health professionals.

The report presents the above in the wider context of the RSG's work with the Roma community and the identified needs, aims and objectives of the project. Additionally the report includes how the project was delivered and future questions and points of interest.

1.2.1 RESEARCH QUESTIONS

At the beginning of the project we set the following three research questions:

- 1. What is the socio-cultural profile of the Roma service user wishing to access mental health services?*
- 2. How does the relationship between client (Roma service user) and mental health advocate and its dynamics effect empowerment of the client?*
- 3. What type of cultural information is given to mental health professionals by the advocates in the process of their mental health advocacy support and how does it change their knowledge?*

1.3 NEEDS FOR THE PROJECT

Over the course of our Advice and Advocacy Project (1997- ongoing) and Health Awareness and Advocacy Project (2005 - 2008), we discovered that there was a lack of statutory and voluntary mental health advocacy provision that recognised the specific health, cultural and linguistic needs of Roma refugees and migrants. We have also noted frequently an ignorance and lack of willingness to provide adequate assessment at the entry level, which could then refer Roma patients for further specialist treatment. However, we have also experienced positive feedback from health professionals, including counsellors, psychiatrists, psychologists, and educational psychologists who expressed their acute need to understand better the socio-dynamics, culture and historical background of Roma people in order to offer more effective medical treatment to their Roma patients.

1.3.1 CHARACTERISTICS OF THE USERS

In 2005 we set up a Roma Health Awareness and Advocacy Project funded by the Department of Health (Opportunities for Volunteers), which enabled us

to better understand the health needs and situation of Roma community members. Our observations and collected data reflected the findings of officially commissioned reports (*The Health Status of Gypsies and Travellers in England*, Department of Health, 2004; *How Fair is Britain?* Triennial Review, EHRC, 2010⁴; *2001 UN Report; Gypsy, Traveller and Roma Needs Assessment*, Children's Fund, 2002). The data collected identified that the Roma community have poor physical health such as cancer, diabetes, epilepsy, hepatitis B, cardiovascular and respiratory ailments, multiple sclerosis and life expectancy being approx. 5-6 years lower than amongst other socially disadvantaged and ethnic minority populations in the UK. We have collected statistical data, which indicated poor mental health amongst a high number of service users accessing our Health Project. Our records showed that approx. 50% of over 300 clients were suffering from mental health problems, including depression, personality disorders, dementia, learning disabilities, suicidal tendencies, self-abuse, dependency/misuse of drugs, etc. About a hundred of our existing service users stated their wish to access mental health services and we recorded a further 9 clients, who had already accessed services but came up against barriers, which they could not overcome.

1.3.2 BARRIERS IN ACCESSING MENTAL HEALTH SERVICES

Prior to the commencement of the RSG's Roma Mental Health Advocacy project 100% of our beneficiaries, who expressed their wish to access Mental Health services, stated their lack of knowledge related to where to seek help. Meanwhile 60% of those who had already accessed specific mental health services, were referred there by the Roma Support Group's staff working collaboratively with GPs and social services, 25% received this service as a result of being referred by Accident and Emergency Departments following their suicide attempts and only 15% were referred by their GPs without our intervention. Those service users, who have experienced mental health services in the UK, reported a range of problems, including communication problems, language barrier, not knowing their rights and not understanding how the mental health system works. In some cases these problems resulted in exclusion from the service or a loss of continuity of mental health support.

1.4 MENTAL HEALTH IN THE CONTEXT OF MARGINALISATION AND EXCLUSION OF THE ROMA COMMUNITY

The high number of Roma service users suffering mental health problems can be understood as resulting from recent traumatic life events (war and the Holocaust, racist attacks, bullying, frequent incidents of rape, etc.)⁵, which forced them to leave their home countries to seek asylum in the UK. Issues faced by the Roma community included systematic discrimination and marginalisation; social exclusion as Gypsies and refugees; insecurity related to their former status as asylum seekers; individual and/or family experience

⁴ Equality and Human Rights Commission, *How fair is Britain? Equality, Human Rights and Good Relations in 2010*, Triennial Review 2010, pp 278

⁵ Angus Fraser, *Dzieje Cyganow*, original title *The Gypsies*, PIW, Warszawa 2001, Chapters 8 and 9

of detention centres; pressure to conceal their Roma identity in schools and work places due to widespread anti-Gypsy prejudice and discrimination.

The poor state of mental health can be seen as both a result of and one of the causes of powerlessness and vulnerability. Marginalisation and exclusion have been a major factor in low problem solving/coping skills of some Roma individuals when dealing with health related problems. This is compounded by high illiteracy and low educational attainments amongst Roma refugees and migrants. Frequently forced into segregated special needs education in their home countries, most Roma parents are illiterate and have limited basic skills. 72% of parents accessing RSG services are unemployed, hence there is a lack of role models for young Roma within their families, which would enable them to build their confidence and raise aspirations.

Our action research (2010)⁶ and casework confirm official/ governmental reports, which indicate that Roma children are some of the most disadvantaged and socially excluded in the UK. They are also the worst academically performing group of school children and have the highest rates of permanent school exclusions in Britain. Many feel isolated and subjected to racism for being both "refugee" and "Gypsy", and their self-esteem is often low. (Schools Minister's letters to Directors of Children Trusts, 2006-07; National Statistics, DCSF, 2009; *How Fair is Britain?*, Triennial Review, EHRC, 2010⁷; *The Importance of Teaching*, ROTA, 2010). Gypsy, Roma and Traveller children are 40% beneath the average in national results in the education system.

Our on-going education advocacy casework shows frequent incidents of bullying, school exclusions, underachievement, poor attendance and lack of adequate support in and out of schools. Most of our young beneficiaries (over 80%) experience destitution due to debt, unemployment and homelessness. Our work experience points to the impact of poverty on their physical and emotional health. 55% of the young people we work with are susceptible to drugs, behaviour problems or involvement in the criminal justice system. Over 30% of children accessing our projects have been diagnosed with health problems including learning disability, autism, ADHD, epilepsy, depression, schizophrenia, obesity, diabetes, cardiac illnesses, deafness and blindness.

Another important aspect in the characteristics of the Roma service users of the Mental Health Advocacy Project was the stigma associated with mental health within the Roma community, as well as a well-founded lack of trust in these services. Since the 1950s Eastern European countries adopted a practice of placing many Roma children in special needs schools.⁸ These

⁶ Roma Support Group, *Improving Engagement with the Roma Community Research Report*, 2010

⁷ Equality and Human Rights Commission, *How fair is Britain? Equality, Human Rights and Good Relations in 2010*, Triennial Review 2010, pp 305, 307, 312

⁸ *Education of Roma children in Europe, Towards quality education for Roma children: transition from early childhood to primary education*, Report UNESCO and COUNCIL OF EUROPE Expert Meeting, Paris, September 2007, DGIV/EDU/ROM(2007)5

practices were wide spread and affected nearly all Roma children throughout post-war history of Eastern Europe, making Roma ethnicity the only criteria for this discriminatory and damaging policy. As a result of this, many of our Roma service users expressed their fear and mistrust towards the medical establishment, which deals with mental health issues and they have not been able to access an independent mental health advocacy to represent, empower and guide them through the system.

2. ORIGINAL PROJECT ASSUMPTIONS

2.1 AIMS AND OBJECTIVES OF THE ROMA MENTAL HEALTH ADVOCACY PROJECT

The main rationale of our Mental Health Advocacy Project was to tackle the central problem of "invisibility" of Roma refugees/migrants in the mental health system in the UK. The main aim of the Project was to deliver one-to-one mental health advocacy to empower service users to access relevant mental health services and gain greater control over their own lives.

Empowerment of individual service users would alleviate their fears, enable them to exercise their rights and speak about their concerns while at the same time enabling health professionals to learn more about the needs and specific problems of Roma patients, which would help to improve access to mental health services for Roma people and their level of satisfaction with the available services.

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2.2 MEETING THE IDENTIFIED NEEDS

The RSG was in the best position to deliver the Project due to the trust-based relationship with the Roma communities, which has been built over the last decade. There are many reasons why we are and have been successful in our work with Roma refugees and migrants:

- Roma community members have high levels of ownership of the organisation, its ethos, management and influence on service delivery
- the organisation uses a variety of methods to consult with our service users and to gather feedback from them in order to create services, which are tailored to meet the specific needs of the Roma community;
- we have adopted a holistic approach to individual and families' needs, which involve close collaboration between RSG projects and outside agencies to build a network of support for families and their children;
- in our training and work we emphasise the importance of being culturally sensitive and having respect for Roma and their cultural heritage, as well as having empathy with Roma refugees.

In the light of the above we have been able to gain a great insight into Roma issues being guided by the Roma individuals themselves. Many clients would tell our staff and volunteers about personal issues, which they consider to be taboos that are too embarrassing to be raised within their family structures. This trust that we enjoy, along with our expertise and insight into the community's needs and dynamics gave us confidence that the Mental Health Advocacy Project would be successful.

We planned that the project would be delivered by the part-time Project's co-ordinator (21 hours per week) and two bi-lingual mental health advocates (8 hours per week each = 16 hours per week.) The Project staff were appointed on the basis of their linguistic abilities and their knowledge of and empathy with Roma refugees and migrants. By employing a male and a female advocate, we would address the strict gender distinctions within the Roma culture/community thereby ensuring that service users would feel comfortable with their respective advocates.

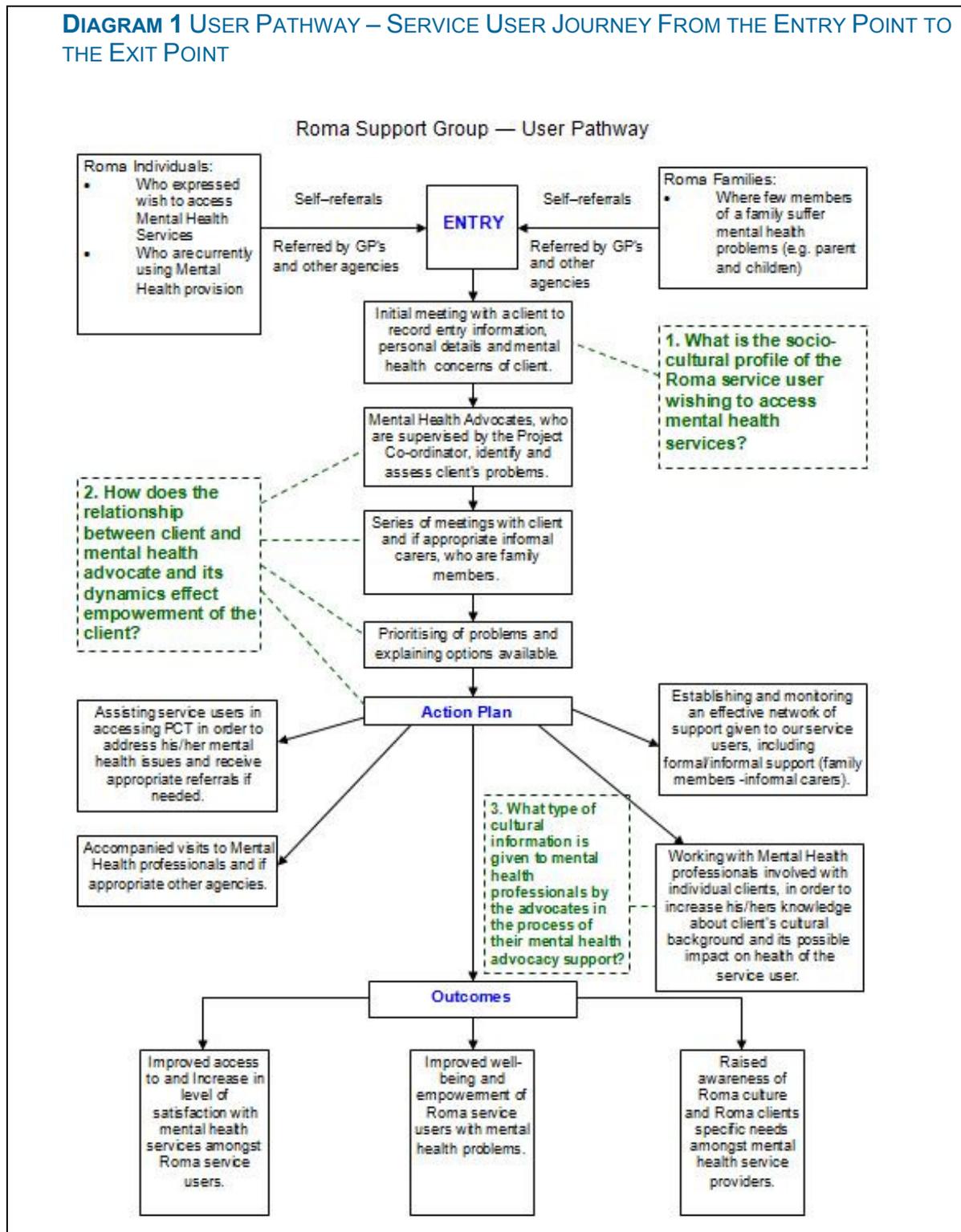
2.3 INTENDED OUTCOMES

The Project aimed to achieve the following outcomes as a result of its intervention:

- Improved access to mental health services for Roma community members, as well as an increase in the level of their satisfaction with mental health services.
- Improved well-being and empowerment of Roma service users with mental health problems.

- Raised awareness of Roma culture and Roma patients' specific needs amongst mental health service providers.

Diagram 1 - the intended outcomes in the context of the *User Pathway* – Roma Mental Health Advocacy Project's service user journey from the entry to the exit point.



2.4 ORIGINALLY PREDICTED BARRIERS AND ENABLERS

2.4.1 BARRIERS

2.4.1.1 BARRIERS WE COULD INFLUENCE

- inability to access mental health services for Roma community members
- lack of information and awareness regarding mental health services and individual rights amongst Roma service users
- family members/carers not understanding mental illness
- lack of knowledge regarding Roma refugees' culture and needs in the mental health sector

2.4.1.2 BARRIERS THAT WOULD IMPACT ON OUR PROJECT, BUT WHICH WE MAY NOT BE ABLE TO INFLUENCE

- mental health stigma in community (family/community pressure)
- anti-Roma prejudice in the wider community, including mental health professionals
- availability of adequate mental health services

2.4.2 ENABLERS

2.4.2.1 ENABLERS WE COULD INFLUENCE

- employing a Project Co-ordinator and two bi-lingual advocates
- empowerment process of service users
- effective dissemination of information about mental health services amongst Roma service users, which would take into account educational, language and other barriers

2.4.2.2 ENABLERS THAT WOULD IMPACT ON OUR PROJECT, BUT WHICH WE MAY NOT BE ABLE TO INFLUENCE

- families' concerns for the service users, attempt to protect the family members suffering with mental health problems⁹
- need to understand more about mental health within families
- need to understand more about Roma patients with mental health issues amongst health professionals

3. THE PROJECT

3.1 INVOLVEMENT OF OTHER RSG PROJECTS AND OTHER VOLUNTARY AND STATUTORY ORGANISATIONS

⁹ Many Roma try to hide the fact that they are suffering from mental health problems from their family and other community members. Once the family knows, they will endeavour to hide the problem from others. This often creates a long delay in seeking medical help. In some cases health professionals are approached only when the situation is completely out of control and the family members cannot cope with the situation.

The project was supervised and supported by the Chief Executive and members of the management committee. It employed a part-time (three days per week) project co-ordinator and two part-time (one day per week) bi-lingual mental health advocates (both female), who acted as bridge builders between service users and health professionals, empowering, informing, facilitating and enabling. The project staff members worked with and were supported by a number of volunteers. The mental health advocacy project closely co-operated with other RSG projects and staff members to ensure the best possible support for the service users.

The project worked with a number of health professionals and other staff members based at NHS Primary Care Trusts, Mental Health Trusts and Hospital Trusts, social services as well as some voluntary organisations providing support for people struggling due to mental health problems.

3.1.1 PROJECT'S CO-ORDINATOR

The Project's Co-ordinator was responsible for setting up the Roma Mental Health Advocacy Project, supervising mental health advocates and project volunteers, supporting and empowering service users and informing and co-operating with health professionals.

The Co-ordinator's working time was divided between different tasks as follows:

- Approximately 30% work time on: inducting, supervising advocates, organising entry appointments and matching advocates with service users, supervising delivery of interventions as agreed with individual clients in their action plans; recruiting and inducting volunteers; overseeing training needs of advocates and volunteers; ensuring availability of confidential space and administrating the Project.
- Approximately 30% work time on: publicising the Project within the community and amongst external health agencies and social care services, maintaining strategic and individual links with mental health practitioners, collecting and supervising dissemination of information about Roma culture, etc. amongst health practitioners, ensuring adequate monitoring and evaluation of the Project under the supervision of the Chief Executive and in collaboration with advocates and supervising and ensuring the collection of feedback from service users.
- Approximately 40% work time on: delivering direct one-to-one mental health advocacy.

3.1.2 MENTAL HEALTH ADVOCATES

The Mental Health Advocates delivered one-to-one mental health advocacy service for Roma individuals.

When selecting the Mental Health Advocates we looked at the following skills: experience of working as mental health advocates, experience of working and

liaising with health professionals and knowledge of and empathy with Roma refugees and migrants.

Originally we aimed to employ one male and one female mental health advocate but we were not able to find a suitable male advocate.

Throughout the Project the working time of the Mental Health Advocates was divided between different tasks as follows:

Approximately 80% of the Mental Health Advocates time was spent on delivering one-to-one mental health advocacy by:

- Offering information about mental health services and choices available;
- Enabling service users to speak for themselves and ensuring that they are being heard;
- Helping clients to communicate their concerns, questions, expectations;
- Helping service users to get what they want from the mental health system by contacting appropriate agencies, accompanying clients to meetings, writing letters, etc;
- Safeguarding the rights of service users - both rights under mental health policy/ law and those under general law;
- Protecting the rights of those clients, who are particularly vulnerable due to their illness or lack of capability;
- Collaborating with health practitioners (e.g. consultant psychiatrist, counsellors, GPs) in disseminating information regarding Roma culture, taboos, identity, socio-dynamics of the community.

Approximately 20% of the advocates' time was spent administering the project, maintaining case records, being supervised and continuous monitoring and evaluation.

3.1.3 VOLUNTEERS

Over the three year period nine volunteers supported the project co-ordinator and advocates in working with Roma service users through language support, advocacy, administrative duties, research and help with monitoring the progress of the Project. The volunteers did not have any experience of working in the mental health sector but received induction, in-house and external training and were supervised by the project co-ordinator.

3.1.4 OTHER RSG PROJECTS AND STAFF INVOLVED IN THE ROMA MENTAL HEALTH ADVOCACY PROJECT

The project closely co-operated with the RSG management and other RSG projects.

3.1.5 CHIEF EXECUTIVE

The Chief Executive used her ten years of experience in managing the organisation and projects development to supervise and manage the project. In addition she also contributed her experience in bi-lingual health advocacy (including mental health), her experience of supervising the evaluation of

various services, skills in strategic planning, training and consultancy work, expertise in Roma history and community dynamics, being involved in the project's focus groups and financial management.

3.1.6 THE ROLE OF OTHER RSG PROJECTS

The Mental Health Advocacy Project closely co-operated with the Advice and Advocacy Projects (including: Roma Elder People's Advice & Information Project, Health Information, Roma Elder People's Advocacy Project, Roma Young Refugees' Advocacy and Campaigning Project), and the Education Support and Mentoring Projects¹⁰. At the commencement of the Roma Mental Health Advocacy Project all the RSG projects were informed about its aims, objectives and planned model of work.

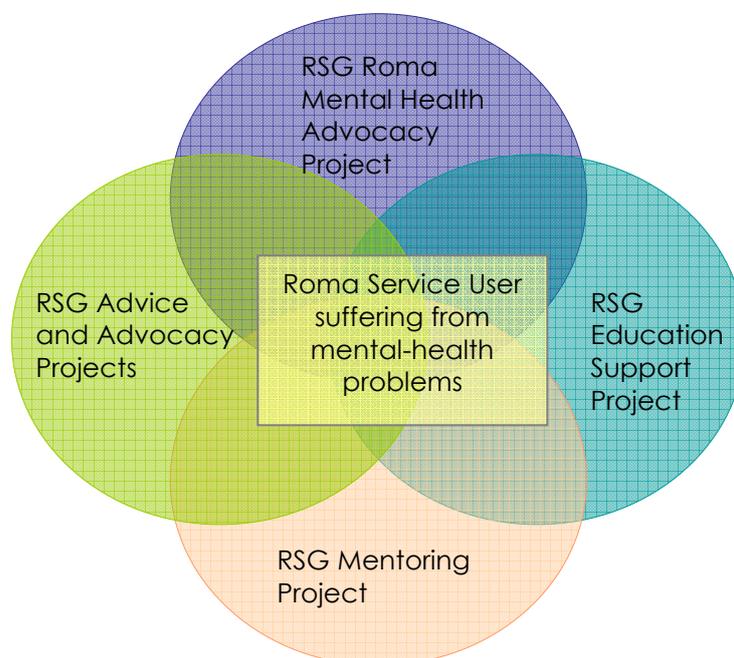
Both the Mental Health Project Advocates worked part-time for the Mental Health Advocacy project and part-time for the Elderly Advice and Advocacy Projects. This enabled them to easily cross refer service users and make sure that the service users were supported not only with health-related issues but also with welfare problems in the most efficient and appropriate way.

