



Marginalisation, Social Inclusion and Health

*Experiences based on the work of
Correlation – European Network Social Inclusion & Health*

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Colophon

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WORLD HEALTH DECLARATION

*Adopted by the world health community at the Fifty-first World Health Assembly,
May 1998*

We recognize that the improvement of the health and well-being of people is the ultimate aim of social and economic development. We are committed to the ethical concepts of equity, solidarity and social justice and to the incorporation of a gender perspective into our strategies. We emphasize the importance of reducing social and economic inequities in improving the health of the whole population. Therefore, it is imperative to pay the greatest attention to those most in need, burdened by ill-health, receiving inadequate services for health or affected by poverty. We reaffirm our will to promote health by addressing the basic determinants and prerequisites for health. We acknowledge that changes in the world health situation require that we give effect to the "Health-for-All Policy for the twenty-first century" through relevant regional and national policies and strategies.
(1)

Abstract

This article discusses the issues of marginalisation and social inclusion and their particular relevance for the well-being of individuals and groups in Europe. Specific attention is paid to the relation between marginalisation and access to health services. The authors look at the situation of drug users, sex workers, (undocumented) migrants and youth at risk. The experiences made in connection with a broad variety of activities of Correlation – European Network Social Inclusion & Health illustrate concrete examples of interventions and skills building, which take into account elements as empowerment and the impact on policy debate.

Integrated approaches and strategies on all levels of society are needed to improve social inclusion and access to health and social services. Also in developed countries, poverty, exclusion and stigmatisation are a reality for millions of people, resulting in illness and poor well-being. National governments and international bodies like the European Union need to increase their efforts to close the gap between the 'haves' and 'have nots'. The authors summarise the policy framework, in which the European Union addresses exclusion and health inequalities of citizens.

The article analyses the situation of particular groups in society - drug users, sex workers, (undocumented) migrants and young people at risk – that may face particular economic disadvantages, stigmatisation, criminalisation and oppression and that, consequently, may experience serious barriers to access health and social services. It calls for projects and interventions that offer evidence-based approaches and services, using the latest findings of social research and evaluations. Participation and empowerment strategies have proven their effectiveness to improve the health condition of people, living in the margins, both at individual and structural levels. The involvement of marginalised groups in decision making and programme development should therefore be seen as an essential element of policy making in this sector.

The Correlation network has contributed to the debate about marginalisation and health by linking experts from different fields and backgrounds, like grass root organisations, researchers and policy makers. By doing so, Correlation developed expertise, implemented innovative approaches and provided profound knowledge in this area.

1. Introduction

Marginalisation and social exclusion of individuals and groups are a reality in virtually every society and in every period of human history. In the second part of the 20th century - driven by human rights aspects and social research – national governments, transnational bodies and institutions (UN/EU) paid more and more attention to the improvement of the situation of those, who are excluded.. Civil society, self -organisations and advocacy groups, social researchers and NGO's played a crucial role in addressing the issue of social exclusion and in advocating sustainable changes.

In the area of marginalisation and social exclusion, many different aspects and issues have to be addressed, such as discrimination, racism, poverty, globalisation, immigration, social welfare, health and human rights. Also the list of potentially or actually marginalised and excluded individuals, groups and populations is extensive: ethnic minorities, immigrants, disabled persons, isolated older persons, ex-prisoners, drug users, people living with HIV/AIDS, psychiatric patients, sex workers, homeless people and marginalised youth. These people and groups face common social, economical and individual problems, even if their backgrounds may be diverse and different. Definitions or indicators for marginalisation and social exclusion might vary in different settings and regions: for instance, poverty is related to the economical level of the particular country, drug users are more excluded and criminalized in particular regions and countries than in others.

This article will briefly summarize the most common definitions of keywords used in this article and describes the efforts within the European Union to tackle the issue of social inclusion. Based on that, we will focus on a particular aspect: the relationship between social inclusion and health regarding four main groups at risk for marginalisation: (undocumented) migrants, drug users, sex workers and youth at risk.

Based on the experiences and results of the work of Correlation – European Network Social Inclusion & Health, we will describe approaches and methodologies to improve social inclusion and access to health for the target groups mentioned above. During it's initial phase from 2005 till 2008, this network brought together nearly one hundred agencies and experts, from different disciplines and with a broad range of expertise – from governmental to grass root organisations. The examples at some stage might be fragmentary with sometimes only local impact, but due to the exchange of information, methods and good practices within the framework of the network, these models can have great relevance for other regions and situations and can contribute to the overall aim of Correlation to improve social inclusion and the access to and the quality of health services.

2. Marginalisation, social inclusion and health: Some definitions

2.1. Marginalisation

Marginalisation describes the position of individuals, groups or populations outside of 'mainstream society', living at the margins of those in the centre of power, of cultural dominance and economical and social welfare. It is defined as, "a process by which a group or individual is denied access to important positions and symbols of economic, religious, or political power within any society...a marginal group may actually constitute a numerical majority...and should perhaps be distinguished from a minority group, which may be small in numbers, but has access to political or economic power". (Marshall, 1998) (2)

"To be marginalized, ..., is to be distanced from power and resources that enable self-determination in economic, political, and social settings...It is an inherent characteristic of 'those in the margin', that they have poor access to economical and other recourses like education and social services, meanwhile participation and self determination are on a low level. However, definitions of what is regarded as marginalised are highly depending on the historical and socio-economical context of a society." (Daniel, Fletcher, Linder, 2002). (3)

In the last decennia, globalisation, migration, economical developments – e.g. in the area of communication technologies – have had a major influence on the economical level of millions of people and consequently, on their place in the society. Gender, culture, language, race, sexual orientation, lifestyle and the socio-economic position or class are factors, which influence the position of an individual or a group in the society. Vulnerable groups like migrants and ethnic minorities, homeless people, drug addicts, sex workers, youth with risk behaviour, isolated older people or people with disabilities face higher risks of social exclusion and marginalisation. Their problems can be related to homelessness, unemployment, poor access to social and health services, low health status and poor living conditions.