Similarly there were cross referrals between the mental health advocacy and RSG mentoring, education, and Roma Young Refugees' Advocacy and Campaigning Projects to ensure appropriate support for the most vulnerable clients. In the case of service users with complex needs RSG project workers co-operated closely, had regular inter-project team meetings during which information was exchanged and tasks divided to ensure appropriate support for the RSG service users suffering from mental health problems and their families and carers.

See Diagram 2 and Table 3 (page 22 of this report) for the number of internal referrals and RSG projects involved in the support of service users with complex needs.

¹⁰ Claire Eustance, Roma Support Group, *Roma Mentoring Project Evaluation Report*, May 2009

DIAGRAM 2 INVOLVEMENT OF RSG PROJECTS IN THE SUPPORT OF THE MENTAL HEALTH ADVOCACY PROJECT ROMA SERVICE USER WITH COMPLEX NEEDS



3.1.7 INVOLVEMENT OF OTHER VOLUNTARY AND STATUTORY ORGANISATIONS

The Mental Health Advocacy Project provided information and co-operated with NHS Trusts and Mental Health Trusts, social services, carers' services and voluntary organisations across London and other places in the UK, please see table 2 for examples of the organisations involved with the project and the nature of the involvement.

The main types of contact and co-operation included:

- referrals to and from mental health teams, social services, carers' support groups, voluntary organisations
- distribution of the information leaflet for health professionals created by the mental health advocacy project (see appendix 2 for the content of the leaflet),
- provision of verbal and written information about Roma culture and health-related customs for mental health and other professionals working with Roma community members.

Table 2 Some of the statutory and voluntary organisations the Roma Mental Health Advocacy Project was involved with and their role

Name of Statutory or Voluntary organisation involved with the Roma Mental Health Advocacy Project	Role
Community Mental Health Teams (CMHT) in various London boroughs (e.g. Barnet, Enfield, Haringey, Redbridge and Newham) and across UK (e.g. Birmingham, Southend), Child and Adolescent Psychotherapy Newham CAMHS, Redbridge Sanibel Psychological Therapies, Newham PCT Psychological Therapies Service	a/ referrals; b/ support for service users and mental health professionals during the assessment meetings and subsequent meetings between Roma service users and professionals, c/ exchange of information regarding Roma mental health service users; d/ providing mental health professionals with written and verbal information about Roma culture and customs related to mental health; e/ disseminating Roma information leaflet for health professionals
General Practitioners across London boroughs and out of London (e.g. Newham, Hammersmith and Fulham, Waltham Forest, Barking & Dagenham, Redbridge and Southend in Essex)	a/ written and verbal requests for referrals to mental health services; b/ support for service users and GPs during the initial appointment and subsequent meetings between Roma service users and professionals, c/ exchange of information regarding Roma service users; d/ providing professionals with written and verbal information about Roma culture and customs related to mental health; e/ disseminating Roma information leaflet for health professionals
East London NHS Foundation Trust Mental Health Carers Service	a/ referrals; b/ exchange of information regarding mental health services; c/ providing written and verbal information about Roma culture and customs related to mental health; d/ providing information about the RSG mental health advocacy project
Bi-lingual Health Advocacy, Newham PCT	a/ referrals; b/ exchange of information regarding mental health services; c/ collaborating in writing information package for Roma community members regarding NHS, PCT and Mental Health Trust; d/ promoting mental health and well-being amongst Roma community, etc.
Language and Interpreting Services, East London NHS Foundation Trust	a/ providing written and verbal information about Roma culture and customs related to mental health; b/ disseminating Roma information leaflet for health professionals
PALS (Patients Advice and Liaison Service) at NHS Newham and in other London Boroughs (formerly PCTs), Hospital Trusts (e.g. Middlesex Hospital, Newham University Hospital, The Royal London Hospital), Mental Health Trusts (e.g. East London Mental Health Trust)	a/ collaborating in raising awareness among health service providers regarding Roma patients' needs and problems they face when accessing health system; b/ logging individual complaints; c/ working towards incorporating Roma patients' experience in improving their access to health services.
Social Services in various London Boroughs (e.g. Newham, Wandsworth, Redbridge, Waltham Forest, Hammersmith & Fulham)	a/ referrals to and from; b/ safeguarding service users' rights; c/ advocating clients' needs and specific circumstances in order to establish a network of support for clients and their families including support during the care needs assessment, d/ supporting project users in child protection cases; e/ providing written and verbal information about Roma culture and customs related to mental health; f/ disseminating Roma information leaflet for health professionals
Newham Hospital Trust – Bilingual Health Advocacy	a/ referrals of service users, who suffer poor physical health
In-volve - Young People's Drug & Alcohol	a/ referrals of service users with drug addiction problems, b/

Treatment Service	providing information
Inreach Mental Health Team HMP Holloway	a/ providing written and verbal information about Roma culture and customs related to mental health; b/ disseminating Roma information leaflet for health professionals
PROMO Study Unit for Social and Community Psychiatry, Wolfson Institute of Preventive Medicine, Queen Mary, University of London ¹¹	a/ supporting their research by providing written and verbal information about Roma culture and customs related to mental health
Multi-Ethnic Counselling Service Waterloo Community Counselling	a/ referring the most excluded service users, who due to their immigration status cannot access adequate mainstream mental health services
Mapesbury Clinic	a/ referring the most excluded service users, who due to their immigration status cannot access adequate mainstream mental health services
Medical Foundation	a/ disseminating information regarding Roma refugees and their recent history of persecution, b/ Training and consultation for the RSG mental health advocacy project staff
The National Autistic Society, Fibromyalgia Association UK,	a/ contact made in order to find out about their work and information and practical support offered – project service users provided with this information
Polish Psychologists' Club – Polscy Psychologowie w Wielkiej Brytanii	a/ referral of service users, b/ providing information (presentation during the club's monthly meeting of Roma Mental Health Advocacy Project and information on Roma and their culture

3.2 SERVICE USERS – NUMBERS AND CHARACTERISTICS

Most of the service users of the Roma Mental Health Advocacy Project were Roma community members who previously accessed other Roma Support Group services. We have supported over 100 community members who expressed a wish to access mental health services and informed further 50 Roma community members about the project, its aims and the support we could offer. Most of the project's service users were supported by the project staff and volunteers from the entry point throughout the duration of the project.

3.2.1 PROFILE OF THE ROMA MENTAL HEALTH ADVOCACY PROJECT'S SERVICE USERS

- The majority of project's service users were female (66%)
- The majority, 88% originated from Poland. We also supported Roma from Romania, Lithuania, Slovakia and Kosovo
- 30% of our service users stated that they are from a Polish tribe known as Polska Roma; second and third largest groups were Galicjaki (14%) and Bergidka/Gorska Roma/Mountain Roma (9%). We also supported Roma who affiliated themselves with the following groups: Austrian and Hungarian Roma, Ukrainian/Russian Roma, Lovari, Lithuanian Roma.
- 45% of service users were between 36 and 50 years old, the youngest person was six years old and the oldest service user was 65

¹¹ PROMO Project, DG Sanco 800197, *Good Practice in Mental Health Care for Socially Marginalized People in Europe: Report on Findings*, Queen Mary University of London, December 2010

years old, only 4% of service users were over 60 years and 3% were under ten years.

- Most of the service users stated that they are Catholic (63%), the second largest group was Jehovah's Witnesses (9%).
- Most of the project's service users stated that they are married (44%), 20% stated that they are either divorced or separated from their partners, 36% were single (either never married or were widowed).

3.3 PROJECT ACTIVITIES

Our activities closely followed our original model for the project's activities as described in the *User Pathway* (please see appendix 1 for the details). However the project was enriched by additional activities such as the Roma women's self-help group and activities delivered through the Roma Mental Health Project funded by the East London NHS Foundation Trust under the Department of Health's Pacesetters Programme. This included the development of Cultural Awareness Training for Health Professionals and Forum Theatre meetings and a performance exploring wellbeing and mental health issues.

3.3.1 DIRECT AND INDIRECT SUPPORT FOR THE PROJECT'S SERVICE USERS

Health advocates provided direct support for the individual Roma service users through one-to-one and group meetings in the RSG's office, outreach visits and accompanied visits for the appointments/meetings with health professionals. Some of the interventions included: direct or indirect referrals of the project service users to the NHS counselling services, NHS Mental Health Teams and counselling provided by the voluntary sector. (Depending on the borough, either GPs were asked to refer Roma suffering from mental health problems for appropriate assessment and follow up treatment, or service users were referred directly by the project advocates to mental health services or service users were supported in making self-referrals). Please see table 3 for information about referrals the project made and the percentage of service users referred internally to other RSG projects and externally to statutory and non-statutory agencies.

The project also supported families where more than one member suffered from mental health problems and learning difficulties – individuals and families were referred to appropriate services including mental and general health, social care and welfare agencies as well as the voluntary sector offering health and welfare-related support. Our aim was to create a well-functioning net of support for the families and ultimately to empower them to access appropriate help/services without our support.

Early on we realised that we needed to support not only the service users suffering from mental health problems but also their carers. In many cases we were able to work only with the carers as communication with the service users was not possible. We outreached organisations providing support and information for carers and some of the carers were referred to appropriate services.

Table 3 Percentage of clients referred to other RSG projects and external services for additional support in relation to mental and general health, wellbeing, welfare, housing, employment and education problems.

Type of referral	Main reasons for referrals	Percentage of clients referred
Internal referrals (RSG Advice and Advocacy Projects, Mentoring Project and Education Support Project)	Clients reported problems and lack of support related to welfare, housing, employment, education as well as child protection issues	70%
External referrals (to statutory and non-statutory organisations including social care provision, solicitors, support for carers, agencies)	Clients reported problems and lack of support related to welfare, housing, employment, education, disability as well as child protection issues	30%
External referrals (to Mental Health Services)*	Roma clients suffering from mental health problems not able/not knowing how to access appropriate services	15%
Requests for referrals to GP (GP asked to refer service users to mental health services and for specialist treatment in relation to various medical problems)	Roma clients suffering from mental health and other health related problems not able/not knowing how to access appropriate services	43%

*The low number of direct referrals to mental health services is caused by the NHS Trusts' structure and acceptable methods/ways for referrals. In many boroughs mental health services would not accept self-referrals or referrals coming from voluntary organisations. The only way to access mental health services was through GP referrals.

3.3.2 DISSEMINATION OF THE CULTURAL INFORMATION

The project organised three focus group meetings with Roma community members to find out their concerns relating to mental health, access to mental health provision and contacts with mental health professionals (see appendix 2a for the list of the focus group questions). Participants included Roma from Poland, Slovakia and Romania. We had a good representation of males and females as well as different age groups including adults, elderly and young Roma. The information provided and recorded was used to create an information leaflet for health professionals (appendix 2b).

This leaflet was distributed amongst health and social care professionals working with RSG service users and NHS information officers in the London

boroughs where there is a large Roma population (data obtained from the Roma Support Group's database) e.g. London Boroughs of Newham, Hammersmith and Fulham, Enfield, Redbridge, Waltham Forest.

Project advocates provided verbal and written information, about the Roma culture and customs related to health and in particular to mental health, to health professionals working with Roma community members. Information was provided to professionals working with the service users supported by the RSG project as well as professionals working with Roma community members not known to the Roma Mental Health Advocacy Project. We also encouraged health professionals to provide written and verbal feedback to assess the impact of the information provided.

3.3.3 ROMA MENTAL HEALTH PACESETTERS PROJECT

In the second year, the Roma Mental Health Advocacy project co-ordinator also worked part time on the RSG Mental Health Pacesetters Project¹². The aims of both projects coincided and the activities carried out through the Pacesetters Programme¹³ enhanced the Roma Mental Health Advocacy Project and the support offered to the service users.

The RSG Mental Health Pacesetters Project¹⁴ aimed primarily to increase awareness of the health needs of the Roma Community within the mental health sector; and secondly to raise awareness of mental health issues within the Roma community. Both aims corresponded with the aims of the Roma Mental Health Advocacy Project funded by the King's Fund. Activities carried out through each project enhanced the outcomes of both projects, enabled service users to participate in a wider range of activities and enhanced the empowerment process.

The Roma Mental Health Pacesetters Project Activities included:

- Designing and delivering a training programme for mental health professionals – the information gathered through the focus group meetings was used to create the information leaflet for mental health professionals and also used for the purpose of this training;
- Exploring mental health and wellbeing issues through group meetings with the Roma community, rehearsals and forum theatre performance – the Roma mental health advocacy project's service users were involved in all the above activities. Participants were very enthusiastic about the meetings and the possibility to talk about various problems in their lives and the impact of these problems on their mental health. The forum theatre meetings were very effective as they allowed the

¹² *Pacesetters Programme* was a partnership between the NHS and the Department of Health (DH) with local communities who experience health inequalities. One of the core changes the programme was aiming to deliver was *Improving the Health Status of Roma, Gypsies and Travellers*. The Roma Support Group participated through the Roma Mental Health Project run from September 2009 until March 2010 in partnership with the East London NHS Trust.

¹³ COI for the Department of Health, *Pacesetters Programme, Look beneath the surface, change the way we think, Equality Impact Assessment*, March 2009

¹⁴ Van Cleemput, P., Bissell, P., Harris, J., *Pacesetters Programme Gypsy, Roma and Traveller core strand, Evaluation Report for the Department of Health*, Public Health Section ScHARR, The University of Sheffield, April 2010, Pages 134-140

community members to support each other and offered not only emotional support but also practical advice. All the participants gave very positive feedback suggesting that their wellbeing, self-esteem and ability to act independently in regards to their problems were improved. They also indicated that similar activities would be welcomed by the Roma community.

“At first I was worried about taking part (in the forum theatre), I did not know what it was about, I never took part in anything like it before. I came to the rehearsals but I did not intend to perform but when I saw people enacting problems they experience I realized that I am not alone with my problems and feelings. Everyone was really encouraging and in the end I really enjoyed performing!”

Roma service user (41)



RSG project's service users and volunteers, Forum Theatre rehearsal, Trinity Centre, December 2009

“It helped me a lot to learn that other people experience similar problems. Working together and enacting my problems made me feel better, it was like a therapy”

Roma service user (37)

3.3.4 ROMA WOMEN'S SELF-HELP GROUP

In early 2009 the RSG mental health advocates noticed that a number of female service users, all in their late thirties/early forties were either diagnosed with fibromyalgia or suffering from similar, fibromyalgia-like symptoms. All of them were very concerned about their state of health due to

lack of information and diagnosis from their GPs and consultants and this led to increased anxiety and feeling of isolation.

Two service users who fitted this profile became the project's volunteers. Both agreed to share with each other information about their health-related problems and peer support was established. From the beginning both women gave very positive feedback stating that for the first time they could talk to someone who was in exactly the same situation which increased their resilience and helped to break their isolation. After a few months of regular support they reported an improvement in their mental health and wellbeing which they contributed to the support received from other people from the community.

This led the project to explore the opportunity of setting up a self-help group of Roma women suffering from mental health and fibromyalgia-related problems.

With the support of a counsellor working with one of our service users the group was established at the end of 2009 by the Roma mental health advocacy project and a number of female Roma service users who fitted the profile. The women participated in the monthly meetings. Despite the fact that talking about health and especially mental health issues was very unfamiliar to the participants' culture the feedback from the meetings was very positive. Most of the self-help group participants expressed a wish to continue with the group meetings for several months.

"...For the first time I felt I am not alone."

Female Roma Service User (49)

"It is really good to talk to someone who has similar problems and really understands what I am talking about."

Female Roma Service User (37)

"My family is really tired of listening about my health problems, they do not understand me and I no longer talk to them about my health and my feelings. Until I started to come to the meetings I felt very lonely and isolated and didn't know that there are other people in similar situation. It helps me a lot to know that I am not alone and that I can talk to someone without fear and shame."

Female Roma Service User (40)

3.4 NUMBER AND SOURCES OF REFERRALS TO THE ROMA MENTAL HEALTH ADVOCACY PROJECT

Most of the community members who accessed the Roma Mental Health Advocacy Project were referred to us by another RSG project, a family member or an external agency. Please see table 4 for the breakdown of the sources of referrals. Only 29% of the project's service users referred themselves directly.

Table 4 Entry point – types of referrals Roma Mental Health advocacy had and sources of the referrals

Entry point – the way service users were referred to Roma mental health advocacy project

Type of Referral	Self-referral	Referred by a Family member/carer	Referred by another RSG project	Referred by an external agency
Percentage (and number) of service users	29% (32)	20.9% (23)	48.1% (53)	1.8% (2)

3.5 TYPES AND NUMBERS OF INTERVENTIONS

Almost from the beginning of the project we were able to categorise the cases/service users into three main groups in relation to their expectations, and the support needed by individual service users or families:

Non-intensive/one-off help

- The first category included the cases with one-off or very few interventions required on our part and the service user was either able to access mental-health services and other support without any further assistance from the Roma mental health advocacy project or the service user moved to another location or did not come back to us for further support but we do not know and were not able to find out why.

Moderate Support

- The second category included individual service users or families where support was needed on several occasions over a period of time or intensive support over a short period of time. Between our interventions or after short intensive period of support service users were able to deal with their own health/welfare situation by themselves or with the help of family members.

Intensive Support

- The third group included very difficult cases where support was needed on an on-going basis not only from the RSG mental health project but also from various other projects and agencies and more than one RSG advocate or staff member had to be involved over a long period of time (months or even years). Frequently help was needed not only by the service user but by the whole family suffering from mental health problems.

It also became apparent that there were a large number of Roma community members suffering from mental health problems who did not wish to access mental health services. This group can be divided into two sub-groups:

1. Service Users who expressed a wish to be supported but later refused our help

Roma community members who were either referred to us, self-referred and initially expressed the wish to access mental health services but the stigma related to mental health and fear of mental health services was so strong that they were not able to overcome these barriers to access mental health services.

2. Community members informed about the project but refused our help

Roma community members who either informed us about their mental health problems themselves or we learned about their problems from other sources (e.g. family members, other RSG projects). We informed them about the mental health advocacy project and the help they could get but they did not at any stage express a wish to access mental health services and did not want to be identified with the project.

When asked to explain why they did not want to be associated with the project, the reasons given were a very strong fear of being stigmatised, distrust towards mental health professionals and a really strong fear of using mental health services.

Over the course of our work the number of community members associated with the second group was quite substantial but we were not able to collect data on this group. However we estimate that it would be approximately 50 individuals. This group is not included in table 5 and we did not include them in any data and any findings described in this report.

Tables 5 – 8 show the types of cases we dealt with, the percentage of service users supported and examples of the intervention pattern for the *Intensive*, *Moderate*, and *Non-intensive* cases.

Table 5 Percentage of service users who initially expressed a wish to access mental health services and Roma Support Group’s Mental Health Advocacy Project to get help for their mental health problems and either accessed relevant services supported by the Roma Mental Health Advocacy Project or refused our help.	
Type of service user/case	Percentage of service users
Service users requiring intensive support - <i>Intensive</i> cases	28%
Service users requiring moderate support - <i>Moderate</i> cases	38%
Service users requiring sporadic support/one-off intervention - <i>Non-intensive cases/one-off help</i>	20%
Service users who initially expressed a wish to access mental health services but in the end refused help	11%

- Clients who expressed a wish to be supported but later refused our help	
Service users on the waiting list	3%

Table 6 Intensive cases – average individual intervention pattern (based on case studies)

	Type and number of interventions required		
Year one, two and three (22 months)	Outreach and office-based appointments*	Follow up **	Telephone contact ***
	29	48	75

***Outreach and office-based appointments: 1 to 2 times per month - average time 2 - 4 hours with client**

(Pre-arranged or unplanned meetings with the service users to talk about their problems and feelings, advocate for service user at meetings with psychiatrist, GP, solicitor, local authorities, social services etc; fill in forms, reading letters, apply for relevant benefits and services liaise with all relevant services, booking doctors' appointments, arranging transport etc, supporting carers with day-to-day matters: utility bills, debts, welfare benefits, health-related matters: i.e. booking appointments, reading letters, arranging instalments asking for time to pay)

****Follow up: 2 times per month - on average 3 hours each time**

(E-mail/telephone contact with social worker, GP, psychiatrist and other consultants, care centre, service user's council, solicitor etc; letters and application writing, filling in forms, faxing and sending documents to relevant parties, research)

*****Telephone contact: 3 to 4 times per month – on average 5-10 minutes each time**

(Talking about service users' problems and feelings, advising service user /carer of any follow up done, checking if they need any more help, follow up on all relevant matters, doctors' appointments etc, reminding service users about appointments, arranging home visits, explaining and interpreting information from/for professionals)

Table 7 Moderate cases – average individual intervention pattern (based on case studies)

	Type and number of interventions required		
Year one and two (15 months)	Outreach and office-based appointments*	Follow up **	Telephone contact ***
	9	4	17

***Outreach and office based appointments: 0.6 times per month – on average 1 hour each time**

(Pre-arranged or unplanned meetings with the service users to talk about their problems and feelings, advocate for service user at meetings with psychiatrist, GP, local authorities, social services etc; filling in

forms, reading letters, applying for relevant benefits and services liaising with all relevant services, booking doctors' appointments, supporting carers with day-to-day matters)

****Follow up: 0.3 times per month - on average 1 to 2 hours each time**

(E-mail/telephone contact with social worker, GP, psychiatrist and other consultants, care centre, service user's council, solicitor etc; letters and application writing, filling in forms, faxing and sending documents to relevant parties, research)

*****Telephone contact: 1.4 times per month - on average 10 to 15 minutes each time**

(Talking about service users' problems and feelings, advising service user/carer of any follow up done, checking if they need any more help, follow up on all relevant matters, doctors' appointments etc, reminding service users about appointments, arranging home visits, explaining and interpreting information from/for professionals)

Table 8 *Non-intensive cases – average individual intervention pattern (based on case studies)*

	Type and number of interventions required		
Year two and three (9 months)	Outreach and office-based appointments*	Follow up **	Telephone contact ***
	5	7	4

***Outreach and office based appointments: 0.5 times per month – 30 to 45 minutes each time**

(Pre-arranged or unplanned meetings with the service users to talk about their problems and feelings, , advocate for service user at meetings with psychiatrist, GP, local authorities, social services etc; filling in forms, reading letters, applying for relevant benefits and services liaising with all relevant services, booking doctors' appointments, supporting carers with day-to-day matters)

****Follow up: 0.8 times per month – 15 to 20 minutes each time**

(E-mail/telephone contact with GP, psychiatrist and other consultants, social worker, care centre, service user's council, solicitor etc; letters and application writing, filling in forms, faxing and sending documents to relevant parties, research)

*****Telephone contact: 0.4 times per month - 3 to 5 minutes each time**

(Talking about service users' problems, advising service user/carer of any follow up done, checking if they need any more help, follow up on all relevant matters, doctors' appointments etc, reminding service users about appointments, arranging home visits, explaining and interpreting information from/for professionals)

4. METHODOLOGY OF THE EVALUATION

4.1 PURPOSE AND METHODOLOGY OF THE EVALUATION

This Evaluation Report is a culmination of a process of continuous evaluation of the Roma Mental Health Advocacy Project. The project was set up in order

to gather data and evaluate the findings related to the three research questions¹⁵ agreed with the King's Fund.