2.2. Social inclusion

'Social inclusion' refers to the position, in which someone can access and benefit from the full range of opportunities available to members of a society. The term is not a fixed theory or concept, but continuously under development, regarding the challenges and problems in different situations and circumstances. Social inclusion has a value as process and as a goal, and should be approached pro-actively, not as a passive defending of rights, but as active interventions, rooted in community (self) organization and leading to real policy changes by transforming given structures.

"Social inclusion is the political response to exclusion. Most analyses of racism and sexism, for example, focus on the removal of systemic barriers to effective participation and focus on equality of opportunity. These analyses tend to be essentialist and consequently are unable to develop a comprehensive vision that cuts across all the areas of injustice.

Social inclusion is about more than the removal of barriers, it is about a comprehensive vision that includes all. Social inclusion, by virtue of the fact that it is both process and outcome, can hold governments and institutions accountable for their policies. The yardstick by which to measure good government becomes the extent to which it advances the well-being of the most vulnerable and most marginalized in society.

Social inclusion is about advocacy and transformation. It is about the political struggle and political will to remove barriers to full and equitable participation in society by all."
(Saloojee (2001) (4)

Even if there is still a gap between policy statements and what is happening in practice, in the last decennia more and more awareness and attention has been given to improve social inclusion of disadvantaged groups and people, also by international bodies as the United Nations (UN Millennium Goals) and the European Union (The Lisbon Strategy, see chapter 4).

National governments and NGO's installed measures and projects to improve the situation on different levels. Usually, the overall aim is to "ensure the marginalised and those living in poverty have greater participation in decision making which affects their lives, allowing them to improve their living standards and their overall well-being" and "to remove barriers for people or for areas that experience a combination of linked problems (...)" (Combat Poverty Agency Ireland, 2007).

Programmes often are set up with multidisciplinary approaches, addressing problems at several levels of society. For instance, the British Social Inclusion Programme 2007 addressed aspects like stigma and discrimination, the role of health and social care in tackling social exclusion, implementing evidence-based practice in vocational services and enabling reintegration into the community, employment and taking part in the local community. (5)

2.3. The link between marginalisation, health and health inequalities

There is a broad consensus that health in general, and health inequalities in particular are strongly related with socio-economic determinants and that the possible level of marginalisation influences the well-being of individuals and groups. Studies have demonstrated the link between social and material disadvantages and poor mental and physical health. Factors as employment, housing and education are identified as health determinants, which can reduce inequalities in health. Meanwhile, poverty – whether defined by income, socio-economic status, living conditions or educational level – is regarded as the largest single determinant of ill health.

“...Human poverty is deprivation in multiple dimensions, not just income. Industrial countries need to monitor poverty in all its dimensions - not just income and unemployment, but also lack of basic capabilities such as health and literacy, important factors in whether a person is included in or excluded from the life of a community.” (UNDP, 1998).

“Living in poverty is correlated with higher rates of substance use (tobacco, alcohol and illegal drugs), depression, suicide, antisocial behaviour and violence, an increased risk of food insecurity and a wide range of physical complaints. Large – and in fact increasing – numbers of people in European societies today are at risk of experiencing poverty sometime in their lives.”(WHO, 1999) (6)

“ People with a lower level of education, a lower occupational class, or a lower level of income tend to die at a younger age, and to have, within their shorter lives, a higher prevalence of all kinds of health problems”. (Mackenbach, 2005) (7)

The WHO concludes in a report on social inequities in health that there are systematic differences in health status between different socio-economic groups. “These inequities are socially produced (and therefore modifiable) and unfair. In practice, all systematic differences in health between socio-economic groups in European countries could be regarded as unfair and avoidable, and therefore regarded as inequities. This judgement about unfairness is based on universal human rights principles”. (Whitehead M. and Dahlgren G, 2006) (8)

Despite progresses on social welfare in western societies, almost all European countries are faced with substantial inequalities in health within their populations, as well as within countries as between countries. In a project of Euro Health Net, which examined the situation in Europe, it is concluded that health inequalities cannot be tackled by the health system alone but only together with inter-sectoral cooperation and multidisciplinary approaches:

“Successful strategies that countries are adopting involve both upstream (wider determinants – the underlying causes) and downstream approaches (measures to reduce the consequences of unhealthy circumstances). Upstream approaches involve efforts to address the macro socio-economic environment (e.g. efforts to ensure that national policies promote human development and reduce social inequalities). They also entail improving access to education, healthy working conditions, reducing unemployment, social and community inclusion policies. Mid- and more downstream measures ensure that lifestyle related programmes (tobacco control, alcohol misuse, nutrition, physical activity and mental health) as well as health care services address the more vulnerable or disadvantaged groups of society.” (Euro Health Net, 2007)

Some of the recommendations to improve the situation, following the report, are

- Improve visibility and gather data.
- Ensure equal uptake of prevention and health promotion measures
- Involve key actors and encourage partnerships across policy areas
- Develop capacities for implementation
- Support the local level and encourage local ‘upstream’ policies
- Strengthen the evidence base and get it into practice. (9)

3. The European Union approach towards social inclusion and health

More than 68 million people throughout the European Union today are affected by poverty and social exclusion. This represents 15% of the population in the EU. EU leaders have pledged to work together to make a decisive impact on the eradication of poverty by 2010. (European Commission, Joint report 2005) (10)

“The European Union has a three-fold approach to overcoming discrimination and increasing the inclusion of vulnerable and marginalised groups – increasing access to mainstream services and opportunities, enforcing legislation to overcome discrimination and, where necessary, developing targeted approaches to respond to the specific needs of each group.

Ethnic minorities and immigrants are identified as disadvantaged in almost every Member State. They exhibit lower scores on social inclusion such as employment rates, income in employment, and higher scores in school drop-out rates, homelessness, financial exclusion and criminal propensity. ...

Disabled people also face higher risk of poverty, social exclusion and discrimination. The European Union works towards narrowing the gap in the employment rates between disabled and non-disabled people through the implementation of active employment measures at Member State level.

Measures are implemented in favour of areas marked by exclusion – combating regional inequalities, tackling disadvantages faced by rural areas, and helping regenerate deprived areas and disadvantaged neighbourhoods. Eliminating the barriers to education and training for all vulnerable groups and at all levels is a key issue.”

(European Commission, Employment, Social affairs & Equal Opportunities) (11)

The Amsterdam Treaty provides the European Union with the legal competence to play an active role in supporting and complementing the activities of Member States in combating social exclusion. The Lisbon European Council of March 2000 also agreed, on this basis, to take steps to make a decisive impact on the eradication of poverty by 2010. The Open Method of Coordination (OMC) in the field of combating poverty and social exclusion was launched and defined the following set of common objectives:

1. To facilitate participation in employment and access to resources, rights, goods and services for all
 2. To prevent the risks of exclusion
 3. To help the most vulnerable
 4. To mobilize all relevant bodies
- (Euro Health Net, 2004) (12)

In 2001, the Commission and the Member States also agreed on 18 common indicators for the measurement of poverty and social exclusion. These indicators cover a variety of domains, such as income poverty, long-term unemployment, health and lifelong learning, to reflect the multidimensional nature of poverty and social inclusion, which cannot be reduced to a single variable. The indicators serve as a basis for the EU and individual Member States to assess the progress of the social inclusion process on the basis of measurable outcomes, translated into National Action Plans for Social Inclusion.

The Directorate General for Employment, Social Affairs & Equal Opportunities is the leading agency within the European Commission on these issues.

The European Commission's important role in health policy has been reaffirmed in the Reform Treaty which was agreed by EU Heads of State and Government in Lisbon on 19 October 2007, and which proposes to reinforce the political importance of health. In a White Paper, the European Commission defines principles of health values as universality, access to good quality care, equity and solidarity. “A core value is Citizens' Empowerment. (...) This includes participation in and influence on decision-making, as well as competences needed for well-being, including 'health literacy', (...) Values relating to improving health must include reducing inequities in health. ..Finally, health policy must be based on the best scientific evidence derived from sound data and information, and relevant research.” (EC White Paper, 2007) (13)

In 2007, the European Parliament and the Council of the European Union adopted a second Programme of Community Action in the field of health, which should further contribute to providing citizens with better access to information and thereby increase their ability to make decisions which best cater for their interests. The programme should help to identify the causes of health inequalities and encourage, among other things, the exchange of best practices to tackle them. (14)

The Directorate General of Health and Consumer Protection deals with public health aspects, such as health information, health threats and health determinants. In the field of illegal drug use (and even legal drugs misuse/abuse in the context of poly drug use), it focuses especially on prevention, education, risk/harm reduction, treatment and awareness raising. (15)

4. Social inclusion and health: Target groups

4.1. Introduction

Beside socio-economic factors, individual choices for a certain lifestyle might cause stigmatisation, discrimination and exclusion from mainstream society. Unconventional lifestyles, being 'abnormal' or being an 'outsider', will often lead to moralistic judgements, which may have consequences for the social positioning of an individual or group.

"A non-judgmental and unbiased attitude is necessary on the part of the social worker. The worker must begin to understand oppression and marginalisation as a systemic problem, not the fault of the individual" (Mullaly, 2007). (16)

Within the framework of Correlation – European Network Social Inclusion & Health, experts work with and for particular groups living permanently or temporarily outside mainstream society, because they belong to a stigmatised group (ethnic minorities, sex workers), engage in unaccepted risk behaviour (drug users) or find themselves in risk situations (e.g. young people experimenting with party drugs), in which they cannot appeal to the protecting safety structures of mainstream society. They cannot be identified as one group or category of people, but they share a combination of the following characteristics: homelessness, stigmatised (risk) behaviour, low social economic status, social exclusion, illegal judicial status and mobility. Many of them are migrants, are part of an ethnic minority group and are involved in drug use and/or sex work.

The Correlation network links different initiatives, it does not focus on groups or particular situations, but on the overall element: marginalisation and exclusion. The general aim is simple as well as complex: to improve the access to and the quality of services.