There are number of theoretical approaches to evaluation. We have considered Theory of change¹⁶, Realist Evaluations¹⁷ and Participatory Evaluation¹⁸ as possible approaches to the evaluation of the Mental Health Advocacy Project. Since we felt that both the Realist Evaluation and Participatory Evaluation would well reflect the intended evaluation, we have decided to combine both approaches using a range of data collection methods consistent with such approaches.

4.1.1 REALIST EVALUATION

Realist Evaluation methodology concentrates on the relationship between three key elements: the context in which the changes measured take place, the mechanisms used to produce the changes and the outcomes which may be measured.

According to Pawson & Tilley's "*Realist evaluation has no particular preference for either quantitative or qualitative methods. Indeed it sees merit in multiple methods, marrying the quantitative and qualitative, so that both programme processes and impacts may be investigated. The precise balance of methods to be used is selected in accordance with the realist hypothesis being tested, and with the available data.*

¹⁵ 1. What is the socio-cultural profile of the Roma service user wishing to access mental health services? 2. How does the relationship between client and mental health advocate and its dynamics effect empowerment of the client? 3. What type of cultural information is given to mental health professionals by the advocates in the process of their mental health advocacy support and how does it change their knowledge? Please see also appendix 1

¹⁶ James P. Connell and Anne C. Kubisch, *Applying a Theory of Change Approach to the Evaluation of Comprehensive Community Initiatives: Progress, Prospects, and Problems*, Published by The Aspen Institute, United States of America, 1998, ISBN # 0-89843-249-9, Available at:

<https://communities.usaidallnet.gov/fa/system/files/Applying+Theory+of+Change+Approach.pdf>

Paul F. McCawley, *The Logic Model for Program Planning and Evaluation*, University of Idaho, Available at: <http://www.uiweb.uidaho.edu/extension/LogicModel.pdf>

Will Allen, *Theory of change and logic models*, Learningforsustainability.net, helping people collaborate and innovate, Available at:

<http://learningforsustainability.net/evaluation/theoryofchange.php>

Avril Blamey, Mhairi Mackenzie, *Theories of Change and Realistic Evaluation, Peas in a Pod or Apples and Oranges?*, Sage doi: 10.1177/1356389007082129 Evaluation, October 2007 vol. 13 no. 4 439-455, Available at: <http://evi.sagepub.com/content/13/4/439.abstract>

¹⁷ Pawson, R. and Tilley, N., *Realistic Evaluation*, Sage, 1997

Ray Pawson and Nick Tilley, *Realist Evaluation*, 2004, available at:

http://www.communitymatters.com.au/RE_chapter.pdf

¹⁸ Ann Zukoski, Mia Luluquisen, *Participatory Evaluation, What is it? Why do it? What are the challenges?*, Community-Based Public Health, Policy & Practice, Partnership for the Public's Health, A collaboration of The California Endowment and Public Health Institute, Issue #5, April 2002, Page 1, Available at: http://depts.washington.edu/ccph/pdf_files/Evaluation.pdf

J. Bradley Cousins, Lorna M. Earl, *The Case for Participatory Evaluation*, Sage, doi:

10.3102/01623737014004397 EDUCATIONAL EVALUATION AND POLICY ANALYSIS

December 21, 1992 vol. 14 no. 4 397-418, Available at: <http://epa.sagepub.com/content/14/4/397.short>

Anita M. Baker, Ed.D., Kimberly J. Sabo, Ph. D., *Participatory Evaluation Essentials, A Guide for Non-Profit Organizations and Their Evaluation Partners*,

http://www.brunerfoundation.org/ei/docs/guide_for_nonprofits.pdf

Realist research is distinctive in its understanding of the research relationship between evaluators and stakeholders.

On the realist approach, stakeholders are regarded as key sources for eliciting programme theory and providing data on how the programme works. But it is not assumed that they are all-knowing, nor that they will necessarily agree on how, for whom and in what circumstances a programme will work. Stakeholders generally have experience of and thus expertise in particular phases and process within an intervention. Realist evaluation requires data on process and outcome, and on individuals, interrelationships, institutions and infra-structures.”¹⁹

The project proposal, User Pathway and the Learning Plan developed through the dialogue and discussions which took place between the RSG and the King’s Fund at the commencement of the Mental Health Advocacy Project formulated a framework for our research. This included context, mechanisms and expected outcomes as well as a number of hypotheses in relation to our research questions which described the expectations of positive change to be brought about by the project. That process supported an approach based on Realistic Evaluation methodology as it fitted with the framework of the project.

4.1.2 PARTICIPATORY EVALUATION AND INSIDER’S PERSPECTIVE

The participatory approach focuses on co-design and community engagement.

According to Ann Zukoski and Mia Luluquisen *“Participatory evaluation is a partnership approach to evaluation in which stakeholders actively engage in developing the evaluation and all phases of its implementation.*

Those who have the most at stake in the program — partners, program beneficiaries, funders and key decision makers — play active roles. Participation occurs throughout the evaluation process including:

- *identifying relevant questions;*
- *planning the evaluation design;*
- *selecting appropriate measures and data collection methods;*
- *gathering and analysing data;”²⁰*

The participatory approach which was utilised in this research is closely related to the ethos of the RSG methods of work which presupposes cultural, historical and socio-political knowledge of our service user group and contribution towards empowerment of our service users. It is very closely related to the high degree of ownership that our service users have in relation

¹⁹ Ray Pawson and Nick Tilley, *Realist Evaluation*, 2004, pages 2,10,12, Available at: http://www.communitymatters.com.au/RE_chapter.pdf

²⁰ Ann Zukoski, Mia Luluquisen, *Participatory Evaluation, What is it? Why do it? What are the challenges?*, Community-Based Public Health, Policy & Practice, Partnership for the Public’s Health, A collaboration of The California Endowment and Public Health Institute, Issue #5, April 2002, Page 1, Available at: http://depts.washington.edu/cph/pdf_files/Evaluation.pdf

to the RSG and our commitment to work with the Roma community in mobilising them into grass root activities and delivery of our projects.

The RSG project workers including the Mental Health Advocacy project workers are frequently the only non-Roma individuals with whom the service users are able to establish relationships which are based on trust, mutual respect and partnership. RSG workers are in a unique position as “insiders” who facilitate and support a process of trust building and assist service users in their journey of self-development and empowerment. In this process we do not try to impose the mainstream values, the outcomes to be achieved or the time framework and direction of this “journey”.

This approach is not only relevant to the process of empowerment of our individual service users but also it is vital to our work which addresses the historical social exclusion and marginalisation of Roma individuals and communities in Europe.

According to Mandy Wilson *“Participatory evaluation is closely related to action research. It involves creating a learning process for the programme participants, involving them in identifying indicators and learning. It aims to mitigate against evaluation being something that is done to people, outside of their sphere of influence*

The main thing about participatory evaluation, ... is that it is not just a set of techniques but a rethinking of the process – who is involved, what they contribute, what they learn and how they benefit.”²¹

4.1.3 EXTERNAL EVALUATION

We felt that the participatory approach with the wide range of subjective data collected would give us a broader understanding when analysing research questions. The choice to adopt the participatory approach in our evaluation has also been motivated by our unsuccessful attempt of external evaluation which could not capitalise on:

- Insiders’ perspective and the knowledge it encapsulates
- The specific dynamics that our perspective as participators and insiders generates in terms of the relationship with our service users e.g.: partnership, trust and ownership of our work

The lack of compatibility of the external evaluator’s methods of data collection and our work motivated our decision to undertake the evaluation of the project ourselves with the support and approval of the King’s Fund’s Grant Manager. To minimise the possible lack of objectivity in our data analysis we worked with an external evaluation consultant who played the role of a “critical friend”.

²¹ Mandy Wilson, Community Development Exchange, *Empowering Evaluation: Evaluating Empowerment, a Practice Sharing Report from CDX*, 2008, Available at: <http://www.cdx.org.uk/sites/default/files/empowering%20evaluation.pdf>

4.1.4 STUDY PHASES

In order to capture data related to each research question we developed monitoring tools which we set up in our learning plan template and created a framework for a regular documentary review of data collection and the evidence gathered. Table 9 shows the study phases and key activities for each research question.

Table 9 Study phases and key activities		
Study phase	Research Question/ Study Objectives	Key activities
Project inception	Research question 1: What is the socio-cultural profile of the Roma service user wishing to access mental health services?	a) Research planning meetings with the King’s Fund b) Recruitment of the Project staff and induction c) Refinement of data collection methods d) Informing other RSG projects and external agencies about the project and its aims e) Outreaching service users and taking referrals.
	Research question 2: How does the relationship between client and mental health advocate and its dynamics effect the empowerment of the client?	a) Research planning meetings with the King’s Fund b) Refinement of data collection methods c) Sessions with the service users and participating in their meetings with mental health professionals.
	Research question 3: What type of cultural information is given to mental health professionals by the advocates in the process of their mental health advocacy support and how does it change their knowledge?	a) Research planning meetings with the King’s Fund b) Setting up focus group meetings to explore the following: <ul style="list-style-type: none"> • Roma attitudes towards mental health services and mental health in general • Mental health issues within the Roma community c) Creating information leaflets for mental health professionals.
Documentary and data review		a) Identification and collation of relevant documents and statistical data b) Desk-based literature review of mental health related conditions and customs of Roma community.
Community engagement	Research question 1: What is the socio-cultural profile of the Roma service user wishing to access mental health services?	a) Outreaching service users and taking referrals b) Initial meetings with service users c) Filling in the service entry forms and their analysis (looking at patterns detectable in the social/cultural profile of our clients. The project becomes better informed about socio cultural differences in a mental health context and more able to explain differences to mental health professionals) d/ Setting up focus group meetings to explore the

		<p>following:</p> <ul style="list-style-type: none"> • Roma attitudes towards mental health services and mental health in general • Mental health issues within the Roma community (Material from the focus groups used to develop an information leaflet for mental health professionals) <p>e) Regular evaluation meetings with the King’s Fund.</p>
	<p>Research question 2: How does the relationship between client and mental health advocate and its dynamics effect the empowerment of the client?</p>	<p>a) Sessions with service users and participation in their meetings with mental health professionals b) Meetings and communication with carers c) Team meetings to exchange the information, discuss problems and findings and develop solutions d) Number of service users take part in the group meetings and rehearsals for the Forum Theatre performance exploring mental health and well being issues e) Self-help group meetings f) Updating records and observations from all the cases dealt with g) Gathering written and verbal feedback from clients h) Filling in distance travelled forms with clients i) Regular evaluation meetings with the King’s Fund.</p>
	<p>Research question 3: What type of cultural information is given to mental health professionals by the advocates in the process of their mental health advocacy support and how does it change their knowledge?</p>	<p>a) Meetings between health advocates and service users b) Meetings with health professionals c) Disseminating information leaflets amongst mental health professionals d) Evaluation of the leaflet by the health professionals through written and verbal feedback; e) Regular review and analysis of information gathered through:</p> <ul style="list-style-type: none"> • advocates' observation notes • case studies • case records • Distance Travelled Forms <p>f) Developing training for mental health professionals (commissioned by the East London Mental Health Trust as part of the Department of Health Pacesetters Programme) g) Regular evaluation meetings with the King’s Fund.</p>
Data analysis		<p>a) Regular data review b) Regular evaluation meetings with the King’s Fund c) Data inputting, cleaning and validation d) Data analysis to identify specific features.</p>
Knowledge synthesis and write up		<p>Data analysis ‘across methods’ and ‘across groups’ to identify common themes for each research area and possible subjects for future research.</p>

4.1.5 DATA REVIEW OF EXISTING EVIDENCE AND STATISTICAL DATA SOURCES

A desk-based rapid review of the literature related to the health and in particular mental health of the Roma community took place at the

commencement of the Mental Health Advocacy Project and throughout the remaining period of the study. We found that data relating to health and mental health of the Roma is almost non-existent. We were able to find only one report in English which concentrated on English Gypsies and Travellers rather than Roma from East Europe. We did not find any reports or articles in Polish and we found very few articles in other languages. We have searched English, Polish, Czech, Slovak and Romanian language websites and publications.²²

“Data relating to Gypsies and Travellers' health is extremely limited and the invisibility of this severely socially excluded group is a major concern. Health service commissioners and planners commonly operate in the absence of any information on the size or needs of these communities.

The Health Status of Gypsies and Travellers 2004 (Parry et al. 2007)²³

*Currently the only substantial, quantitative study of the health of Gypsies and Travellers in the UK, this study was carried out in 2002 and included a relatively modest sample size of 293 'Gypsy-Travellers' across five locations: London, Bristol, Sheffield, Leicester and Norfolk. This study employed a survey including standard health measures, supplemented by 27 in-depth interviews to explore health experiences, beliefs and attitudes. The study identified distinct groups: English Gypsies, Welsh Gypsies, Scottish Gypsy Travellers and Irish Travellers, and sampled in such a way as to include English/Welsh and Irish Traveller samples. The majority of the results are presented for the total group combined, though some differences within the sample are highlighted. The study also included a matched comparator sample of 260 people matched for age and sex and living in one of the five locations, including British people in White, Pakistani, Black Caribbean ethnic groups, urban and rural environments, and those who were socio-economically deprived. All participated in a structured health interview including standardised measures of health status and specific illnesses, medication use, and health service contacts”.*²⁴

4.2 RESEARCH QUESTIONS

The three research questions agreed with the King's Fund at the commencement of the project were:

²² All the documents found are referenced at the end of this report.

²³ Glenys Parry, Patrice Van Cleemput, Jean Peters, Julia Moore, Stephen Walters, Kate Thomas, Cindy Cooper, The University of Sheffield, School of Health and Related Research, Summary of a report to the Department of Health 2004, *The Health Status of Gypsies and Travellers in England*, Department of Health, October 2004

²⁴ Allmark, P., Salway, S., and Piercy, H. (eds), *Life and Health: An evidence review and synthesis for the Equality and Human Rights Commission*, Centre for Health & Social Care Research Sheffield Hallam University, July 2010, Available on the Equality and Human Rights Commission's Triennial Review web pages, Chapter 7, Pages 26-28 and 72

1. *What is the socio-cultural profile of the Roma service user wishing to access mental health services?*
2. *How does the relationship between client and mental health advocate and its dynamics effect empowerment of the client?*
3. *What type of cultural information is given to mental health professionals by the advocates in the process of their mental health advocacy support and how does it change their knowledge?*

4.2.1 CLARIFYING TERMS AND ASSUMPTIONS

The framework was agreed with the King’s Fund prior to the commencement of the Mental Health Advocacy Project. Table 10 clarifies terms, methodology of gathering information and our original assumptions in relation to the three research questions. All the definitions used were agreed with the King’s Fund prior to the commencement of the Mental Health Advocacy Project.

Table 10 Clarifying terms and outcomes for the research questions/areas	
1. HOW TO DEFINE THE SOCIO-CULTURAL PROFILE OF THE ROMA SERVICE USER?	
FACTORS DEFINING THE SOCIO-CULTURAL PROFILE	
a) Country of origin b) Tribal affiliation	Country of origin and tribal affiliation of the service user will influence his/her understanding and experience of the distant and more recent past. It is important to view Roma service users as not belonging to one monolithic community but being a member of one of many Roma communities, which differ in language, historical experience, cultural customs and traditions, lifestyle, self-perception as Roma, attitudes to the outside world, etc.
c) Level of acquired formal education	The level of acquired formal education, will inform us about the service user's ability to function in a non-Roma social environment, his/her literacy and numeracy skills, as well as an ability to express/articulate his/her needs and concerns.
d) Religion	Although in general, Roma individuals/communities adopt the religion of the country/state where they live/come from, recently there are many instances of conversion to Jehovah's Witnesses or Pentecostal churches. Depending on how well this conversion is perceived in one's family or clan, a service user's experience can differ and be more traumatic or less.
e) Degree of integration into mainstream society	The degree of integration into mainstream society can differ depending on the individual’s personal choice and acquired education. This can be either compatible or not with the service user's immediate Roma family and clan environment, hence contributing or not to the individual’s internal conflict

	and tension.
f) Chosen mode of lifestyle and its compatibility with the predominant model of lifestyle in one's Roma community	Being more or less integrated and open to the social environment can be a source of advantage or disadvantage for Roma service users. This needs to be observed and assessed.
2. HOW TO DESCRIBE A SERVICE USER'S PROCESS OF EMPOWERMENT? HOW WILL THE RELATIONSHIP WITH AN ADVOCATE IMPACT ON THE PROCESS OF THE SERVICE USER'S EMPOWERMENT?	
<p>Each service user's process of empowerment will take a different course evolving according to the individual's point of departure and their empowerment indicators. A service user's relationship with an advocate will mutually influence the service user and the advocate, enabling both to gain a greater understanding of themselves and each other. The service user and advocate will be able to "travel" together, while developing tools and means to empowerment (measured by "Distance-Travelling Forms", the advocate's diaries, case studies, case records, observation notes, etc) of the service user, as well as expanding and enriching the mental health advocate's understanding of the process of empowerment and what influences it.</p>	
3. WHAT TYPE OF CULTURAL INFORMATION IS GIVEN TO MENTAL HEALTH PROFESSIONALS IN ORDER TO ENSURE A POSITIVE "CHANGE/SHIFT" IN THEIR ATTITUDES TOWARDS ROMA PATIENTS?	
<p>Cultural diversity in the UK and a necessity to assimilate knowledge related to many different cultures in order to work effectively with patients from an ethnic minority background puts heavy pressure on mental health professionals. This can also cause some reluctance to acquire this information, especially given time restrictions and a heavy workload. In the case of Roma patients, health professionals may also be inclined to use stereotypes and clichés in relation to Roma/Gypsy matters, which will hinder their relationship with Roma patients. It will be of fundamental importance to disseminate historical and cultural information by an advocate, which will be the most relevant to the successful progress of the professional's work with a patient. This will also need to be done in a sensitive and non-challenging way and will include an insight into Roma culture as a culture of people who have been powerless, discriminated against and excluded from wider society for the whole period of their European history. The syndrome/culture of "exclusion" as both: imposed from the outside, as well as self-imposed, will need to be examined in the context of individual patients and the impact it has on their mental health.</p>	

4.3 METHODS OF DATA COLLECTION AND DATA ANALYSIS

4.3.1 METHODS OF DATA COLLECTION

The Mental Health Advocacy project relied on a combination of quantitative and qualitative methods to collect and analyse information. The use of mixed methods was consistent with the different research questions asked which were best addressed in different ways. Qualitative information was collected

using individual and group-based methods. The choice of method was dictated by considerations of each research question and an assessment of the most appropriate method.

The main methods used were documentary review of relevant statistical data gathered through entry forms, feedback questionnaires and verbal feedback from the service users and mental health professionals, distance-travelled forms, individual service users' action plans, advocates' observation notes, case records, focus group meetings, one-to-one interviews and minutes of meetings. Shown in table 11 below is which methods were utilised for each of the 3 questions.