To categorize groups into 'target groups', as often done by policy makers or social workers, might cause stigmatisation, especially, if these target groups are described as 'hidden' or 'difficult to reach', rather than to identify the barriers, which prevent access to health and inclusion.

However, to identify and to develop best practices and approaches, it's useful to specify the characteristics of the different groups in first instance separately.

4.2. Drug users

Speaking about drug use and drug users in the context of marginalisation and access to health/health inequalities, means to focus on the adverse consequences of a particular lifestyle regarding social exclusion, barriers to access adequate social and health services, stigmatisation and legal aspects like criminalisation.

Meanwhile, policies in the past were driven by a more moralistic approach, using law enforcement, punishment and obliged drug free treatment to create a "drug free society". ("A Drug Free World—We Can Do It!" The United Nations and the International Drug Control Programme, UNDCP, 1998).

In the last decennia, more pragmatic and harm reduction approaches were developed and applied world-wide and in particular in Europe. Nowadays, harm reduction is an integral part of the European Drug Action Plan (EU drug action plan 2005 – 2009, objective 15) (17) and is – for the first time – officially acknowledged by the United Nation Office Drugs and Crime:

“ ‘Harm reduction’ is often made an unnecessarily controversial issue as if there was a contradiction between prevention and treatment on one hand and reducing the adverse health and social consequences of drug use on the other. This is a false dichotomy. They are complementary.”(Costa, 2008) (18)

An integrated part of the concept of harm reduction is to ‘meet people where they are’, to ‘call for non-judgmental, non-coercive provision of services and resources to people who use drugs, and to the communities where they live and to assist them in reducing drug-related harms. The approach is holistic and ‘client centred’ and aims to empower people, so that they take responsibility for their own life and health.

“While the evidence base for the reduction of drug-related health harms continues to emerge - particularly on the more experimental approaches such as Heroin Prescribing or Consumption Rooms, and delivery in developing countries - there is now ample evidence that the core ‘Harm Reduction’ activities, when implemented in a timely and professional manner, have proved their worth in averting large-scale transmission of infections, and reducing death rates amongst drug users.” (Hunt, Trace, Bewley-Taylor, 2005) (19)

Even if a lot of progress is made, the situation is far from optimal in almost all countries and regions, even in Europe. Still, there is criminalisation because of drug use and the part of drug users in prison is surpassing high¹, there is lack on sufficient services, tailored for particular groups (like drug using sex worker, drug using migrants, youth and recreational drug users), there are unacceptable rates of Hep C, SDI and HIV in many countries, and overdose rates remain high². The involvement of drug users in the political debate and the development of services, devoted to them, is dramatically low.

In the framework of the Correlation network, multi disciplinary expert groups – including service users - worked together on different levels, to contribute to the available knowledge and to test innovative approaches³.

4.3. Sex workers

Sex worker faces, often even more than other marginalised populations, social exclusion, barriers to services, stigmatisation and oppression and in most countries serious legal limitations, resp. criminalisation.

The public debate and national and international policies are currently dominated by addressing the problems of trafficked women in the sex industry. This approach includes the risk to deny and underestimate sex work as a ‘profession of choice’ and to avoid the development of policies and services in order to regulate work conditions and to organize access to health and social services.

In the current situation, sex workers belong to an extremely marginalised and socially excluded group. In case they are using drugs and/or belong to an ethnic minority, they face additional stigmas.

“Sex work is legally ambiguous in virtually every country in Europe. For the most part, selling sex is legal, but many of the activities associated with selling sex are either illegal or subject to license or civil regulation. Individual State governments use a combination of social policy, criminal law and civil law to intervene in sex work. In practice, this means that in all but one Europe country it is legal to exchange sex (or sexual services) for money but different governments use a combination of social policy, law and civic regulations to control how, where, when and in what ways sex can be exchanged for money as well as who can do it.” (Correlation practical guidelines for sex worker, 2008)

Many countries criminalize sex workers or have introduced specific legal regulations, which discriminate and stigmatise women and men, who sell sex, with obvious consequences for their well being. Often, they are denied the right to work in decent working conditions. Besides that, sex workers have to face serious violations of their basic human rights.

1 According to estimates by the United Nations and the World Health Organisation, and to information provided by the EMCDDA's *Reitox national focal points*, drug users are disproportionally over-represented among the 350,000 people imprisoned persons throughout Europe.

2

HIV: Overall positive assessment, but 3 500 new infections among drug injectors in 2005 underline need for continued efforts. Up to 200 000 drug injectors live with HIV. Up to 1 million live with HCV, ‘Europe’s hidden epidemic’. Deaths: Europe risks failing to meet targets to reduce drug-related deaths. Between 7 000 and 8 000 overdose deaths per year, with no downward trend detectable in the most recent data. (EMCDDA, 2007)

3 E.g. snowball action for Russian speaking clients in Helsinki, hr on rave parties in Hungary, internet outreach(see chapters on research, outreach, internet, empowerment, policy debate)

The Parliamentary Assembly of the Council of Europe adopted the following recommendations regarding voluntary prostitution in 2007:

- 1 Refrain from criminalizing and penalising prostitutes and develop programmes to assist prostitutes to leave the profession should they wish to do so.
- 2 Address personal vulnerabilities of prostitutes, such as mental health problems, low self-esteem and childhood neglect or abuse, as well as drug abuse.
- 3 Address structural problems (poverty, political instability/war, gender inequality, differential opportunity, lack of education and training), including in countries from which prostitutes originate, to prevent people being “forced” into prostitution by circumstances.
- 4 Ensure prostitutes have access to and enough independence to impose safe sexual practices on their clients.
- 5 Respect the right of prostitutes who freely choose to work as a prostitute to have a say in any policies on the national, regional and local level concerning them.
- 6 End the abuse of power by the police and other public authorities towards prostitutes by developing special training programmes for them. (Platvoet, 2007) (20)

However, also in countries which legalized prostitution, research shows that this didn't necessarily improve the position of sex workers in society, that sex workers face more health problems than the average population and that the improvement of working conditions and health protection drop behind other economic areas. (Vanweesenbeeck a.o., 2007) (21)

“The current situation in the prostitution field reflects 19th century conditions and relations (...) This has negative consequences for the well-being and the health situation of prostitutes. The prostitutes self are the most important actors in order to improve the situation”, a recent report about the Netherlands suggests. (SOAAIDS, 2007) (22)

A Correlation expert group compiled an update of comprehensive guidelines for delivering health services for sex worker (Gaffney e.o., 2008), addressing the legal situation, adequate approaches and health issues. (23)

Particular attention needs to be paid to the issue of male sex work. In the majority of countries, male sex work is a non-issue, ignored by policy makers, funding agencies and service providers. Male sex workers are confronted with specific problems and various forms of discrimination. The taboo on homosexuality and prostitution leads to particular marginalisation. Experience shows that specific service provision for male sex workers is the exception rather than the rule. (ENMP, 2002) (24) Many services have contact with male sex workers, but do not recognise their specific needs or even acknowledge their identity as sex workers. The perceived small number of boys and young men selling sex to men, and the taboos on male sex work, combined with the difficulties of receiving funding, discourage agencies from developing specific services in this field. Correlation collected models of good practice regarding approaches in the field of male sex work. (www.correlation-net.org)

4.4. (undocumented) Migrants

Ethnic minorities, gypsies, migrants and refugees are at particular risk of poor health status. Their needs often receive insufficient attention, and they cannot always be reached through usual health and welfare channels. This problem is increasing in many countries. (WHO, health 21). (6) If they engage in drug use and/or sell sex, they are facing a double or triple stigma.

“Ethnic minorities and immigrants are identified as disadvantaged in almost every European country. They exhibit lower scores on social inclusion such as employment rates, income in employment, and higher scores in school drop-out rates, homelessness, financial exclusion and criminal propensity. The European Union strives to increase the labour market participation of immigrants and ethnic minorities to the same level as the majority population, and to promote their participation in social, cultural and political life. The precarious situation of Roma is tackled accordingly in all countries where they reside.” (European Commission, 2008) (25)

Although many national health systems acknowledge the importance of including programmes for and with migrants in their health action plans, and the European Union has set up comprehensive programmes for social integration and equal opportunities, there are still striking discrepancies between laws and regulations and the entitlement of migrants to access services on the one hand, and the reality of the accessibility of these services on the other. Many examples which are addressed by the Correlation expert group ‘migrants’

highlighted this gap between theoretical service delivery and real life. In particular, social groups that face double stigma (such as migrant drug users, migrant sex workers, or migrants living with HIV) are exposed to considerable health risks. Inadequate and culturally insensitive health and social services contribute to the vicious circle of marginalisation, which is fuelled by language barriers, a lack of transcultural competence and the absence of political interest and support. The latter is especially significant, as it is often necessary to act against mainstream public opinion in order to break the circle of marginalisation and to allocate sufficient financial and professional support for suitably-tailored service delivery. (Correlation, 2008) (26)

During the Correlation conference in Sofia in September 2007, several major workshop were dedicated to the particular topic of migration. Correlation supported a statement with community recommendations on migration and HIV, to be launched on several major conferences in 2007/2008. "Strategies to address the health needs of marginalised groups including undocumented migrants, migrant IDUs, migrant transgender people, migrant PLWHA, migrant sex workers and incarcerated migrants should be integrated into public health strategies and action plans at local, national and international levels." Towards community members, the statement recommends: "Community representatives should engage in the policy making process, promote their community agendas to higher political levels, contribute to research efforts and promote non-discriminatory coverage in the media." (EATG, 2007) (27)

4.5. Youth at risk

The term 'youth at risk' is used for a broad range of possible risk factors regarding social exclusion and health for young people between 16 and 24 years, like the socio-economic status, environment, friends, family situation, behavioural problems, physical or mental health and violence.

In the framework of the Correlation network, an expert group focused on a particular phenomenon of the youth culture: drugs and the party scene. Inadequate policies (e.g. criminalisation of young, experimental drug consumers), the lack of appropriate services and prevention measures in this particular scene can have negative consequences for the prevalence of drug use of young people and consequently for their well-being and social inclusion, even if experimenting with drugs is often associated with brief periods in an individual life and only a small minority of experimental drug user face serious problems with drugs later on.

"Drug use and the recreational activities of young people have been linked ever since the concept of youth culture emerged in the 1960s. Research over the past two decades has shown that the prevalence of drug use in dance music settings is significantly greater than in the general population. The emergence of the electronic dance music scene in parts of Europe during the late 1980s and 1990s brought with it an increase in the availability and consumption of 'dance drugs' such as ecstasy (MDMA) and amphetamines". (EMCDDA, 2007) (28)

Correlation stimulated the implementation of a comprehensive campaign in the party scene in Budapest, Hungary. Budapest has a significant number of Hungarian party goers, while at the same time, Hungary is one of the top destinations for young European party goers during the summer. The developed model is expected to be adjustable for other regions and countries and to give insides in effective approaches in comparable settings. It took into account negative experiences regarding media attention, business interests, police appearance, policy approach.