Table 11 Study objectives/research questions and data collection methods											
Research questions	Data collection methods										
	Focus Group Meetings	Entry Form	Service Users Action Plans	Distance-Travelled Form	Case Notes	Observation Notes	Case Records	Minutes of meetings	One-to-one interviews	Feedback forms	Verbal Feedback
Question 1*	X	X	X								
Question 2**			X	X	X	X	X	X	X	X	X
Question 3***	X				X	X	X	X	X	X	X

* Question 1 - What is the socio-cultural profile of the Roma service user wishing to access mental health services?

** Question 2 - How does the relationship between client and mental health advocate and its dynamics effect empowerment of the client?

*** Question 3 - What type of cultural information is given to mental health professionals by the advocates in the process of their mental health advocacy support and how does it change their knowledge?

The focus group methodology was used with the following groups:

- a) middle aged Polish Roma
- b) mixed ages and genders Romanian Roma
- c) mixed gender young Roma.

24 participants took part in three focus group meetings of which 15 were females and 9 males. Discussions were conducted in English, Romanian and Polish, with the project co-ordinator moderating the event and Mental Health Advocates/project volunteers taking detailed notes. The discussion themes addressed four key areas: perception of mental health problems amongst the Roma communities, barriers in accessing mental health services, experience of accessing health services including professionals' knowledge and understanding of Roma culture and what they should know. (See appendix 2a for focus group questions).

4.3.2 METHODS OF DATA ANALYSIS

Data was collected (using qualitative and quantitative methods, please see figure 4.3.1 and table 11 for all the methods) throughout the duration of the Mental Health Advocacy Project.

4.3.3 SAMPLING

For the purpose of the evaluation ten case studies were chosen on the basis of their representative value. Our intention was to analyse in greater depth all the case types we dealt with including samples of *Intensive* cases, *Moderate* cases and *non-Intensive* cases. We had to change some of the initially chosen cases as it became obvious that their representative value changed over time and not all the case types were represented by our original choice.

4.3.4 ANALYSIS OF DATA, TEMPLATE ANALYSIS

We collected written feedback from as many service users as possible and analysed data collected through action plans, observations, advocates' case notes and records and verbal feedback from service users not only for the sample case studies but for as many other cases that we dealt with as possible. The record of minutes from meetings, team reflection and case review have also been analysed as well as analysis of minutes and audio-visual records from focus and self-help group meetings and the forum theatre (rehearsals and performances).

In relation to empowerment the benchmarks/indicators were set up case by case including both the sample case studies and other cases we dealt with. Regular team meetings and meetings with the King's Fund Grant Manager and an external evaluation consultant took place over the project's existence to discuss and analyse empowerment indicators, data collected and professional observations and to act upon emerging themes.

Feedback interviews were conducted in the preferred language of the client by the project co-ordinator and by advocates; where appropriate, care providers or relatives of the service users were also invited to interviews. These interviews were conducted over the telephone and face-to-face through a semi-structured questionnaire. In relation to question three we analysed feedback (both written and verbal) from mental health professionals and service users who worked with these professionals.

Quantitative data collected through methods such as entry forms and distance travelled forms was input manually into a database and analysed. Data was collected throughout the duration of the project and analysed on a regular basis at approximately six-monthly intervals.

The template analysis²⁵ method was used to thematically analyse qualitative data collected for the sample cases. The data was analysed with the research questions acting as a guide to "filter" emerging themes.

²⁵King, N (2004) *Template analysis - What is Template Analysis?*

Available on line at: http://www.hud.ac.uk/hhs/research/template_analysis/whatis.htm,
http://www2.hud.ac.uk/hhs/research/template_analysis/index.htm

4.4 RESEARCH ETHICS AND LIMITATIONS

4.4.1 RESEARCH ETHICS

Information about the evaluation was provided to each service user in his/her language and verbal consent obtained at the entry point; this could be withdrawn by the service user at any time. Service users were only interviewed and data collected if they were happy to take part in the research and for the information provided to be used for the research purposes. All the group meetings and individual interviews were recorded with the consent of the participants.

All the service users' names used in this report were changed in order to protect their identity.

4.4.2 RESEARCH LIMITATIONS

The data gathered was limited by the omission of the views of the service users who had severe learning difficulties and were considered too ill to be interviewed or provide the required information. Although this could not be avoided, where appropriate the views of their carers were sought instead.

Due to the restrictions on time and resources, it was not possible to organise focus group meetings for every nationality group that exists within the Roma refugee and migrant community in the UK. Hence, there were no meetings organised specifically for Roma from Slovakia, the Czech Republic, Lithuania or Kosovo. Instead, one of the focus group meetings was open to all Roma community members who wished to participate.

In addition, the work with individual service users focused on Roma community members who were already known to the RSG through their use of services and involvement in projects over many years and the Roma community members who either self-referred to the project or were referred by the external agencies. The restriction of time and resources did not allow the research team to go beyond the scope of the already developed networks and contacts. However, since the RSG supports over 860 Roma families (approx. 5,000 individuals) and as it has been acting as the voice of the Roma community in London for over a decade, it was decided that sufficient mechanisms were in place to reach out to a representative sample of the Roma community.

4.5 PROBLEMS WITH DATA COLLECTION

King, N. *Template Analysis*, in G. Symon and C. Cassell (eds) *Qualitative Methods and Analysis in Organizational Research*, 1998, London, Sage

King, N., *Using templates in the thematic analysis of text*, in C.Cassell and G.Symon (Eds.) *Essential Guide to Qualitative Methods in Organizational Research*, 2004, London, Sage

Most of the problems we encountered were envisaged from the outset of the project but were frequently easy to overcome, e.g. many Roma service users were more open and willing to help with the research and talk about their mental health problems than we expected at the commencement of the Mental Health Advocacy Project. Table 12 lists problems encountered for each data collection method.

Table 12 Data collection methods and problems encountered	
Data collection method	Problems encountered
Focus Group Meetings	<p>a) Difficulties with recruitment of participants. The majority of the Roma community members are afraid to talk about mental health in front of others and especially in front of Roma community members.</p> <p>b) Difficulties to understand some of the focus group questions; mental health is a taboo subject and many Roma community members never discuss it, many lack even basic understanding of mental health problems and the vocabulary to talk about it.</p>
Entry Form	<p>a) Some clients were reluctant to answer some of the questions, especially during the first few meetings, before trust between them and a RSG health advocate was established.</p> <p>b) Some clients had difficulties with understanding some of the <i>Entry Form</i> questions due to poor literacy skills, new concepts, and lack of vocabulary.</p> <p>c) Most service users needed help to fill in the form due to poor literacy skills.</p> <p>d) In some cases only the carer was able to answer the entry form questions.</p>
Service Users' Action Plans	<p>a) Some clients were reluctant to provide all the information required, especially during the first few meetings, before trust was established.</p> <p>b) In some cases only the carer was able to answer the entry form questions.</p>
Distance-Travelled Form	<p>a) Some clients had difficulties to understand some of the questions due to poor literacy skills, new concepts and lack of vocabulary.</p> <p>b/ Most service users needed help to fill in the form due to poor literacy skills.</p> <p>c) In some cases it was not possible to complete Distance -travelled forms due to the severity of mental health problems or other disabilities and in some cases only the carer was able to answer the questions asked in the distance -travelled form.</p>

Case Notes	Time constraints – a large number of clients with complex needs meant that time for each client and case notes was very limited
Case Records	Time constraints – a large number of clients with complex needs meant that time for each client and writing case records was very limited.
Observation Notes	Time constraints – a large number of clients with complex needs meant that time for each client and keeping record of observations was very limited.
Minutes of meetings	Time constraints – a large number of clients with complex needs meant that time for team meetings was very limited.
One-to-one interviews	<p>a) Some clients had difficulties to understand some of the questions due to poor literacy skills, new concepts and lack of vocabulary.</p> <p>b) Health professionals frequently too busy or reluctant to communicate with external agencies such as RSG and our Mental Health Advocates.</p>
Feedback forms	<p>a) Most service users needed help to fill in the service user feedback form.</p> <p>b) Service users were usually helped by the Roma Mental Health Advocacy Project staff or volunteers hence we do not know how true the answers were in regards to the RSG Mental Health Advocacy project and its usefulness and impact.</p> <p>c) Mental health professionals too busy or reluctant to provide written feedback.</p>
Verbal Feedback	a) Health professionals having time constraints preventing them from reading information leaflet and providing feedback.

5. RESULTS

This section of the evaluation report describes what we learned from the analysis of each of our research questions.

5.1 WHAT IS THE SOCIO-CULTURAL PROFILE OF THE ROMA SERVICE USER WISHING TO ACCESS MENTAL HEALTH SERVICES?

5.1.1 GENDER

The majority of the project's service users were female (66%) - which might be related to the fact that the project co-ordinator and both advocates were female (we aimed to employ a male advocate but unfortunately we did not get any male candidates).

5.1.2 COUNTRIES OF ORIGIN AND IMMIGRATION STATUS

The majority (88%) originated from Poland. This is consistent with the other RSG services as we have a long established good working relationship with the Polish Roma community and many of Polish Roma accessed our previous health-related projects and events. We also supported Roma from Romania, Lithuania, Slovakia and Kosovo.

The majority of the project's service users came to the UK before 2004 as asylum seekers (77.5%).

5.1.3 TRIBAL AFFILIATION

30% of our service users stated that they are from a Polish tribe known as Polska Roma (Polish), the second and third largest groups were Galicjaki 14% and Bergidka/Górska Roma (Mountain Roma) 9%. We also supported Roma who affiliated themselves with the following groups: Austrian and Hungarian Roma, Ukrainian/Russian Roma, Lovari, Lithuanian Roma. Tribal affiliation was based on the information provided by the service users. Approximately 26% did not want to disclose their tribal affiliation, did not understand the question or did not know the answer.

5.1.4 AGE

45% of service users were between 36 and 50 years old, the youngest person was six years old and the oldest service user was 65 years old, only 4% of service users were over 60 years and 3% were under ten years old.

5.1.5 EDUCATION

Over 60% of the project's service users did not acquire education at a level higher than secondary school. Out of that number 6% had no formal education, 30% did not finish primary education and only 2% finished secondary school. Only 2% of the entire number of service users stated they had undertaken higher education

Level of education	Percentage of service users
No formal education	6%
Primary school - not finished*	30%
Primary school - finished*	15%
Secondary school - finished	2%
College/Vocational Training including music/High school	16%
Higher education	2%
Special needs schools	6%
Special provision/home tutorials	2%
Still in education	7%

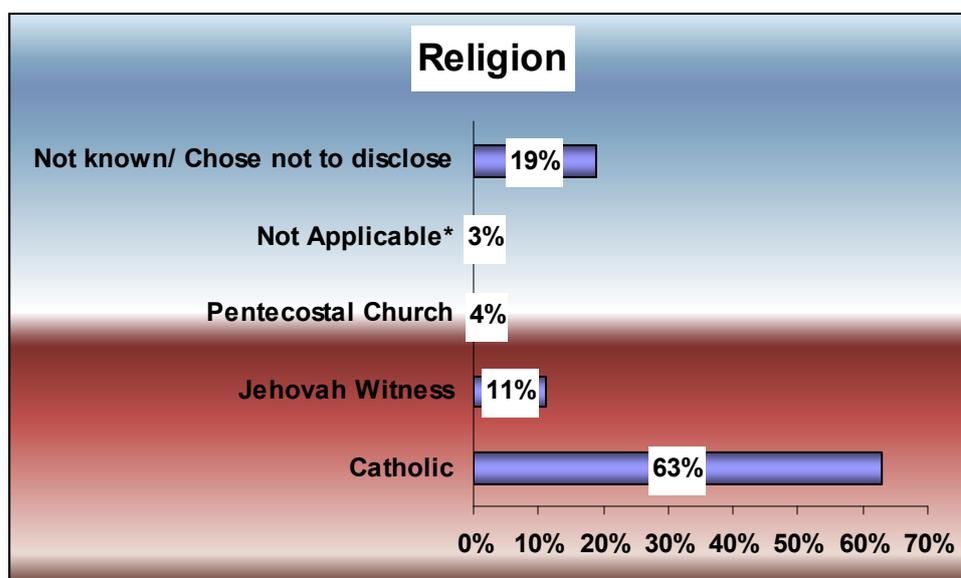
Not known	14%
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* Most of the service users attended primary education in their countries of origin. It often meant that they started education at the age of 7 and stayed in the same school (which would cover education at the primary and secondary level) for 8 years. After that they could pursue education in a college, high school or attend vocational training.

5.1.6 RELIGION

Most of the service users stated that they are Catholic (63%), which is consistent with data gathered in relation to the countries of origin. Most of the project service users originated from Poland, where Catholicism is the dominant religion.

However we also supported a relatively large number of service users who are Jehovah’s Witnesses (11%). Some of the clients who stated that they are Catholic mentioned that they are thinking of becoming Jehovah’s Witnesses. We did not collect data related to possible future change of religion so we cannot provide exact numbers.



5.1.7 GEOGRAPHICAL LOCATION

The largest group of service users were residents of the London Borough of Newham (38%), other service users included residents of the London Boroughs of Redbridge (14%) and Enfield (11%), we also worked with residents of the London boroughs of: Barking & Dagenham, Hammersmith & Fulham, Waltham Forest, Haringey, Croydon, Islington, Lambeth, Hounslow, Lewisham, Wandsworth and with service users from Essex (Southend-on-Sea).

Area	Detailed breakdown of the area	Percentage of service users
London Boroughs	Newham	38%

	Redbridge	14%
	Enfield	11%
	Barking & Dagenham	9%
	Hammersmith & Fulham	8%
	Waltham Forest	7%
	Haringey	3%
	Croydon	2%
	Islington	2%
	Lambeth	2%
	Hounslow	1%
	Lewisham	1%
	Wandsworth	1%
Outside of London	Southend	1%

5.1.8 EMPLOYMENT STATUS

Most of the service users accessing the Mental Health Advocacy Project stated that they are unemployed.

Table 15 Employment Status of Roma who accessed the Roma Mental Health Advocacy Project

Employed	Unemployed	Below employment age or unable to work due to severe learning disability/mental health problems
6%	72%	22%

5.1.9 MARITAL STATUS AND FAMILY LIFE

Most of the project's service users stated that they are married (44%). 20% stated that they are either divorced or separated from their partners, 36% were single (either never married or were widowed).

Most of the service users stated that they have family and are supported by family members.

5.1.10 SOCIAL LIFE

We found that many Roma service users suffering from mental health problems often live in isolation. Most of the service users stated that they have both Roma and non-Roma friends but at the same time most of them cannot or find it difficult to talk about their mental health even to their closest family members, friends or carers. They frequently avoided participating in both Roma and non-Roma community events and activities. Many service users stated that they only leave home on good days.

Less than half of the service users participated in local community events, (those who participated mentioned mainly Roma community events such as concerts, weddings and funerals).

Most of the service users did not participate in any activities which would enable them to engage with the non-Roma community.

5.1.11 MENTAL HEALTH PROBLEMS

Mental health problems listed by the service users are listed in table 16.

Table 16 Breakdown of all mental health problems listed by the project’s service users and the percentage of service users who suffered from them*	
Mental health problem	Percentage of service users
Organic, including symptomatic, mental disorders due to brain damage	1%
Substance-related disorders (alcohol dependency)	6%
Schizophrenia and other psychotic disorders	11%
<ul style="list-style-type: none"> • psychosis • paranoid schizophrenia • schizophrenia 	3% 2% 7%
Mood disorders	61 %
<ul style="list-style-type: none"> • Bipolar Disorder • Depression 	1% 61%
Anxiety disorders	19 %
<ul style="list-style-type: none"> • Anxiety (includes co-morbid anxiety: 2%) • Panic attacks • Post traumatic stress disorder 	11% 7% 2%
Disorders usually first diagnosed in infancy, childhood, or adolescence	17%
<ul style="list-style-type: none"> • Autism • Behavioural issues • Emotional difficulties • Learning disability 	4% 2% 2% 9%
Other mental health problems	4%
<ul style="list-style-type: none"> • suicidal thoughts and attempts • self-harm 	3% 1%

* Service users listed multiple problems therefore the breakdown of the problems shows the percentage of service users who listed each problem.

5.1.12 OTHER HEALTH AND NON-HEALTH-RELATED PROBLEMS

The majority of the project’s service users (over 90%) stated that they suffer not only from mental health problems but also other health problems.

90% stated that they struggle with non-health-related problems. 48% had problems with housing, 35% had problems related to low income, 29% had debts and 26% were worried about or were looked after by family members suffering from various long term illnesses.

Please see appendix 3 for a full breakdown of all the data collected in relation to the profile of the project's service users.

5.2 HOW DOES THE RELATIONSHIP BETWEEN CLIENT AND MENTAL HEALTH ADVOCATE AND ITS DYNAMICS EFFECT EMPOWERMENT OF THE CLIENT?

5.2.1 EMPOWERMENT AS UNDERSTOOD IN THIS RESEARCH

A discussion about service users' empowerment and its defining features has attracted significant academic attention, which explores the concept of power, models of empowering practices, and the role that professionals can play in these processes. In an article, *Mental Health Service User's Social and Individual Empowerment*, by S. Masterson and S. Owen, the authors state that *"There is a universal acceptance that the concept of empowerment is especially important in mental health and social care, given the relative powerlessness of those experiencing poor mental health. Concurrent is a social-wide disempowerment in the form of poverty and social exclusion with many Mental Health service users facing barriers in access to housing, employment, education and training, goods and services and social networks."*²⁶

Whilst accepting a general disempowerment of mental health services users and the multiple barriers that they face, the context of our work and research pointed at an additional dimension, which is related to marginalisation, discrimination and social exclusion of the Roma community. According to S. Ingmire: *"As we struggle to define empowerment at a community or individual level, agreeing that there is no one label to define it and that it changes its meaning depending upon the specific socio-political or psychological circumstances, the Roma experience of empowerment is particularly sensitive. The social, economic and political relationship between Roma and Gadje (non-Roma) has always delineated the context of this process, determining its dynamics and direction."* Sylvia Ingmire²⁷

Traditionally the relationship between Roma and non-Roma was heavily moulded by a narrative of *power* and *powerlessness*. In our work and research, we have taken into account that Roma as Mental Health service users are the powerless and non-Roma (those with power) constituted a group of professionals: i.e., mental health advocates, as well as "external" medical practitioners and experts. Thus, in implementing our models of empowering practices, our project needed to address these differences in power in order to better assess the empowerment process of our service users.

²⁶ Steve Masterson, Sara Owen, *Mental Health Service User's social and individual empowerment: Using Theories of Power to Elucidate Far-Reaching strategies*, Journal of Mental Health, February 2006, 15(1), Page 20

²⁷ Sylvia Ingmire, The Roma Support Group, *Improving Engagement with the Roma Community Research Report*, 2010, Available at: <http://www.romasupportgroup.org.uk/documents/Roma%20Support%20Group%20Research%20Report.pdf>

Our model of supporting service users towards empowerment closely resembles the model/definition of empowerment as described by Per-Anders Tangland in *Empowerment: A Conceptual Discussion*. Empowerment as a process in which a relationship between advocate and service user plays a paramount role in creating the opportunity and environment and in which the advocate is giving “expertise” support so the service user can gain greater control over the relevant determinants of his/her life through an increase of the service user’s knowledge and/or health and/or freedom. The interaction between advocate and service user involves limiting advocates influence over the service user in regard to goal/problem formulation, decision-making and acting and service user taking at least some control over the situation or process. Ultimately this leads to achieving a goal which is understood as control over one’s life and the ability to control determinants of quality of life.²⁸

In our work we initially concentrated on individuals and in particular on the psychological model of empowerment but in the course of our work and with the increasing level of service users’ self-confidence it became apparent that there was a need to widen the scope of our work and engagement with service users through the creation of a platform for the social level of empowerment through grassroot community actions such as the focus groups, the self-help group meetings and forum theatre. This approach aligned with Masterson and Owen (2006) views who noted that the *“...combination of individual and social approaches is necessary. ...Helping individuals to feel more personally powerful will have limited effect without social change to allow that power to be exercised. Likewise, social change will not be empowering if individuals perceive themselves as unable to make use of those changes.”* (Townsend, 1998, Masterson and Owen, 2006)²⁹

5.2.2 EMPOWERMENT AS AN INDIVIDUAL’S JOURNEY

For the purpose of this research we looked at empowerment as a process of supporting individuals in a process of self-development which would enable them to take greater control over some aspects of their lives and in particular in relation to addressing their mental health issues and getting the help they needed.

The process of empowerment took a different course depending on the individual’s point of departure. At the point of departure the service users’ personal circumstances and level of inclusion differed. The level of empowerment depended on the level of education, mental health, awareness of mental health, knowledge about services available and their rights, ability to talk about problems, level of support received from family members, attitude (fear and lack of trust) towards mental health services and professionals.