"The aims of the CRITICALEX.HU campaign were to help accept and strengthen the diffusion of services that facilitate safer partying in the Budapest party scene by addressing and uniting political decision makers with party visitors and party organizers. During the campaign we have considered the specific ways of functioning of the different party scenes, while working out a strategy that can deal with the stigmatisation of commercial media, the business interests and limits of governmental competency. We could involve the party organizers with the support of opinion shapers and the municipalities, which is a benchmark of the competency and legitimacy of PS like services. Avoiding mass media proved to be useful, as we could successfully negotiate without pointing the fingers at the responsible bodies in a TV news or criminology broadcast. Messages of the CRITICALEX.HU campaign did not cross the frames of the previously set target audience, which shows that we can turn a sensitive issue towards visibility and changeability without offending participants interests.

Successfulness of the CRITICALEX.HU campaign will be measurable by the appearance and integration of further viable models and later by how these programs can further help new developing programs."(Varga a.o., 2008) (29)

5. Improving access to health and improvement of health services: Examples from the practice

5.1. General: exchange, multidisciplinary approach, skills building

As outlined in the chapters before, marginalisation is a complex problem, which includes socio-economic developments, national and international policy strategies and human rights. Health inequalities and barriers to access to health are in particular interrelated with socio-economic factors. The improvement of social and health services (in terms of methodologies, approaches and taking into account the special needs of those in the margin) can contribute a lot to change the situation. Almost all national and international strategies in this sector are referring to these factors, suggesting and implementing programmes on all levels of society.

“The most successful projects (...) seem to be those that address both physical and psychological issues, involve and empower people and develop linkages between different actors and policy sectors”, a report of Euro Health Net on health and social inclusion resumes. (Stegemann, 2005) (30)

Correlation – Network of Social Inclusion and Health works with a multidisciplinary approach, bringing together researchers, service providers, grass root and self-help organisations and policy makers from different areas. Summarizing the first project period 2005 – 2008, evaluation shows that there is substantial added value to learn from each other experiences and knowledge: 98 % of all involved experts agreed with this statement (Final report, 2008). Researchers on methods of data collection were able to discuss their tools with service providers; internet experts discussed how advanced outreach methods through the internet in the sex industry could be used for drug users and homeless people; empowerment strategies of drug users were discussed and compared with the ones of sex workers; strategies to improve policies and to make voices heard were exchanged between sex workers, drug users, migrant experts and policy makers.

Based on the general network aims – to change experiences and knowledge, to collect and gather data, to provide and to disseminate results – concrete innovative actions were carried out. Examples from various Correlation expert groups, like data collection, outreach and internet, were described as models of good practice. The aspects of empowerment and policy debate are discussed in chapter 8 and 9. (for all Correlation results please visit www.correlation-net.org)

5.2. Data collection

To increase drug users' access to services that help prevent and reduce drug-related harm is an important objective in public health policy within the European Union (EU drug strategy 2005-2012). Within a comprehensive, state-of-the-art system of care for drug users, low-threshold agencies play the most important role for increasing drug users' access to care. These agencies are not only important entry points for establishing contacts with populations of drug users that are not in touch with the care system, but are also an essential service delivery setting, where drug users benefit from basic health and social care services.

Although all agencies have systems for monitoring types and level of service delivery in place, reporting is mainly oriented towards accountability to funding bodies and not used as tool for internal quality management or towards service planning and evaluation at national level.

The measurement of extent, availability and coverage of harm reduction service delivery is complicated by the fact that data collection tools are usually not standardised, even though very similar datasets are collected. As harm reduction funding typically comes from local budgets, data-flow does often not go beyond this level, which makes it complicated to obtain a reliable overview at national and subsequently also European level. (Hedrich, 2005) (31)

At European level, information on the provision of harm reduction services is collected by the EMCDDA through its network of National Focal Points (NFPs), who report on an annual basis about harm reduction policies and provision of services. The analysis of the information provided by NFPs showed that in many countries, these specialised national level bodies had little access to data and where such data were available, they were difficult to interpret, as data collection procedures were not standardised.

In the framework of the Correlation network, an expert group under lead of the EMCDDA developed a draft European data collection protocol for standardised annual reporting of service delivery, structure and functioning of agencies delivering harm reduction services.

The logical framework for the project specifies its overall goal as 'to contribute to increasing reliability and comparability of information on harm reduction service provision in Europe'.

The protocol consists of the agency inventory, of a technical manual providing definitions and instructions with regard to how to fill out this inventory, and of the reporting sheets for the field test. The inventory aims to describe the profiles of the agencies, their scope of service provision, staffing, management and functioning. If implemented at national scale, such inventories could be used to characterise the harm reduction philosophy, activities and their geographical distribution. The different options for monitoring service provision are described and the respective data reporting sheets provided. The field test addresses the comprehensiveness and relevance of the 'agency inventory' for documenting service provision and the feasibility of different methods to monitor the utilisation of core-services.