²⁸ Per-Anders Tangland, *Empowerment: A Conceptual Discussion*, Health Care Anal. 2008 Jun, 16(2), Pages: 93, Published online: 2007 Nov 6, Pages 77, 80

²⁹ Elizabeth Townsend, *Good Intentions Overruled: A Critique of Empowerment in the Routine Organization of Mental Health Services*. Toronto, University of Toronto Press, 1998
Steve Masterson, Sara Owen, *Mental Health Service User’s social and individual empowerment: Using Theories of Power to Elucidate Far-Reaching strategies*, *Journal of Mental Health*, February 2006, 15(1), Page 26

These factors impacted on the speed and depth of development and the results achieved.

5.2.3 ADVOCACY

The role of the advocates was crucial to address the problems experienced by the Roma community in regards to their health and access to health care provision.³⁰

“Inequalities in access to appropriate and acceptable healthcare contributes to a pattern of poorer health status, reduced life expectancy and greater dissatisfaction with healthcare amongst people from Black and minority ethnic communities (BME). Language acts as a further barrier to access. The development of bilingual advocacy fuses two key functions – interpretation and advocacy – to ensure that people from BME communities are able to have their healthcare needs met appropriately.” Walid El Ansari³¹

In practical terms the role of the advocates was very much in keeping with the role of the advocate as described in the report *A Standards Framework For Delivering Effective Health and Social Care Advocacy for Black and Minority Ethnic Londoners*: *“The role of the advocate (who provides health and social care advocacy) is to inform, empower and represent the interests of the service user to improve access to health and social care services, and to improve health and social care outcomes. Advocates help patients and their families make decisions about care and work with health and social care professionals to develop more appropriate and sensitive services. Advocacy sees things from the service user’s perspective and recognises that the user or patient is often in an unequal power relationship with the service provider.”*³²

The project’s advocates endeavoured to empower Roma service users through

“...seeking all available avenues to raise users’ awareness of the opportunities they have to affect their own treatment and conditions;
· ensuring that the client has control over the process at all stages;
· working with people towards developing their self-confidence, aspirations, opinions, and skills to stand up for themselves in the long term;
· informing the patient that it is their right to make a complaint, comment or suggestion about the service they receive;
· encouraging people to speak up for themselves and helping people to become more confident about dealing with organisations and staff;

³⁰ Please see paragraphs 1.3 and 1.4 of this report

³¹ Walid El Ansari MBBCh MPH PhD PhD, Karen Newbigging MA MSc DipClinPsych, Carolyn Roth BSc and Farida Malik BSc, *The Role of Advocacy and Interpretation Services in the Delivery of Quality Healthcare to Diverse Minority Communities in London, United Kingdom*, Health and Social Care in the Community (2009) 17(6), Pages 636–646, Available at: http://www.glos.ac.uk/research/dhsc/Documents/elansari_advocacyinterpretation.pdf

³² Rukshana Kapasi & Mike Silvera, Silkcap Consultants, A Consultancy Partnership project by Silkcap and OPM funded by the King’s Fund, *A Standards Framework For Delivering Effective Health and Social Care Advocacy for Black and Minority Ethnic Londoners*, March 2002, Available at: http://www.kingsfund.org.uk/publications/a_standards.html

· giving people the information they need to make their choices;
· helping people to ask for services that suit them and which respond to their needs;
· striking a balance between giving enough help and giving too much: i.e. not smothering or overprotecting the user/client/partner and recognising that learning and developing requires certain risks – this requires support rather than an over-protective reaction.”³³

For more information about the role of the advocates in the context of this project please see chapters 3.1.1.2 and 3.5 of this report.

5.2.4 RELATIONSHIP BETWEEN SERVICE USERS AND ADVOCATES

The working relationships which developed between individual service users and the advocates influenced both the service users and the advocates, enabling them to gain a greater understanding of themselves and each other. The individual service users and advocates developed together tools and means to empowerment (measured by "distance-travelled forms", the advocate's diaries, case studies, case records, observation notes, etc) of the service user, as well as expanding and enriching the mental health advocate's understanding of the process of empowerment and what influences it in individual cases. Through these relationships the advocates gained a greater understanding of the Roma community and culture and progressed in their own journey of self-development.

In taking such an approach to developing a relationship with service users we created conditions which have been highlighted by Rogers in Mastersons and Owen as “*the core conditions*” for “*facilitation of personal growth through relationships cultivated by ... genuineness, unconditional positive regard and empathy. ...personal growth encourages personal power and therefore personal empowerment*” (Rogers, 1961, Gilbert, 1995, Katz, 1984, Ryles, 1999, Masterston and Owen, 2006)³⁴

A holistic and individualised approach to service users’ needs was crucial to building a relationship of trust between the advocates and the service users which in turn enabled the health advocates to effectively support the service users in the process of self-development and empowerment.

³³ Rukshana Kapasi & Mike Silvera, Silkap Consultants, A Consultancy Partnership project by Silkap and OPM funded by The King’s Fund, *A Standards Framework For Delivering Effective Health and Social Care Advocacy for Black and Minority Ethnic Londoners*, March 2002, Available at: http://www.kingsfund.org.uk/publications/a_standards.html

³⁴ Steve Masterson, Sara Owen, Mental Health Service User’s social and individual empowerment: Using Theories of Power to Elucidate Far-Reaching strategies, *Journal of Mental Health*, February 2006, 15(1), Page 23

Tony Gilbert, Nursing: Empowerment and the Problem of Power, *Journal of Advanced Nursing*, *Volume 21, Issue 5*, pages 865–871, May 1995

Katz, Richard, *Empowerment and synergy: Expanding the community's healing resources*. *Prevention in Human Services*, Vol 3(2-3), Win-Spr 1984, 201-226.

Carl Ransom Rogers, *On Becoming a Person: a Therapist’s View of Psychotherapy*. Constable and Co., London, 1961. Shaun M. Ryles, *A Concept Analysis of Empowerment: its Relationship to Mental Health Nursing*. *Journal of Advanced Nursing*, *Volume 29, Issue 3*, pages 600–607, March 1999

The holistic approach adopted by the project took into account the overall situation and needs of the individual service users and helped them not only with accessing mental health services but also offering practical and emotional support in other aspects of their lives. This approach is advocated by Masterson and Owen in that poor mental health can improve as an outcome of socio-economic empowerment stating that *“the social inclusion agenda is ... essential in the empowerment of service users....Thus the often chronic poverty and social exclusion that many mental health service users experience should be of the utmost concern to health and social care professionals”*.³⁵

5.2.4.1 DEPENDENCY ON ADVOCATES' SUPPORT

Early on we noticed a reoccurring pattern in the relationship between the service users and the advocates; many service users with multiple needs who developed a relationship of trust with the advocates and became more confident in accessing health services and talking about their mental health problems started to develop dependency on the contact and support provided by “their” advocate. It became obvious that supporting service users in developing working relationships with other professionals (including other advocates, other RSG staff members and external agencies) is crucial to prevent the dependency on one person and further support the process of empowerment.

RESULTS

5.2.5 DISTANCE TRAVELLED FORM

The distance travelled form was one of the tools used to gather data related to empowerment of our service users specifically in the areas of service users' ability to talk about their own mental health and their ability to access Mental Health Services (see chapter 2 of this report for intended outcomes and barriers).

The distance travelled form was used only in relation to service users who benefited from one-to-one advocacy. It was not used to measure empowerment of service users participating in group activities (social level of empowerment).

We used this questionnaire to ask service users a series of questions related to their ability to communicate with family members, other Roma community members and non-Roma about their mental health issues, their knowledge of mental health services, their rights, ability to access the help they needed. In order to register changes which happened as a result of accessing the project the same questions were asked when the service users started to access the service and then again approximately six to eighteen months later depending on the type of case (see paragraph 3.5 for more details about the types of the cases and length of support offered). For the full list of questions asked in the distance travelled form and breakdown of the data collected see appendix 5.

³⁵ Steve Masterson, Sara Owen, Mental Health Service User's social and individual empowerment: Using Theories of Power to Elucidate Far-Reaching strategies, Journal of Mental Health, February 2006, 15(1), Page 22

5.2.5.1 DISCUSSING MENTAL HEALTH ISSUES WITH FAMILY MEMBERS, EXTENDED FAMILY, OTHER COMMUNITY MEMBERS AND NON-ROMA

When we first asked service users how easy it was for them to talk about their mental health to others 54% said that it was either difficult or very difficult to talk to close family members and 23% told us that it was easy or very easy 85% stated that it was difficult or very difficult to talk about their mental health problems with the extended family or other community members (there were no service users who found it easy to talk about mental health issues with extended family or other community members). 62% of service users stated that it was either difficult or very difficult to talk to non-Roma community members (including health professionals and RSG staff members).

After a six months and twelve months period we asked the same questions and 61% of service users stated that it was easier for them to talk about their mental health problems with family members and 46% of this group a 25% improvement in their mental health. 15% declared an improvement by 50%. However 39% of the service users stated that talking to family members about their mental health problems had not become easier. There was less improvement in the ease of communication with the extended family members and other community members. 69% of service users reported no change and only 31% of service users stated that it was easier (by 25%). The biggest change took place in communication with non-Roma, 77% of service users stated that it was easier for them to discuss their mental health issues with non-Roma and in particular with the advocates.

5.2.5.2 KNOWLEDGE OF RIGHTS AND EXISTING SERVICES AVAILABLE TO PEOPLE SUFFERING FROM POOR MENTAL HEALTH

When the service users were assessed at the beginning, only 15% knew their rights and what services were available for people suffering with mental health problems. 31% stated that they had some knowledge and 54% told us that their knowledge is either very limited or did not have any knowledge of their rights and services offered by the NHS in relation to mental health.

When the same question was asked after a six months and twelve months period of accessing the Roma Mental Health Advocacy Project 38% of service users did not notice any improvement in their knowledge however 62% reported different degrees of improvement (39% stated that their knowledge had improved by 25%, 8% stated improvement by 50% and 23% stated improvement by 75%).

5.2.5.3 ABILITY TO ACCESS RELEVANT SERVICES

In this section we asked service users to answer three questions:

- **Do you know how to access relevant services?**

31% of service users stated that they knew how to access relevant services, 15% were not sure and 54% did not know. After a few months of accessing the Mental Health Advocacy Project 62% of service users reported a positive change in their knowledge of how to access relevant services.

- **Are you able to access these services?**

When first asked 53% of service users stated that they were not able to access NHS services in relation to their mental health, only 8% of respondents reported no difficulties with accessing relevant services. After using our project 46% of service users reported an improvement in their ability to access relevant health services, however 54% of service users were still not able to access the services they wanted. It might be due to the fact that in many London boroughs a GP referral is needed in order to access mental health services. In many cases even after the advocate's intervention GP's were either reluctant to refer our service users to relevant mental health services or a referral was made but the waiting time for the first contact/assessment meeting was not due to take place for up to several months.

- **Do you need help in order to access mental health services?**

All of the respondents (100%) stated that they needed some level of help to access relevant services in relation to their mental health. Out of that number 15% stated that they needed help sometimes, 31% needed help frequently and 54% always needed help to access the relevant services. When asked again after six months and twelve months period 23% of service users did not report any change in their needs, however 77% reported that their need for help when accessing relevant health services decreased, 54% stated a 25% decrease in the need for help when accessing services, 15% a decrease by 50% and 8% a decrease by 75%.

5.2.5.4 HEALTH PROFESSIONALS' KNOWLEDGE OF ROMA CULTURE

When first asked 61% of the service users stated that the health professionals involved in their care did not know much or did not know anything about Roma culture, customs and taboos including those related to health. 31% could not tell what the health professionals knew and only 8% felt that health professionals knew enough. When asked the same question a six months and twelve months period 54% stated that the knowledge of the health professionals involved in their care had improved and 46% of the service users did not notice any improvement,.

5.2.5.5 LEVEL OF SATISFACTION WITH THE SERVICES

When asked about their level of satisfaction with the health services accessed in relation to their mental health issues 46% of service users stated that they were not satisfied, only 16% were either fairly or very satisfied, while 30% of service users did not access any health provision in relation to their mental health problems. When asked the same question after a six months and twelve months period 77% of service users reported an improvement in their level of satisfaction with the mental health services they accessed.

5.2.6 SERVICE USERS' FEEDBACK

Feedback forms informed us about the level of satisfaction with the support from the project in their individual journeys towards empowerment. The forms were filled in by the service users who accessed mental health services and were supported by the Mental Health Advocacy Project. In the case of

children and clients with severe learning disabilities or who were too ill to answer for themselves (22% of the total number of clients) the feedback was gathered through their carers. In most cases service users needed RSG staff members or volunteers to help them to fill in the forms. We did have a concern that using RSG staff or volunteers might have had an impact on the objectivity of some of the answers.

All of the service users (100%) stated that the Mental Health Advocacy Project was needed and that the advice and support provided by the project's advocates was useful.

Again all the service users stated that they were happy about their relationship with the advocates and project volunteers.

When asked if the project should be changed in any way 60% of respondents said it should not, while the remaining 40% suggested some changes. The main issue mentioned was the project's capacity, 80% of service users felt that the capacity should be increased. Some of the other suggestions included the following:

"I would like the advocate to be available to accompany me to all doctors' visits."

"I would like the Roma Mental Health Advocacy Project to have a counsellor or a dedicated person who I could talk to or call about my problems."

The last part of the form provided space for service users to express their views and offer their suggestions. Below are examples of comments made by the service users:

"When I started to access the Roma Mental Health Advocacy project I was already receiving specialist treatment but I knew a lot of people with mental health issues who would benefit from this project as there is little awareness of services amongst Roma and no other organisation offers this sort of help."

"I would like to say thank you."

"It would be useful to have offices in different parts of London so more people could have access to help from this project."

5.2.7 REOCCURRING THEMES

The analysis of the data gathered through the qualitative methods such as advocates' observations, case notes, action plans, interviews, minutes of team meetings and service users' feedback identified reoccurring overlapping themes. These were lack of trust, lack of knowledge, communication difficulties and isolation. All of those "themes" were closely interrelated and impacted negatively not only on the mental health but also on the empowerment of individual service users. All of the "themes" were a key aspect in the advocacy process and shaped the dynamics between the

service users and the advocates. The changes related to these four themes impacted on the mental health and empowerment of the service users.

5.2.7.1 LACK OF TRUST

Discrimination and exclusion faced by Roma in relation to accessing health and mental health services as well as the wide-spread practice of placing Roma children in special needs education in their countries of origin created deep distrust towards mental health provision and professionals. (See chapter 1, paragraph 1.4 of this report for more information on that subject).

Overcoming that lack of trust was one of the greatest challenges faced by the project's advocates. It was crucial to address this in order to increase the service users' ability to access the help they needed in relation to their poor mental health and the process of empowerment.

In order to support service users in the process of overcoming their fears and distrust and increasing their ability to access mental health services advocates had to create a positive environment in which this change could take place. Through one-to-one sessions and other forms of contact advocates addressed various needs presented by the individual service users. Advocates took a holistic approach in the support offered to individual service users, respected service users' autonomy and ensured that service users were in control of all the actions undertaken by the advocates on their behalf as well as all the information passed on to mental health professionals. To further develop service users' self-confidence, autonomy and ability to take control over their own lives the advocates and service users created joint action plans with the roles of both parties clearly defined. This led to developing a relationship based on the mutual respect, positive regard, sense of collaboration and partnership in which meaningful and constructive discussion about mental health and NHS provision was possible. Through this empowerment process service users were able to be more confident in their relationships with other agencies and professionals.

Case study

"I was afraid that I would be locked in mental health institution and lose my children if I talked to a doctor about my problems".

Karina

Karina is a Roma female in her mid-thirties suffering from severe depression and anxiety. She was referred to mental health services by her GP. She approached one of the project's advocates with a letter offering her an assessment in relation to her mental health problems. Initially, on learning what the letter was about, Karina refused to act upon it. However the advocate was able to convince her to become a service user of the project. After initially addressing various other health and welfare-related issues, the advocate was able to gain Karina's respect and trust. That enabled meaningful and honest communication between them. Karina was able to talk to the advocate about her fears related to mental health stigma and mental health services. In turn the advocate was able to provide her with information

related to both issues which lead to an increase in her knowledge and self-confidence. As an outcome Karina decided that if the project's advocate would accompany her to offer "moral support" and bilingual, culturally sensitive interpretation she would be prepared to attend the assessment session. The advocate's presence during the session and her role as a "cultural interpreter" proved to be vital for the establishment of good communication between the counsellor and Karina. The advocate was able to provide information about Karina's fears and put it in the context of Roma history and taboos related to mental health. That enabled the counsellor to address them in a culturally appropriate way. As an outcome Karina decided to access therapy offered to her in relation to her mental health problems.

"Roma usually do not talk about mental health. It's possible to talk to non-Roma about mental health but it can be very difficult to talk about it with health professionals and it is not possible with extended family and other community members."

Polish Roma Focus Group Participant

5.2.7.2 LACK OF KNOWLEDGE

"... Mental health problems must be hidden. There are two major taboos in the Roma culture, sexuality and mental health Roma usually do not know anything about mental health problems, they fear mental health illnesses..."

Romanian Roma Focus Group Participant

Due to persistent discrimination, exclusion, isolation, low levels of education and cultural taboos relating to mental health and communication difficulties many Roma do not have the knowledge about mental health, services available, how to access appropriate services and their rights. This feeds the fears related to mental health, deepens isolation, leads to disempowerment and has a negative impact on mental health. Raising awareness of mental health problems and mental health services amongst the Roma community was at the centre of the advocacy process.

To address these issues advocates provided comprehensive information for individual service users, their families and carers throughout their involvement with individual service users. It was primarily addressed on the individual level during the one-to-one sessions. Information was provided mainly in verbal form to ensure that those with poor literacy skills would not be discriminated against and to create an environment in which the service users/carers would feel comfortable to voice their fears and ask questions. It was further enhanced on a social level by discussions during the self-help group and forum theatre meetings.

Another added dimension was the lack of knowledge amongst the health professionals about Roma, their history and cultural taboos related to mental health. This has been a contributing factor in the miscommunication between

professionals and Roma patients and the distrust and fear of mental health services amongst Roma community members.

The advocates actively involved service users in addressing this issue. The subject was discussed during the focus group meetings at the commencement of the project. During those meetings service users suggested information which they felt should be included in the *Information leaflet for the health professionals*.³⁶ To increase their autonomy and control over their lives service users were encouraged by advocates to choose the information which they wanted to provide to the health professionals involved in their care.

All of the activities relating to “lack of knowledge” contributed to a further development of the professional relationship between the advocates and service users in which the service users were encouraged to take control over the change process. More than half of the service users confirmed an increase in their knowledge about mental health and mental health services provision (see distance travelled from results paragraph 5.2.5), improvement in ability to communicate with family members/carers and various professionals (health, social services, local authorities) about their mental health problems and ability to ask for the help they needed. It had a positive impact on their self-confidence, autonomy, independence and ability to control their own lives and lead to an increase in empowerment.

Increased knowledge amongst health professionals lead to better communication with Roma patients, ability to support them in overcoming their fears, improved care for the Roma patients and more appropriate therapy and therefore improved mental health and an increase in empowerment.

5.2.7.3 COMMUNICATION DIFFICULTIES

“When I was asked questions or told something I did not understand I would usually nod or try to say something which I thought they expected to hear. I did not know that I can tell health professionals that I do not understand something and ask them for explanation.”

Polish Roma, 52

The importance and complexity of communication difficulties was apparent from the beginning of our work and was reconfirmed by the data gathered. 59% of service users had no spoken English, out of the remaining 41% only 17% stated that they were fluent in English.³⁷ Most of the service users were not able to communicate directly with health professionals and needed interpreting assistance during appointments. Another dimension was that most Roma are bilingual³⁸, their first language is one of the Romani dialects, however since there are no Roma interpreters available for health-related appointments, their second language (language used in the countries of origin

³⁶ Please see appendix 2B for the full content of the Information leaflet.

³⁷ See appendix 3, table 16 for the full breakdown of the data related to the level of acquired spoken English.

³⁸ See appendix 3, table 14 and 15 for the full breakdown of the data related to languages spoken by the service users.

e.g. Polish, Slovak, Romanian) was used during the appointments with professionals. Most Roma speak a second language well but since in most cases our service users only had a few years of primary or secondary education³⁹ their vocabulary was limited to everyday expressions. In addition due to stigma and taboos related to health and mental health the Romani dialects do not have the vocabulary for mental health. The service users' lack of confidence and knowledge of mental health also meant that explaining their problems and expressing feelings presented a huge challenge. The situation was not helped by the lack of cultural understanding amongst health professionals and interpreters/bi-lingual health advocates. Project staff observed that most of the service users who accessed our mental health advocacy support found it very difficult to communicate with mental health professionals and felt that they were misinterpreted and misunderstood on a regular basis. Project staff observed that the above contributed to a lack of trust towards mental health professionals and further isolation.

To address these difficulties advocates assisted service users during the assessments and appointments, providing culturally-sensitive bi-lingual health advocacy. During the meetings advocates explained the cultural issues impacting on the mental health of service users, their attitude towards mental health services, their problems with communication and their lack of knowledge about mental health and the services offered. To make sure that the service users had a good understanding of what was happening during those meetings and had full control of the situation advocates encouraged the professionals to fully explain the diagnosis and what it meant in practical terms as well as the possible treatment/therapy. Advocates made sure that service users were able to ask questions, that their fears were addressed and that they were fully engaged in the decision-making process.

However as the need for this kind of intervention exceeded the available resources we had to develop other strategies to provide adequate support to our service users. One of the main tools that aided communication between professionals and service users was our *Information Leaflet for Professionals*. The information leaflet for health professionals was owned by the community and was created as a result of the information provided by the community during the focus group meetings. It contained information which Roma felt was important for health professionals to know in order to better engage with Roma patients. Collective input into creating this information was very important given that Roma feel very fearful of passing on information to non-Roma as this is viewed as a betrayal of the traditional values which are rooted in the historical experience of anti-Roma discrimination, holocaust and pogroms when the information gathered was used against them. Participation in the creation and dissemination of the leaflet put service users in control of a communication process and was a step towards empowerment.

In practical terms the leaflet was used during meetings between the advocates and service users to identify the most pressing issues in access to

³⁹ See appendix 3, table 7 for the full breakdown of the data related to the level of formal education acquired.

treatment and in communication with the mental health professionals. Once the problems were identified, if service users wished the advocates would either contact the health professionals directly or write to them explaining the cultural context, issues identified and what impact it had on the service users' ability to access mental health services and the help they needed. Service users were encouraged to take further responsibility by showing the leaflet to professionals (either with areas in need of improvement highlighted or together with the letter from a RSG advocate).

Through the feedback from both service users and professionals we know that the above interventions led to service users having greater control over their lives, an increased ability to access mental health services and overcame their fears of mental health and the lack of trust of professionals and services.

5.2.7.4 ISOLATION

Another important theme which emerged was the isolation experienced by the service users and their inability to talk freely about mental health either with family/carers/friends or with health professionals. Isolation experienced by the Roma suffering from mental health problems has been related to many contributing factors, these include marginalisation experienced through their ethnic background which was further amplified due to cultural stigmas and taboos related to mental health, lack of ability to talk about mental health and lack of language and basic skills to address problems when working with professionals coupled with lack of awareness of existing services.

The advocates tried to ensure that service users accessing the mental health project felt safe to talk about their mental health problems. It was achieved through reassuring service users that the service was confidential and that advocates would act upon service users' instructions and that there would be time to talk about their other problems. These included issues such as welfare, housing, debts, relationship with family members, general health, attitudes towards mental health, relationship with health professionals, attitude to health services, fears and problems with communication. This was offered to all service users by the project advocates. This helped to develop a trust-based relationship between the advocates and service users and to increase confidence, self-esteem and improve knowledge and the ability to access health services in relation to mental-health problems.

In feedback received from service users this safe space and time offered by health advocates was quoted as one of the most important aspects of the project and a crucial element in the process of empowerment.

As we started to overcome the isolation of individual service users we were able to widen the scope of our work in empowerment to the social level through group activities.

5.3 WHAT TYPE OF CULTURAL INFORMATION IS GIVEN TO MENTAL HEALTH PROFESSIONALS BY THE ADVOCATES IN THE PROCESS OF THEIR

MENTAL HEALTH ADVOCACY SUPPORT AND HOW DOES IT CHANGE THEIR KNOWLEDGE?

At the commencement of the project we had a number of individual and group meetings with Roma community members and the project's service users to identify the communication problems that existed with mental health professionals and accessing mental health services. The Roma community members highlighted cultural information, taboos and customs related to health and mental health which they felt health professionals should know in order to better engage with and support Roma who suffer from mental health problems. The information gathered was further enhanced by the knowledge of RSG staff members who had supported Roma in accessing health services through the RSG's past health projects. From this the *Information Leaflet for Professionals* was created. The main areas included:

- Brief background information on Roma, their origins and history
- Taboos and customs related to health
- Attitude towards mental health, health professionals and services
- Barriers in accessing services and communication problems

See appendix 2b for the full content of the *Information Leaflet for Professionals*

EFFECTIVENESS OF THE CULTURAL INFORMATION PROVIDED

The information leaflet was distributed amongst health and mental health professionals throughout the project's existence. Different methods were used to maximise effectiveness.

Mental Health Trusts and individual health professionals were emailed an electronic version of the leaflet followed by a feedback form. Unfortunately it became apparent that with a few exceptions this was not the most effective method as often the leaflet did not reach the professionals who were working directly with Roma community members and we were not able to gather feedback from those outreached in that way. This meant that we were not able to assess how the leaflet changed their knowledge in relation to working with Roma community members.

One example of how the information provided was used practically by the NHS was the inclusion of information on the Roma community in the revised version of the Cultural Competency Tool-kit produced by the Diversity Unit, West London Mental Health [NHS] Trust. See appendix 2c which portrays how the information produced by the project has been mainstreamed by the mental health services in order to increase cultural awareness of their clinicians.

"...I am in the process of revising the attached Cultural Competency Tool-kit, please see the attached letter. I have received a very helpful information leaflet⁴⁰ on the

⁴⁰ Please see appendix 2B for the full content of the Information leaflet.

Roma community, which I believe you produced and would like to include some of this information within the tool-kit...”

Fragment of email from Diversity Lead [Employment], Learning & Development Centre, West London Mental Health NHS Trust, Trust Headquarters, St Bernard's Hospital

We discovered that in order to improve the effectiveness of this leaflet it had to be accompanied by additional measures such as meetings with health professionals, letters explaining the importance of the leaflet and how it could be utilised with individual Roma patients' participation in mental health assessments and appointments.

Verbal information supported by written material (leaflet) proved to be the most effective in the improvement of communication between mental health professionals and Roma service users.

The forum theatre gave us and the service users another opportunity to disseminate cultural information to a wide spectrum of professionals. The use of drama as a medium had a great impact due to its visual and cultural aspects (performing arts play an important role in Roma culture). The service users were in full control of what they wanted to present, the message they wanted to communicate and the changes they envisaged for the future. It enabled Roma service users to portray their experiences focusing on their fears, the lack of empathy amongst the professionals, the inadequacy of services and the impact it has on their mental health. The feedback from the audience was very positive. Many stated that what they learned would enable them to improve the way they worked with the Roma community.

The attitudes of health professionals changed most when there was a self-recognition of the gap in their knowledge and when they recognised the need of addressing the gap. In practical terms it meant that effectiveness of the information and the change achieved was most apparent in the cases where professionals approached us of their own accord in relation to their work with individual Roma patients.

TYPES OF CULTURAL INFORMATION PROVIDED FOR HEALTH PROFESSIONALS

The main cultural information provided verbally during the meetings with professionals and most frequently highlighted by service users in the leaflet was related to:

- Problems with communication (see figure **5.2.7.3** of this report)
- The reasons for the lack of trust towards the mental health professionals and services
- Fear of mental health and mental health services and the reasons behind it

CHANGE ACHIEVED

There was an increase in the knowledge of health professionals in some aspects of Roma culture related to fears and lack of knowledge of mental

health and the impact of this on the Roma community's ability to access the help needed. This led directly to a better understanding of individual patients and the Roma community in general.

It also enabled the health professionals to tailor interventions better to meet the needs of Roma patients ensuring greater effectiveness and the progress to recovery. Additionally, the health professionals reported improved satisfaction in their work with Roma patients.

The improved communication with health professionals led to increased confidence and improved access to mental health services for Roma patients who reported feeling more empowered.

Case study

"I felt that what I had to say is misinterpreted and not understood. I felt I cannot express my thoughts and feelings in a way that can be understood by the therapist. I felt that I am not going to get the help I need so I did not want to attend any more sessions with my therapist".

Mila

Mila is a Roma female in her late-thirties suffering from post-traumatic stress disorder. After she started therapy she realised that communication with her therapist is so poor she is not able to voice and explain her problems and feelings. She can speak some English but not good enough to communicate fluently with the therapist. She was provided with an interpreter, however there was no Roma interpreter available so she had to communicate in her second language and neither the therapist nor the interpreter were aware of her language difficulties. She approached one of the project's advocates and explained that she is going to resign from the therapy as it was not helping her. On learning about her difficulties the advocate suggested that they analyse the information leaflet developed by the Mental Health Project (see appendix 2B) in detail and together with Mila identified fragments which were relevant to Mila's problems in communication with the therapist. Those areas were highlighted in the letter written by the advocate, which Mila took together with the leaflet for her next session with therapist. The therapist responded very positively to the information provided in the letter and leaflet and made every effort to ensure meaningful communication during the sessions. That enabled the counsellor to address Mila's problems in a culturally appropriate way. As an outcome Mila not only decided to carry on with the therapy offered to her in relation to her mental health problems but also felt in control of her own situation.

6. DISCUSSION

Our understanding of the community's needs in terms of support in order to improve access to mental health services and facilitate communication with mental health professionals were confirmed by the project's work and

findings. As predicted we worked with individual service users and families (where more than one family member suffered from mental health problems). An additional dimension was the extent of communication and support offered to family members who were carers of our service users. An unexpected development of the project was the opportunity to widen the focus on empowerment not only at the individual level but also at social levels of empowerment.

INDIVIDUALS, FAMILIES AND CARERS

The family plays an important role for most Roma individuals. As we anticipated our work often concentrated not only on the service users but also their families and carers (who were in most cases related to the service users). In many instances more than one person in a family had mental health problems. It became apparent early on that in order to support our service users suffering from mental health problems we would have to work closely with other family members. By working with family members we were able to provide adequate support and ensure that carers could overcome their own fears and distrust in order to enable service users to access mental health service provision and take greater control over their lives and health.

The carers we worked with and supported were in the following 3 categories: :

- Carers without mental health problems
- Carers who developed depression themselves due to their family situation
- Carers suffering from serious mental health problems but able to communicate better than other family members suffering from mental health problems

Working with carers enabled us to not only improve the process of empowerment of individual service users but also to widen the scope to the social level of empowerment by influencing perceptions of mental health with the wider Roma community..

GOOD COMMUNICATION AND HOLISTIC APPROACH

Initial focus group meetings and information provided by the Roma participants drew our attention to the importance of communication. Effective service user orientated communication became a key aspect of our work and much effort and time was put into ensuring good communication.

Empowerment was possible only where good communication and trust had been established. Only then were service users able to communicate with advocates openly, take in the information provided and understand the actions suggested by the advocates and act upon it.

Good communication and the building of a good relationship enabled the advocates to better understand individual service users, their families and carers and develop support centred on the service users' needs. In order to ensure that service users got the help they needed, advocates had to anticipate and accommodate all the barriers service users and carers might face in accessing RSG and other services. In most cases this meant adopting

a holistic approach in order to address a wide range of problems faced by the service users in order to ensure that individuals and families did not fall out of the system. This approach was based on years of experience in supporting Roma community members in accessing mainstream services as well as RSG services.

Our case work observations and forum theatre initiative reconfirmed the importance of this approach.

The project tried to help health professionals to engage more positively with Roma patients, one of the tools used was the project's leaflet. Project advocates observed positive outcomes when practitioners engaged *in person-centred care formed upon relationship of trust, support, equality, respect, genuineness, empathy and positive regard.*⁴¹ Masterson and Owen.

Through our work with Roma suffering from mental health problems we have noticed that one of the reoccurring problems which they have faced is the non-effectiveness of the mental health treatment which they were offered. One of the most striking and most frequent examples was the cognitive behaviour therapy which most of our service users were unable to benefit from. We think that this might be connected to the fact that Roma do not have the words and vocabulary to describe mental illness. This is the case in many languages where the closest translation of mental illness is 'madness'. Thus it is a terrifying notion to label how one feels as being mad. Not having words for ailments such as depression, anxiety attacks etc makes it difficult for Roma patients to describe how they might be feeling. This can then lead to a breakdown of communication between the Roma patient and the health professional. We raised this issue during a consultation with The Medical Foundation and one of their therapist suggested that psychotherapy might be a more appropriate method of working with Roma patients. We feel that more research should be done in exploring the most effective therapies in the mental health care of Roma and other BME communities who have a similar profile and experiences.

We linked our observations and results with the theories of empowerment and in particular Per-Anders Tengland's⁴² theories related to empowerment as a goal. He presents the idea of empowerment being determined by the individual's ability to control life and in particular overlapping areas/indicators which determine what people should be able to control to some extent in order to feel empowered. According to Tengland those indicators include one's health, home, work (including domestic work, education and training, means to security and a decent style of life), family/close relationships, social

⁴¹ Steve Masterson, Sara Owen, Mental Health Service User's social and individual empowerment: Using Theories of Power to Elucidate Far-Reaching strategies, *Journal of Mental Health*, February 2006, 15(1), Pages 26-27

Carl Ransom Rogers, *On Becoming a Person: a therapist's view of psychotherapy*. Constable and Co., London, 1961.

⁴² Per-Anders Tengland, *Empowerment: A Conceptual Discussion*, *Health Care Anal.* 2008 Jun, 16(2), Pages: 77-96, Published online: 2007 Nov 6.

life and values (political, religious, sexual, moral, what values to hold and how to pursue them).

Analysing the profile of service users (see appendix 3, tables 7,10,19, 21, 26, 27, 28), we noticed that over 90% of the project's service users had problems and lacked control over areas of life relating to housing, education, work/income, welfare, difficulties in family life (including stigma and taboos related to health and mental health) and social life. Additionally service users had little or no access to education, training and other opportunities to improve their lives. All these factors closely correspond with the determinants of life as described by Tengel.

Our observations and the anecdotal evidence we have heard has informed us that that many of the fundamental Roma cultural values (for instance age centred respect, implementation of the Roma code of behaviour (known as Romani pen) have been undermined as a result of the process of immigration and asylum-seeking. On the other hand we observed an enormous effort made by the Roma to understand and fit into the new reality. All these factors have a number of consequences such as mental health problems, excessive drinking amongst the older generations and drug addiction amongst young people.

The experience of vulnerability and inability to control their quality of life is further affected by the negative experience of discrimination and anti-Roma racism and exclusion of Roma on the basis of their ethnicity. (See chapter 1.1.1.2). Most of the service users we worked with faced some form of discrimination ranging from bullying at school to experiencing segregated education, physical threats and systemic abuse in health care system in their countries. There is not enough research that explores the connection between anti-Roma discrimination and how it impacts on their mental health. The findings from such research would be very useful in furthering the discourse on mental health and empowerment amongst the BME communities.

IMPACT OF TRAUMA ON THE MENTAL AND PHYSICAL HEALTH OF FEMALE SERVICE USERS

During the life of the project we also noticed that a significant number of Roma women of a similar age and profile were diagnosed with fibromyalgia or suffered from similar symptoms. From our observations it emerged that all these service users experienced the asylum seeking process, had responsibility for their families, fought for the welfare of their families and were under the huge stress of trying to fit into a new social, linguistic and political reality. Once the situation stabilised and the fear of deportation was removed from their lives they started to suffer from different physical problems. We have developed a theory that possibly fibromyalgia and other similar physical symptoms are psychosomatic and are related to the trauma experienced in their recent past and combined with lack of other means to express and deal with their feelings. However it was outside of our project's remit and we have not had the resources necessary to gather sufficient and conclusive data to

support our assumption but we think that it would be interesting to carry out further research into this area.

SOCIAL LEVEL OF EMPOWERMENT

The project started with the individual approach to empowerment. We originally envisaged it as advocacy-based, one-to-one work with individual service users. We anticipated that any form of group debate about mental health would not be possible due to the taboos and stigmas attached to general health and in particular to mental health. However as the project and the process of empowerment of individual service users progressed and they acquired more self-awareness, their skills and potential as well as knowledge about the situation they were in and ways of addressing their problems increased. We observed a growing interest and desire for community action and ways for effective change in the community. We first witnessed an indication of this trend at the focus group meetings at the beginning of the project. This helped us to think about the further development of the project and the creation of an environment for social empowerment. In their article Mastersons and Owen review theories of Mullender and Ward and Ryles bringing forward the argument that *“individual and social empowering practices should be seen as complimentary, rather than either-or options”* therefore Mastersons and Owen argue that *“the combination of individual and social approaches is necessary”*.⁴³

One of the mechanisms for community action and social change was a self-help group set up in order to create peer support network for the women diagnosed with fibromyalgia or suffering from similar symptoms.

Another of the mechanisms used by the project to effect social change and bring individual empowerment at the social level was forum theatre.⁴⁴ The majority of the forum theatre participants were the Mental Health Advocacy Project’s service users who overcame a lack of self-confidence and cultural

⁴³ Steve Masterson, Sara Owen, Mental health service user’s social and individual empowerment: Using theories of power to elucidate far-reaching strategies, *Journal of Mental Health*, February 2006, 15(1), Page 26

Mullender, A. and Ward, D. (1991) *Self-Directed Groupwork. Users take action for empowerment*. London: Whiting and Birch.

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Elizabeth Townsend, *Good Intentions Overruled: A Critique of Empowerment in the Routine Organization of Mental Health Services*. Toronto, University of Toronto Press, 1998

⁴⁴ *Forum Theatre is an interactive form of theatre that encourages audience interaction and explores different options for dealing with a problem or issue. Forum Theatre is often used by socially excluded and disempowered groups. Forum Theatre (also known as Boal's Theatre, 'Theatre of the Oppressed', 'Theatre for Development') is an interactive theatre form invented (or discovered) in the early 1970s by Augusto Boal who wanted to empower the audience of his plays.)*

<http://www.peopleandparticipation.net/display/Methods/Forum+Theatre>

fears and taboos related to mental health in order to change the community's perception of mental health issues.



Participants (project's service users, other Roma community members, RSG staff members and volunteers) of the RSG's Forum Theatre meetings, Trinity Centre, 2010

Both the group initiatives became a successful tool for service users to challenge the health care system, highlight persistent problems within this system and propose solutions for a more culturally sensitive and appropriate health care model.

One-to-one advocacy and the focus and self-help group meetings as well as the Forum Theatre meetings became tools for the project and service users to influence social change.

"Helping individuals to feel more personally powerful will have a limited effect without social change to allow that power to be exercised".⁴⁵

RELIGION

One of our original assumptions at the beginning of the Mental Health Advocacy Project was that many Roma who are Jehovah's Witnesses are more likely to suffer from mental health problems. This assumption was based on our previous experience of supporting Roma service users in accessing health services. For many of the Roma accessing our services religiousness and spirituality plays an important role. Traditionally Roma would adopt the main religion of the country they lived in e.g. Catholicism, Orthodox, Muslim

⁴⁵ Steve Masterson, Sara Owen, Mental health service user's social and individual empowerment: Using theories of power to elucidate far-reaching strategies, *Journal of Mental Health*, February 2006, 15(1), Page 26

but recently we have noticed a growing trend to convert mainly to the Pentecostal Church and Jehovah's Witnesses. We also noticed that a "new" religion on the one hand gives Roma strength which positively impacts on their mental health but on the other hand pressure from other Roma, family members for having converted and conflicting values have a negative impact on their mental health. In particular we noticed that many Roma who became Jehovah's Witnesses became more integrated into the wider society and their values started to change but the conflicting beliefs and models of behaviour have created huge pressure and often lead to the development of mental health problems. Through the Mental Health Advocacy Project we were trying to collect data to verify our original assumption. However we found that the data gathered was not conclusive. We felt that the number of our Roma service users who affiliated themselves with Jehovah's Witnesses was relatively large but to verify our original assumption more in-depth research would have to be carried out into this subject which is outside of the scope of the Mental Health Advocacy Project.⁴⁶

RECOMMENDATIONS

On the basis of our three years work and the findings from our evaluation we would like to recommend a model of work which would focus on:

- Improving communication strategies with Roma mental health service users
- A person-centred care
- A holistic approach that combines individual and social empowerment
- A holistic approach that supports individuals to improve other aspects of their lives that improve mental health such as housing, welfare etc.
- Research to explore the impact of racism and discrimination on the mental health of the Roma

In our opinion this would ensure effective engagement leading to empowerment and improved mental health amongst Roma mental health service users.

In addition we think that individual empowerment would not be meaningful without creating opportunities for participation in community actions which aim to impact on social change and address inequalities. It resonates with Townsend's statement that "*professionals and mental health services should facilitate collective action for empowerment*".⁴⁷

These recommendations would help to ensure meaningful communication to build a working relationship based on trust, support, equality, respect, sincerity, empathy and positive regard in addressing the needs to create a starting point for a process enabling Roma mental health service users to regain control over their lives and hence their empowerment.

⁴⁶ The RSG is currently taking part in pilot research with Tavistock Institute (<http://www.tavistock.org/>) and Grubb Institute (<http://www.grubb.org.uk/>) on Roma spirituality and religiousness and its impact on social inclusion.