"Outreach workers have, from our point of view, the responsibility to collect data in a rigorous and systematic way about the drug phenomenon changes over time, their clients' needs, the services provided and their clients' opinions about them (...) In fact, outreach harm reduction projects are very often the only professional way to get in a proximal, consistent and generalized contact with drug users and sexual workers and their daily life and sexual/drug consumption behaviours. That's why we share the opinion that outreach teams should systematically collect data regarding their work monitoring and evaluation. The analysis of this material would certainly contribute to fieldwork optimisation and to prevent more effectively the consequences of risky practices linked to drug use and sexual activity in an action-research logic.

This procedure is not only important for the individual teams which adopt it but also to all those who work in the harm reduction ground: if we use common tools we can learn a lot more about good practices, clients needs and drug phenomenon. That way it will be possible to empower the generalized implementation of more effective interventions in the field reducing more and more the risks connected with psychoactive substances consumption. Northern Portuguese harm reduction workers are linked through a network – R3 – and its members are very worried with the fact that the data collection in each project is not truly comparable with each other. We've been, for that reason, working on a common tool to share in the future, having in mind the analysis of the common data every year giving birth to a kind grounded observatory for drug consumption in the streets and, in the other hand, for outreach Portuguese northern interventions." (Pinto, 2007) (32)

5.3. Outreach ⁴

"Outreach work is a way of contacting and working with marginalised groups and can be done amongst any target group. The method is useful with all excluded groups of people that might benefit from services. Most commonly, outreach work is carried out amongst marginalized groups of people such as drug users, homeless, youth at risk and sex workers." (Mikkonen e.o., 2007).(35)

The main aim of outreach work is to design more accessible social and health care services for people in need, those who otherwise would not be able to use or benefit from the society's care system. It has a preventive working approach as it is at the front line of services. Therefore it has to be responsive, flexible and innovative in its approach. It employs harm reduction measures combined with early intervention work and provides means to gain contact with groups at risks, prior to their issues (such as drug use) have become problematic. Acting at grass root level, it is also an important tool to signal new trends (e.g. new drugs) and to respond to new developments (e.g. internet outreach).

The main reasons to provide outreach are:

- existing services are not reaching the target group effectively
- existing services are not offering interventions based on target groups needs

The WHO states that "The provision of outreach (...) can improve the health of people living in poverty. Outreach services are particularly important for reaching vulnerable groups, such as the elderly, ethnic minorities, etc. who may not be aware of how to access the support they need or may be hindered from using such services by social, psychological, or even physical barriers." (WHO, 2006) (36)

However, focus should be to adjust services to the needs of the particular target groups rather than to fit target

4 based on the findings of the Correlation expert group on Outreach, 2007

groups to existing services.

The Correlation expert group describes in their report: “The main principle in outreach work is that the (e.g. social or health) services are taken to the target group’s own environment. Outreach work appears at many levels and in different connections. It exists in between primary prevention measures and treatment programmes. Outreach work provides direct, flexible and responsive services, including education and preventative services. Delivering the services directly to the target group means, that the work is done in the places, where people spend their time: when working with women involved in prostitution, this means for example restaurants, massage parlours and streets.”

Besides offering services for hard to reach groups, outreach work is also an important tool for gathering information and knowledge about the target group’s living conditions, needs and perceptions of services. An important aim is to involve the target group actively in the process of designing policy, which is concerning them.

“The knowledge gathered through outreach work is valuable and it should be utilised to advance the rights of people living in the margins of our society both in local and national political level and also in international collaborative networks.” (Correlation, 2007, page 13)

To provide evidence on effectiveness and needs, proper data collection have to be an integrated method of outreach work, the European Monitoring centre developed a guideline for this purpose. (37)

The expert group highlights the strong ethical guidelines, which should be taken into account by outreach services: e.g. the human rights and human dignity concept, the right of autonomously and self determination.

An integrated approach of most outreach activities is the involvement of peer supporter and peer educators (definitions see Rhodes, 1996) (38)

“Peer support in the field of harm reduction is based on the idea that peer workers can act responsibly and as important information distributors and support mentors, even if they themselves use drugs or work in the sex work industry. Peer workers belong to the target group, for whom the support organisation offers services. The strength of peer activity lies in the similar lifestyles of the peer workers and the people they are helping. Peer workers can ultimately change attitudes, habits and beliefs in their own social networks. Peer workers have the unique opportunity of getting involved in those concrete, daily situations, in which the target group lives. Peer workers can also reach those people who do not for some reason or another join the service organisation” the Correlation guidelines explain.(35)

The Finish Correlation partner A Klinikka implemented with support of the Correlation network a peer training in a multi-cultural environment, using the snowball method. The final report provides both theoretical background and practical experiences and results of peer support and peer training. (Puro e.o., 2006) (39)

5.4. Internet

Information and communication technologies (ICTs) are central to modern life. They are increasingly used at work, in day-to-day relationships, to access everything from public services to culture and entertainment, and for community and political participation.

“While Information & Communication Technologies (ICTs) can reinforce social inclusion, offering new opportunities for many people currently excluded from today’s society, we must make them accessible to everyone if we are to avoid creating a new divide between the “digital haves” and “have nots”. The most excluded groups are therefore the elderly, the unemployed and those with a low level of education. In addition, only 3% of public web sites fully comply with web accessibility standards, creating additional hurdles for the 15% of the EU population with disabilities ” writes the European Commission on its web portal on ‘information society’. (40)

Online venues are becoming one of the preferred locations for many groups and subgroups, who face problems in the public sphere (e.g.youth at risk, sex worker)Therefore, an increasing number of service providers would like to approach their target group directly through the internet. However, many services seem to lack financial resources as well as the knowledge, which will enable them to contact their target group appropriate. What to do when you meet a homeless kid in Second life?