⁴⁷ Elizabeth Townsend, *Good Intentions Overruled: A Critique of Empowerment in the Routine Organization of Mental Health Services*. Toronto, University of Toronto Press, 1998

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APPENDICES

Appendix 1 User Pathway

Appendix 2a Focus Group Questions

Appendix 2b Content of the Information Leaflet for the Health Professionals

Appendix 2c Letter from West London Mental Health Trust asking for permission to use extracts from the RSG Information Leaflet for Health Professionals in the Revised Cultural Competency Tool-kit

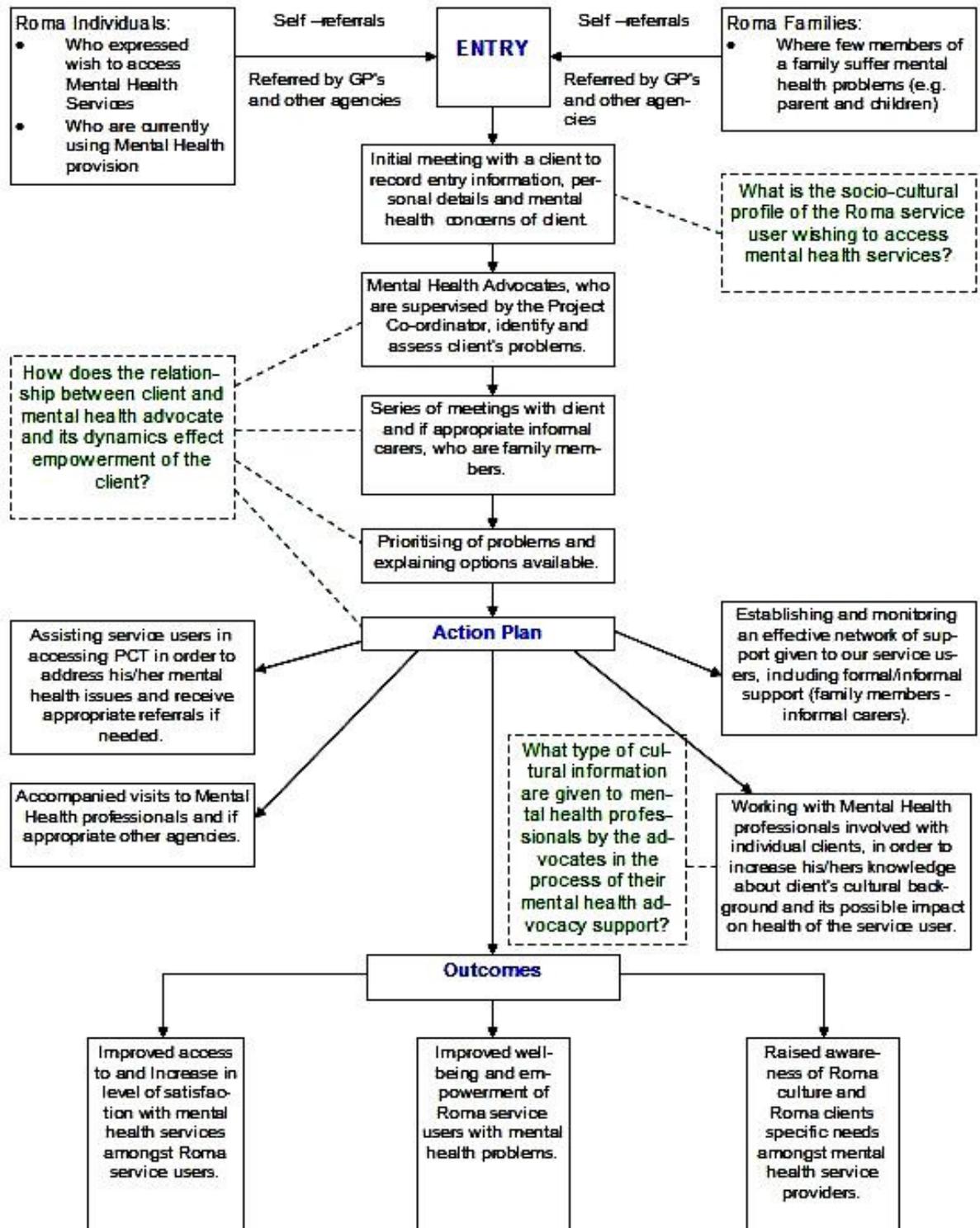
Appendix 3 Full break down of the data collected for the socio-cultural profile of the mental health advocacy project's service users

Appendix 4 Clients' feedback – summary

Appendix 5 Distance-Travelled Forms Summary and Analysis

APPENDIX 1 USER PATHWAY

Roma Support Group — User Pathway



APPENDIX 2A FOCUS GROUP QUESTIONS

1. What do Roma think about mental health problems?

- What are the main mental health issues within the Roma community?
- What happens when Roma community members become unwell especially with mental health problems?
- How do Roma community members feel about mental health problems?
- What are the customs and taboos related to mental health problems?
- What impact does the discrimination faced by Roma in their countries of origin have on their health including mental health?
- What impact does the discrimination faced by Roma in their countries of origin have on their contacts with non-Roma including health professionals?

2. What happens when Roma community members have to see a GP or a specialist in relation to their mental health problems?

3. Could you tell me from your experience of contacts with health professionals including mental health professionals, what they knew about Roma culture, history, customs, taboos, language in order to offer a more culturally sensitive and effective service?

4. What do you think health professionals should know about Roma culture, history, customs, taboos and language?

5. Summary of the conclusions, asking the community whether they agree with what was said.

Additional questions:

6. What does it mean for you to be a Roma?

7. How would you describe your culture?

8. What do you think about your and your community's life in the UK?

a) How does it compare to life in your country of origin?

b) Are you able to do things and take part in things you were not able to do in your country of origin?

c) Do you participate in activities organised by non-Roma communities? What are the issues related to participation?

d) Do you feel accepted by the non-Roma community, e.g. your neighbours?

The Roma Community

This is an information leaflet for healthcare professionals and general NHS personnel. All Roma customs and taboos were researched in collaboration with Roma communities based in London. This information has been compiled via focus groups and meeting sessions with Roma community members in cooperation with Roma Support Group staff.

If you have any questions relating to this leaflet, would like further information or to give us feedback, please email Gaba at Roma Support Group: gaba@romasupportgroup.org.uk

You can find more information about RSG on our website: www.romasupportgroup.org.uk

Roma and Mental Health

Main Problems and Attitude to Mental Health

- Mental Health is treated as a greater taboo than any other health issue; it is rarely discussed amongst the Roma. If it is, Roma talk about being sad, feeling down or referring to a specific problem in their life. For this reason mental distress and depression often goes unreported. Some people will be open to talk about issues in front of others, but not in front of other Roma. They also describe their mental health concerns as problems with *the head* or *being crazy* without necessarily recognising and naming relevant mental health conditions.
- Drug addiction is a controversial subject and its existence is often denied within a Roma community, clan, tribe or family.
- Rape is often stigmatized; victims rarely discuss their traumas.
- Alcohol abuse can be construed as a social activity and most of the time will not be treated as addiction.
- The situation is changing amongst the youth who are more aware of various mental health problems. Some however are still reluctant to discuss private matters.
- Social disadvantage scores high by European standards. Unemployment, education, and infant and adult mortality fall below national averages.

There is a strong belief that mental health problems can be passed on genetically without taking into account environmental factors, this can jeopardise the prospect of marriage, affecting relations within the family unit and Roma community. Mental health is therefore a furtive, even shameful issue.

Seeking Help

Roma try to hide the fact that they are suffering from mental health problems from their family and other community members. Once the family knows, they will endeavour to hide the problem from others. This often creates a long delay in seeking medical help. In some cases health professionals are approached only when the situation is completely out of control and the family members cannot cope with the situation.

Relationship with the Health Professional

Barriers in Accessing Health Services

- Discrimination of the Roma whilst accessing health services in countries of origin; branding of Roma children as having learning difficulties; forced placement in special schools for handicapped pupils or identification of mental health problems when none exist, has led to distrust of healthcare providers in the UK. Roma almost always find it problematic trusting doctors when talking about sensitive issues for fear of negative consequences.
- Another barrier is often created by language misinterpretation. Non-Roma interpreters might not be aware of the language limitations of a Roma patient, misunderstanding or mistranslating the subject discussed. There can also be an element of distrust between Roma and non-Roma interpreters. If a Roma interpreter is present a Roma patient might be reluctant to talk about their mental health issues. Even when the Roma patient speaks good English they may need an interpreter to explain the medical and emotional condition since they may not possess an adequate English vocabulary. Therefore, it is important to be sensitive about the patient/interpreter relationship.
- For the above reasons, as well as low self-esteem, a lack of knowledge about the help available and limited access concerning UK patient rights can often mean Roma find it hard to voice concerns. These issues can limit the acquisition of referral to a mental health professional.

Contact with Health Professionals

- A relationship of trust and respect between the health professional and the Roma patient is necessary to open conversation on all sensitive issues, especially to talk about their mental health.
- Friendly and respectful body language displayed by the health professional can help Roma to gauge trust. A notion of unconditional positive regard is recommended.
- Eye contact while talking is one of the most important things for the Roma patient. (They find it offensive if the doctor looks at the computer or his notes whilst communicating.)
- Roma are opposed to what they call *difficult questions*, these are personal enquiries asked before trust is established. If a *difficult question* is asked prematurely it may undermine the future relationship with the patient.
- Older doctors are trusted more than younger ones. For many Roma continuity with the same doctor is extremely important.

Roma and General Health

Taboos and Customs

There are many taboos and related customs associated with general and mental health. Below are just a few examples.

- Health itself is a taboo subject often not to be discussed, even with close family members.
- In many tribes health is treated as an “unclean” subject. Roma who become health professionals or involve themselves in related health care roles such as health advocacy or interpreting can be treated as “unclean”, and sometimes ostracised by the community.
- Many of the health-related issues cannot be discussed in mixed (male/female) company; this includes family members, healthcare providers and interpreters.

- Everything relating to female gynaecological health is treated as an “unclean” subject/object and is to be discussed in a female-only environment.
- Traditionally, as a token of respect, health-related issues are not discussed in groups of Roma where the age gap is greater than 10 years.

Background information

Who are the Roma?

The Roma are the largest ethnic minority group in Europe. Many Roma in Western Europe are migrants from East European countries such as Poland, Slovakia, the Czech Republic, Romania, Lithuania, Latvia and numerous countries world-wide. Sometimes this group are also referred to as Gypsies.

Origins and History

The Roma people are thought to have originated in the Punjab and Rajasthan regions of India. Over 1000 years ago their ancestors began to emigrate. They did so in several waves, travelling through Asia to Europe and later to the Americas.

The Roma holocaust saw the systematic murder of large proportion of the Roma population. Exact numbers are disputed between 250,000 to 500,000 dead.

For centuries Roma led nomadic lifestyles. In the 1950s, under the communist regimes of Eastern Europe and following the dissolution of the Soviet Union, the Roma were forced to settle.

Throughout the centuries Roma have faced persecution and forced assimilation. In many countries Roma remain marginalised, confronting various discriminations in everyday life.

Roma came to the UK in ever increasing numbers during the 1990s. As asylum-seekers Roma were subjected to stressful immigration procedures, incurring great impact on their mental health. (This includes a distrust of questionnaires and detailed enquiry about themselves.)

Since the 2004 and 2007 EU accessions (which included several east European countries) Roma have gained wider access to settlement within the UK.

Language and Education

Romany is an endangered language, as listed by UNESCO. Roma speak one of the many Romany dialects. Usually they speak a second language well: that of their country of origin (e.g. Polish, Slovak, Romanian etc). However, this can be limited to a basic vocabulary dependant on education levels. Due to cultural/customary factors they often lack a vocabulary related to health and state of mind. Many Roma adults are illiterate.

A combination of cultural and literal understanding is therefore needed to aid Roma welfare and provide sustainable relations as a healthcare provider.

Please return completed feedback form to Gaba at Roma Support Group:

gaba@romasupportgroup.org.uk

**APPENDIX 2C LETTER FROM WEST LONDON MENTAL HEALTH TRUST
ASKING FOR PERMISSION TO USE EXTRACTS FROM THE RSG
INFORMATION LEAFLET FOR HEALTH PROFESSIONALS IN THE REVISED
CULTURAL COMPETENCY TOOL-KIT**

<p>West London Mental Health  NHS Trust</p>	
<p>Roma Support Group health@romasupportgroup.org.uk</p>	<p>Diversity Unit West London Mental Health [NHS] Trust Uxbridge Road Southall UB1 3EU Tel: 0208 354 - 8638 Fax: 0208 354 - 8710 Email: Margaret.Morgan-Valentine@wlmht.nhs.uk</p>

24/03/2011

Dear Madam/Sir,

Revised Cultural Competency Took-kit

We produced a Cultural Competency Tool-Kit in 2007; this is a resource with guidance on the cultural and religious practices of the ethnic groups that live within our catchment area.

We would very much like to include your organisation within the revised Tool-kit. Are you happy to be referred to as a resource that our clinicians can contact for information and guidance on your particular cultural/religious/diversity interest?

We would appreciate it if you could let us know whether you are happy to be listed. We have attached a copy of the tool-kit, please feel free to make any suggestions for further information that you feel should be included.

We look forward to hearing from you.

Yours sincerely



Mrs Maggie Morgan –Valentine
Head of Diversity – West London Mental Health [NHS]Trust

Enc

APPENDIX 3 FULL BREAKDOWN OF THE DATA COLLECTED FOR THE SOCIO-CULTURAL PROFILE OF THE MENTAL HEALTH AVOCACY PROJECT'S SERVICE USER

Table 1 Country of origin

Appendix 3, Table 1 Country of origin				
Lithuania	Romania	Kosovo	Poland	Slovakia
4%	3%	1%	90%	2%

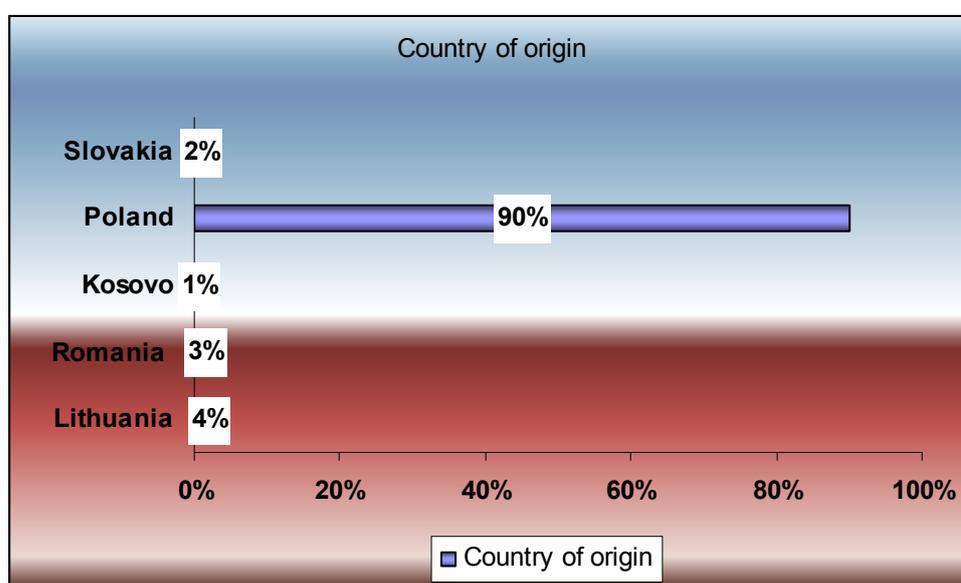


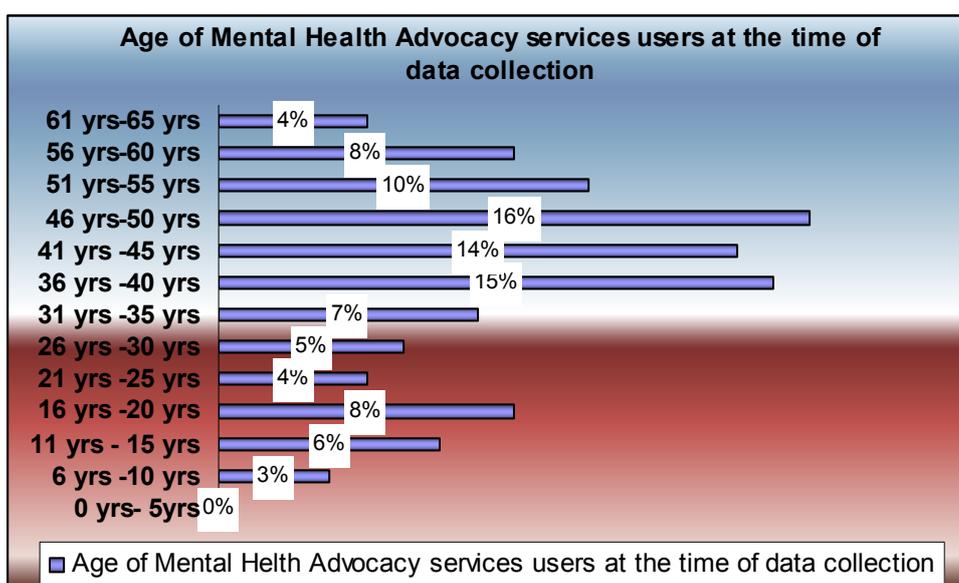
Table 2 Tribal Affiliation

Appendix 3, Table 2 Tribal Affiliation										
Polish Roma Polish Roma	Galicjaki	Bergidka Roma Mountain Roma	Austrian Roma	Hungarian Roma	Ukrainian/ Russian Roma	Lovari	Lithuanian Roma	Mixed	Not Known/ Did not disclose	Non-Roma affiliated with the Roma community
30%	14%	9%	5%	3%	2%	1%	1%	3%	25%	5%

Table 3 Age of service users who accessed Roma Mental Health Advocacy Project

Appendix 3, Table 3 Age of Mental Health Advocacy Service Users at the time of data collection													
Age group	0-5	6-10	11-15	16-20	21-25	26-30	31-35	36-40	41-45	46-50	51-55	56-60	61-65*
% Total	0	3	6	8	4	5	7	15	14	16	10	8	4

* We had no users over 65 years.



* We had no users over 65 years.

Table 4 Gender of the Roma Mental Health Advocacy Project’s Service Users

Appendix 3, Table 4 Gender breakdown for the Roma Mental Health Advocacy Project’s Service Users	
Female service users	Male service users
66%	34%

Table 5 Religion

Appendix 3, Table 5 Religion	
Religion	Percentage of service users
Catholic	63%
Jehovah Witness	11%
Pentecostal Church	4%

Not Applicable*	3%
Not known/Chose not to disclose/No religion	19%

*Service users who could not make their own choice due to severe learning difficulties/being too ill.



Table 6 Level of involvement in their Church/Religion

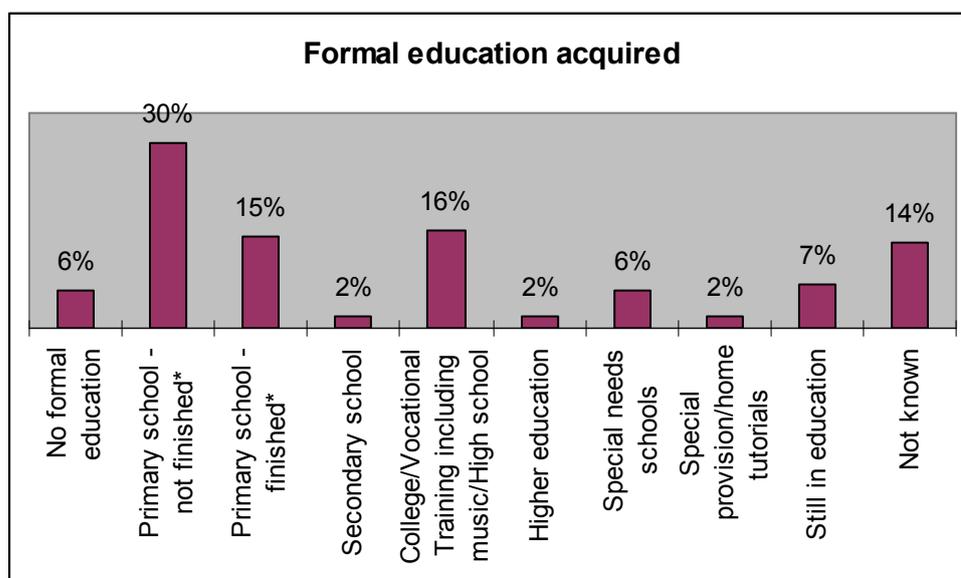
Appendix 3, Table 6 Level of involvement in their Church/Religion	
Level of involvement in church/religion	Percentage of service users
Practising	56%
Not practising	26%
Unable to practise (due to severe mental health problems)	4%
Not stated	14%

Table 7 Level of acquired formal education

Appendix 3, Table 7 Level of acquired formal education	
Level of education	Percentage of service users
No formal education	6%
Primary school - not finished*	30%
Primary school - finished*	15%
Secondary school - finished	2%
College/Vocational Training including music/High school	16%
Higher education	2%

Special needs schools	6%
Special provision/home tutorials	2%
Still in education	7%
Not known	14%

* Most of the service users attended primary education in their countries of origin. It often meant that they started education at the age of 7 and stayed in the same school (which would cover education at the primary and secondary level) for 8 years. After that they could pursue education in a college, high school or attend vocational training.



* Most of the service users attended primary education in their countries of origin. It often meant that they started education at the age of 7 and stayed in the same school (which would cover education at the primary and secondary level) for 8 years. After that they could pursue education in a college, high school or attend vocational training.

Table 8 Marital Status

Appendix 3, Table 8 Marital Status of Roma who accessed Roma Mental Health Advocacy Project					
Marital status	Single	Married	Separated	Divorced	Widowed
Percentage of service users	31%	44%	18%	2%	5%

Table 9 Geographical location of the project's service users

Appendix 3, Table 9 Geographical location of the project's service users		
Area	Detailed breakdown of the area	Percentage of service users
London Boroughs	Newham	38%

	Redbridge	14%
	Enfield	11%
	Barking & Dagenham	9%
	Hammersmith & Fulham	8%
	Waltham Forest	7%
	Haringey	3%
	Croydon	2%
	Islington	2%
	Lambeth	2%
	Hounslow	1%
	Lewisham	1%
	Wandsworth	1%
Outside of London	Southend	1%

Table 10 Employment status of the project's service users

Appendix 3, Table 10 Employment Status of Roma who accessed the Roma Mental Health Advocacy Project		
Employed	Unemployed	Below employment age or unable to work due to severe learning disability/mental health problems
6%	72%	22%

Table 11 Number of years the project's service users have been in the UK

Appendix 3, Table 11 Breakdown of the data related to the number of years since the arrival in the UK*			
0-5 years	6-10 years	11-15 years	16-20 years
21.5%	18%	55.5%	5%

*data calculation for 2010

Table 12 Year of the arrival in the UK

Appendix 3, Table 12 Year of arrival in the UK	
Year of arrival	Percentage of the project's service users
1992	2.5%
1993	0%
1994	2.5%
1995	14%
1996	7.5%
1997	9%

1998	10%
1999	15%
2000	9%
2001	1%
2002	1%
2003	1%
2004	6%
2005	5%
2006	5%
2007	4%
2008	1%
2009	4%
2010	2.5%

Languages spoken by the Roma Mental Health Advocacy Project's Service Users (Tables 13 – 16)

Table 13 Combination of languages spoken by individual service users

Appendix 3, Table 13 Combination of languages spoken by individual service users	
Combination of languages spoken by individual service users	Percentage of service users
Romani and Polish	47%
Romani, Polish and English*	31%
Romani, Polish, Russian, English	5%
Romani, Polish, German	3%
Romani only	3%
No spoken language **	2%
Slovak, Hungarian and English	1%
Romani, Serbo-Croat, English	1%
Romani, Russian, Lithuanian	1%
Romani, Polish, Slovak, English	1%
Romani, Polish, Russian	1%
Romani and English only	1%
Polish only	1%
Polish and English only	1%

Lithuanian only	1%
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*Includes 1 speaker of 4 Romani dialects, Polish and English, we did not keep records for number of various Romany dialects spoken by individual service users.

**No spoken language due to severe learning disability and mental health problems

Table 14 Number of languages spoken by individual service users

Appendix 3, Table 14 Number of languages spoken by individual service users	
Number of languages spoken by individual service users	Percentage of service users
0	2%
1	6%
2	49%
3	36%
4	6%
6	1%

Table 15 List of languages used/spoken by the Roma Mental Health Advocacy Project's Service Users

Appendix 3, Table 15 List of languages used/spoken by the Roma Mental Health Advocacy Project's Service Users	
Language	Percentage of speakers
Polish	90%
English	41%
Romani	93%
Lithuanian	2%
Slovak	2%
Russian	7%
German	3%
Hungarian	1%
Serbo-Croat	1%
No language	2%

Table 16 Level of acquired spoken English

Appendix 3, Table 16 Level of acquired spoken English				
English Speakers	41%	Fluent	Some English	Limited
		17%	66%	17%

No Spoken English	59%	
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Health Related Data - Tables 17 - 26

Table 17 Number of years the project’s service users have been suffering from mental health problems

Appendix 3, Table 17 Number of years the project’s service users have been suffering from mental health problems*						
Number of years	0-5	6-10	11-15	16-20	21-25	26-30
Percentage of service users	51%	16%	12%	14%	1%	2%

* Data for 2010, included service users (4%) suffering from mental health problems/learning difficulties since birth

Table 18 Year when mental health problems started for the individual service users

Appendix 3, Table 18 Year when mental health problems started for the individual service users	
Year	Percentage of clients
1980	1%
1982	1%
1988	1%
1990	7%
1991	3%
1992	3%
1994	1%
1995	1%
1996	4%
1997	1%
1998	3%
1999	3%
2000	5%
2001	5%
2002	3%
2003	1%
2004	4%

2005	9%
2006	3%
2007	14%
2008	13%
2009	9%
2010	3%

Table 19 Awareness of mental health problems amongst the project service users – formal diagnosis

Appendix 3, Table 19 Awareness of mental health problems amongst the project service users – formal diagnosis		
Aware	Not aware (Service user was not informed about the diagnosis)	Not aware (service users do not know the diagnosis due to a severe learning disability or are waiting for a diagnosis)
65%	24%	11%

Table 20 Breakdown of all the mental health problems listed by the project's service users and percentage of service users who suffered from them

Appendix 3, Table 20 Breakdown of all the mental health problems listed by the project's service users and percentage of service users who suffered from them	
Mental health problem	Percentage of service users
Organic, including symptomatic, mental disorders due to brain damage	1%
Substance-related disorders (alcohol dependency)	6%
Schizophrenia and other psychotic disorders	11%
<ul style="list-style-type: none"> • psychosis • paranoid schizophrenia • schizophrenia 	3% 2% 7%
Mood disorders	61 %
<ul style="list-style-type: none"> • Bipolar Disorder • Depression 	1% 61%

Anxiety disorders	19 %
<ul style="list-style-type: none"> Anxiety (includes co-morbid anxiety: 2%) Panic attacks Post traumatic stress disorder 	11% 7% 2%
Disorders usually first diagnosed in infancy, childhood, or adolescence	17%
<ul style="list-style-type: none"> Autism Behavioural issues Emotional difficulties Learning disability 	4% 2% 2% 9%
Other mental health problems	4%
<ul style="list-style-type: none"> suicidal thoughts and attempts self-harm 	3% 1%

Table 21 Breakdown of the mental health problems/combination of problems suffered by the project's service users*

Appendix 3, Table 21 Breakdown of the mental health problems/combination of problems suffered by the project's service users*	
Mental Health Problem(s)	Percentage of service users suffering from the listed problems
Children disorders	
Autism (children)	2%
Autism and learning disability (children)	2%
Behavioural problems (children)	2%
Adult disorders	
Learning disabilities caused by brain damage	1%
Depression and Severe depression	39%
Depression and alcohol dependency	4%
Depression and anxiety	4%
Depression and panic attacks	3%
Depression and Psychosis	2%
Depression with suicidal thoughts/attempts	2%
Depression, anxiety, panic attacks	2%
Depression, co-morbid anxiety, suicidal thoughts	1%
Emotional difficulties	2%
Depression related to Fibromyalgia	1%

Learning disabilities	3%
Learning disability and self-harm	1%
No diagnosis	2%
No mental health problem diagnosis and alcohol dependency	1%
Paranoid schizophrenia	1%
Post Traumatic Stress Disorder, Anxiety, Agitation	1%
Post traumatic stress disorder	1%
Psychosis	1%
Schizophrenia	8%
Severe learning disability	1%
Severe learning disability, anxiety and panic attacks, violent outbursts	1%
Trauma related to abuse	1%

*Data as provided/stated by service users, we were not always able to confirm it with mental health professionals or medical reports

Table 22 Percentage of service users who were offered treatment in relation to their mental health problems*

Appendix 3, Table 22 Percentage of service users who were offered treatment in relation to their mental health problems*	
Offered treatment	82%
Not offered treatment	7%
N/A**	11%

* Combined data from before and after our intervention

**Clients who have not seen GP or any other specialist/clients who have not been diagnosed

Table 23 Types of treatment/combination of treatments and other support offered to Roma service users in relation to their mental health problems*

Appendix 3, Table 23 Types of treatment/combination of treatments and other support offered to Roma service users in relation to their mental health problems*	
Type of treatment or combination of treatments offered	Percentage of service users
Medication	47%
Counselling	3%
Counselling and medication	10%
Counselling and education support	1%
Counselling, medication and self-help group	1%

Counselling, medication and special education support	1%
Medication and hospitalisation/mental health clinic	4%
Medication and social care services support	3%
Medication, hospitalisation, social care services support,	4%
Medication and other therapy (includes: psychotherapy 1, psychological care 1, psychiatric care 3)	9%
Medication, psychiatric care, special education and social care services support	1%
Medication and neurological treatment	1%
Psychiatric treatment	1%
Special education	1%
Speech therapy	1%

*Data as provided by service users, we were not always able to confirm it with mental health professionals or medical reports

Table 24 Number of service users who used listed treatments and support

Appendix 3, Table 24 Number of service users who used listed treatments and support	
Type of treatment	Percentage of service users
Medication	81%
Counselling	17%
Hospitalisation/mental health clinic	9%
Social care services support	9%
Psychiatric treatment/care (includes psychotherapy 1)	7%
Education support (includes special education 3)	6%
Self-help group	1%
Neurological treatment	1%
Psychological care	1%
Speech therapy	1%

Table 25 Number of the project's service users stated to have other health problems

Appendix 3, Table 25 Number of the project's service users stated to have other health problems

Do you have other health problems	Percentage of service users
Yes	91%
No	9%

Table 26 Health problems (excluding mental health problems) and disabilities listed by the project's service users*

Appendix 3, Table 26 Health problems (excluding mental health problems) and disabilities listed by the project's service users*	
Health problem	Percentage of service users
Back pain/problems	29%
Memory problems (includes memory loss 2%)	16%
Dizzy spells	10%
Fibromyalgia	10%
Mobility impairment	10%
Arthritis and rheumatism	8%
Asthma/respiratory problems	8%
Alcohol related liver problems	6%
Alcoholism	6%
Severe sight impairment/blind	6%
Generalised pain	6%
Hearing impairment	6%
Heart problems	6%
Hypertension	6%
Incontinence	6%
Behavioural problems	5%
Cancer/history of cancer	5%
Diabetes	5%
Epilepsy	5%
Gynaecological problems	5%
Muscle pain	5%
Speech impediment	5%
Carpal tunnel syndrome	8%
Eczema/skin problems	3%
Facial deformity	3%
High cholesterol	3%

History of stroke	3%
Insomnia	3%
Kidney failure	3%
Violent outbursts	3%
Hepatitis	3%
Atherosclerosis	2%
Bladder problems	2%
Broken leg with complications	2%
Chronic eye and ear infections	2%
Deafness	2%
Dementia	2%
Discopathy	2%
Eyesight problems	2%
Frozen shoulder	2%
Growth deformity	2%
Hand problems	2%
Headaches	2%
Hernia	2%
Health problems following serious car accident	2%
Health problems caused by brain surgery	2%
Multiple Sclerosis	2%
Obesity	2%
Osteoporosis	2%
Poor hand-eye coordination	2%
Recurrent ear infections	2%
Stomach problem	2%
Serious dental problems	2%

* Data as provided by service users, we were not always able to confirm it with health professionals or medical reports

Information about non-health related problems Roma service users struggled with and needed support - tables 27 and 28

Table 27 Number of service users who had non-health related problems and concerns

Appendix 3, Table 27 Number of service users who had non-health related problems and concerns	
Do you have other serious problems/concerns?	Percentage of service users
Yes	90%
No	10%

Table 28 Other concerns and problems experienced by the Roma Mental Health Advocacy service users

Appendix 3, Table 28 Other concerns and problems experienced by the Roma Mental Health Advocacy Project's service users	
Concern/problem	Percentage of service users*
Poor housing conditions and other housing problems	48%
No/very low income	35%
Debts	29%
Other family members with severe illness	26%
Welfare benefits issues	23%
Incapable of work	14.5%
Dependency on family	11%
No access to public funds	6%
Problems at school (includes poor attendance)	6%
Family member with alcohol/drug dependency	5%
Relationship/marriage breakdown	5%
Single mother	5%
Bereavement	3%
Child protection	3%
Financial difficulties	3%
High level of stress	3%
Other family members suffering from mental health problems	3%
Pending asylum case	1%
Homelessness	1%
Limited family support	1%

* A majority of clients have experienced a combination of the above problems

Data collected through the entry form, related to integration in the wider society and isolation of the individual Roma community members who accessed the RSG Roma mental health advocacy project

Table 29

Appendix 3, Table 29 Do you have family?	
Yes	No
100%	0%

Table 30

Appendix 3, Table 30 Do you keep in touch with your family?		
Yes	No	n/a due to severe learning disability/mental health or illness
92%	6%	2%

Table 31

Appendix 3, Table 31 Do you have Roma friends?		
Yes	No	n/a due to severe learning disability/mental health or illness
75%	21%	4%

Table 32

Appendix 3, Table 32 Do you have non-Roma friends?*		
Yes	No	n/a due to severe learning disability/mental health or illness
58%	38%	4%

*Frequently Roma Support Group staff and volunteers were counted as non-Roma friends

Table 33

Appendix 3, Table 33 Do you use your local library?		
Yes	No	n/a due to severe learning disability/mental health or illness
14%	82%	4%

Table 34

Appendix 3, Table 34 Do you participate in any local community events (Roma or non-Roma)?*		
Yes	No	n/a due to severe learning disability/mental health or illness
46%	50%	4%

*Almost all the examples given by the service users included Roma community events (e.g. weddings, christenings, funerals and concerts)

Table 35

Appendix 3, Table 35 Are you volunteering for any organisation?		
Yes	No	n/a due to young age/severe learning disability/mental health or illness
11%	74%	15%

Table 36

Appendix 3, Table 36 Have you done any courses in the UK?		
Yes	No	n/a due to young age/severe learning disability/mental health or illness
22%	56%	22%

Table 37

Appendix 3, Table 37 Do you have any hobbies?		
Yes*	No	n/a due to severe learning disability/mental health or illness
46%	50%	4%

***HOBBIES LISTED BY THE ROMA SERVICE USERS:**

Basketball, Beauty, Cleaning, Collecting pigeons, Computers, Cooking, Cycling, Dancing, Embroidery, Fishing, Football, Fortunetelling, Gambling, Games, Gardening, Healthy eating, Horses, House decorating, Learning English, Listening to music, Looking after grandchildren, Playing on musical instruments, Playing cards, Playing organs, Playing with friends, Pottery, Reading, Sewing/making clothes, Shopping, Socialising, Swimming

Table 38

Appendix 3, Table 38 Do you belong to any clubs or community groups?		
Yes	No	n/a due to severe learning disability/mental health illness
16%	80%	4%

APPENDIX 4 CLIENTS FEEDBACK - SUMMARY

Client feedback forms were filled in by the service users who accessed mental health services and were supported by the Roma mental health advocacy project. In the case of children and clients with severe learning disabilities/too ill to answer for themselves (22% of the total number of clients) feedback was gathered through their carers. In most cases service users needed RSG staff members or volunteers to help them to fill in the forms.

TABLE 1

Appendix 4, Table 1 Clients feedback - Questions 1-3			
Questions 1-3	yes	maybe	no
Do you think that Mental Health Advocacy Project is needed?	100%	0%	0%
Were the advice and support provided useful?	100%	0%	0%
Were you happy about the contacts with our staff members and volunteers and the way they treat you?	100%	0%	0%

TABLE 2

Appendix 4, Table 2 Clients feedback - Question 4			
Question 4		yes	no
Would you like to change something about the Mental Health advocacy Project?		40%	60%
If yes, what would you change?	Increase capacity	80%	n/a
	Other*	20%	n/a

*Some of the changes suggested by service users included:

I would like Roma Support Group's Mental Health Advocate to be available to accompany me to all doctors' visits.

I would like the Roma Mental Health Advocacy Project to have a counsellor or a dedicated person whom I could talk to or call about my problems.

TABLE 3

Appendix 4, Table 3 Clients feedback – Other comments	
Do you have other comments	Percentage of clients
Yes**	33%
No	67%

**Some of the comments:

“When I started to accessed Roma mental health advocacy project I was already receiving specialist treatment but I knew a lot of people with mental health issues who would benefit from this project as there is little awareness of services amongst Roma and no other organisation offers this sort of help.”

“I would like to say thank you.”

“It would be useful to have offices in different parts of London so more people could have access to help from this project.”

APPENDIX 5 DISTANCE-TRAVELLED FORMS SUMMARY AND ANALYSIS

TABLE 1 DISTANCE TRAVELLED FORM – ENTRY POINT

Appendix 5, Table 1 Distance Travelled Form – answers given when the form was filled in by the service users when they started to access the Roma Mental Health Advocacy Project						
	PERCENTAGE OF SERVICE USERS WHO TICKED THE FOLLOWING ANSWERS:					
DISTANCE-TRAVELLED FORM QUESTIONS	1	2	3	4	5	N/A
1a: How easy is it for you to talk about your mental health problems (MHP) with your close family?	Very easy	Easy	So-so	Difficult	Very difficult	
	8%	15%	23%	15%	39%	
1b: How easy is it for you to talk about your MHP with your extended family/community members?	Very easy	Easy	So-so	Difficult	Very difficult	
			15%	15%	70%	

1c: How easy is it for you to talk about your MHP with non-Roma?	Very easy	Easy	So-so	Difficult	Very difficult	
			38%	54%	8%	
2: Do you know what services are available within NHS in relation to your MHP? (your rights)	Yes, very well	Yes, fairly well	So-so	Not really	Not at all	
		15%	31%	39%	15%	
3: Do you know how to access relevant services?	Yes, very well	Yes, fairly well	So-so	Not really	Not at all	
		31%	15%	23%	31%	
4: Are you able to access these services?	Yes, easily	Yes, with some difficulties	So-so	With great difficulty	Not at all	
	8%	39%	15%	23%	15%	
5: Do you need help in order to access MH services?	Never	Rarely	Sometimes	Frequently	Always	
			15%	31%	54%	
6: Do you think that your doctor knows the Roma community and culture?	Yes, very well	Yes, enough	I do not know	Not enough	Not at all	
		8%	31%	23%	38%	
7: Are you satisfied with the services you access for your mental health problem?	Yes, very	Yes, fairly satisfied	So-so	Not really	Not at all	
	8%	8%	8%	23%	23%	30%*

* Percentage of service users who at the time did not access any services for their mental health problems

TABLE 2 DISTANCE TRAVELLED FORM – SIX TO TWELVE MONTHS LATER

Appendix 5, Table 2 Distance Travelled Form – answers given when the form was filled in by the service users after 6 months to 1 year of support from the Roma Mental Health Advocacy Project’s Advocates						
	PERCENTAGE OF SERVICE USERS WHO TICKED THE FOLLOWING ANSWERS:					
DISTANCE-TRAVELLED FORM QUESTIONS	1	2	3	4	5	N/A

1a: How easy is it for you to talk about your mental health problems (MHP) with your close family?	Very easy	Easy	So-so	Difficult	Very difficult	
	8%	23%	38%	31%		
1b: How easy is it for you to talk about your MHP with your extended family/community members?	Very easy	Easy	So-so	Difficult	Very difficult	
		8%	23%	8%	61%	
1c: How easy is it for you to talk about your MHP with non-Roma?	Very easy	Easy	So-so	Difficult	Very difficult	
		31%	54%	15%		
2: Do you know what services are available within NHS in relation to your MHP? (your rights)	Yes, very well	Yes, fairly well	So-so	Not really	Not at all	
		61%	23%	8%	8%	
3: Do you know how to access relevant services?	Yes, very well	Yes, fairly well	So-so	Not really	Not at all	
	8%	61%	15%	15%		
4: Are you able to access these services?	Yes, easily	Yes, with some difficulties	So-so	With great difficulty	Not at all	
	23%	39%	15%	23%		
5: Do you need help in order to access MH services?	Never	Rarely	Sometimes	Frequently	Always	
	8%	15%	38%		39%	
6: Do you think that your doctor knows the Roma community and culture?	Yes, very well	Yes, enough	I do not know	Not enough	Not at all	
		31%	23%	38%	8%	
7: Are you satisfied with the services you access for your mental health problems?	Yes, very	Yes, fairly satisfied	So-so	Not really	Not at all	
	39%	23%	15%	15%		8%*

* Percentage of service users who at the time did not access any services for their mental health problems

TABLE 3 DISTANCE TRAVELLED FORM PROGRESS STATED BY THE SERVICE USERS OVER THE PERIOD OF SIX TO TWELVE MONTHS

Appendix 5, Table 3 Distance Travelled Form Progress stated by the service users over the period of six to twelve months					
	PERCENTAGE OF SERVICE USERS WHO STATED THE FOLLOWING:				
DISTANCE-TRAVELLED FORM QUESTIONS	No IMPROVEMENT	IMPROVEMENT			
		BY 25%	BY 50%	BY 75%	BY 100%
1a: How easy is it for you to talk about your mental health problems (MHP) with your close family?	39%	46%	15%	-	-
1b: How easy is it for you to talk about your MHP with your extended family/community members?	69%	31%	-	-	-
1c: How easy is it for you to talk about your MHP with non-Roma?	23%	62%	15%	-	-
2: Do you know what services are available within NHS in relation to your MHP? (your rights)	38%	39%	15%	8%	-
3: Do you know how to access relevant services?	38%	31%	8%	23%	
4: Are you able to access these services?	54%	15%	23%	8%	-
5: Do you need help in order to access MH services?	23%	54%	15%	8%	-
6: Do you think that your doctor knows the Roma community and culture?	46%	39%	15%	-	-
7: Are you satisfied with the services you access for your mental health problem?	23%	23%	15%	15%	24%