A few small agencies have already started Internet outreach in several European countries. Boysproject and Adzon in Belgium started an experiment with internet outreach, targeting male sexworkers. The Working Men’s

Project in the UK and the Foundation Regenboog Amoc in the Netherlands started as one of the pioneers with virtual outreach for male sex workers. Guidelines, protocols, new methods and strategies were developed, because of the specific nature of Internet-based HIV/STI prevention. Some initiatives seem to have very good outreach results among sex workers, among gay men and among young people in specific risk situations. But online initiatives are not always harmless as wrong strategies can harm the whole professional group of health and social workers.

A Correlation expert group developed a cd rom with rules and recommendations on how to approach and organize e-health, e-counselling and e-outreach. This tool is integrated into the European 'e-Inclusion – be part of it' campaign. In one of their recommendations, the experts state: "Besides the importance of cooperation with other (commercial and non-commercial) services, cooperation with your service users is important. Cooperation with peers or grassroots organisations is essential to get to know the World Wide Web. They know the newest venues, the popularity and the reliability of the web and they know their own virtual community better than anyone else. Working with peers is very important when you are even starting to think about e-Outreach. They can be your virtual guide and will keep you updated." (Vriens, 2007) (41)

6. Policy debate - Making voices heard

Health and social services have the task to support marginalized populations. But grass root professionals, service providers and interest groups often feel unable to meet the needs of their target group. They have limited resources, practical restrictions and they have to operate in a changing political climate. Issues like social inclusion and health promotion for marginalized populations have little priority and look subordinate to issues like maintaining public order. The actual policies don't seem to support what they intend to do. Policy-makers are often unaware of the situation on the street and the actual implications of their efforts. Policy-makers seldom have direct communication with grass root organizations and have often inadequate information on the actual situation of specific populations. So they develop policy in a one sided setting that is often dominated by political demands. Exchange of information and communication between both service providers, policy makers and the target group is vital but is practically lacking

All actors feel isolated on their side of the fence. The target group doesn't have the access to policy-makers, while service providers have limited tools and structures to bridge the gap between the target group and policy-makers.

The general objective of the policy debate expert group within the Correlation network is to stimulate and support the development of adequate, comprehensive national policies on social inclusion and health promotion among marginalized population, by providing a platform dialogue with policy makers, service providers and interest groups.

On a Correlation Policy seminar in Dublin in 2006, researchers, service providers, service users and sex workers activists, drug user and migrant organisations came together with national and international policy makers⁵ to discuss integral effective ways for policy making towards marginalised populations.

The following elements were identified as most important:

- International standards
- Involvement of all relevant players
- Involvement of Media
- State of empowerment of marginalised populations
- Effectiveness of interventions/campaign
- Timing
- Size of affected population
- Relevance/urgency to find a solution to the problem
- Quality of data provided to support arguments for change

Another seminar addressed the importance of monitoring and evaluation and methods for lobbying and

5 Policy makers from Ireland, the Netherlands, Czech Republic, Hungary and the Pompidou group, Red Cross

advocacy6 (Correlation seminar report, Mainline, 2007).

“The Relevance of Research and Evaluation for Policy-Making might rise in the last decade, however, evidence base does not necessary lead to policy commitment, adaptation or change. It is recommended to involve policy makers as much as possible into research tailoring and evaluation and as key informers in the research process.” (Verbraeck, 2006) (33)

Correlation initiated a study in order to contribute to the access to social and health services for marginalized people by stimulating the political debate and the empowerment of service users. The study was conducted in four European countries – Bulgaria, Hungary, the Netherlands and Slovenia - and focused on ‘access & impact of health and social services and client satisfaction’. The whole process (to develop and carry out the study with strong involvement of service users and the organisation of policy debates) can function as model of good practice and will contribute to an advocacy toolkit on that matter. It will also function as a pilot and try out with the potential to develop it to a pan-European research on that issue in the future.

Concrete results from the research in the particular countries, resulting in policy recommendations and guidelines for agencies on how to organise research and a related policy debate are currently in the final stage of editing and will be presented and disseminated by the network in April 2008. (34)

7. Empowerment

The term ‘empowerment’ has become popular in the public debate on integration of excluded populations, often combined with the terms ‘participation’, ‘social inclusion’, ‘influencing policy’ and also in the context of health inequalities and health literacy. However, empowerment often has different meanings and is used in the most diverse settings.

“Empowerment is a multi-dimensional social process that helps people gain control over their own lives. It is a process that fosters power (that is, the capacity to implement) in people, for use in their own lives, their communities, and in their society, by acting on issues that they define as important... Empowerment is multi-dimensional, social, and a process. It is multi-dimensional in that it occurs within sociological, psychological, economic, and other dimensions. Empowerment also occurs at various levels, such as individual, group, and community. Empowerment, by definition, is a social process, since it occurs in relationship to others. Empowerment is a process that is similar to a path or journey, one that develops as we work through it. Other aspects of empowerment may vary according to the specific context and people involved, but these remain constant. In addition, one important implication of this definition of empowerment is that the individual and community are fundamentally connected.” (N. Page, C. Czuba, 1999) (42)

There is an increasing number of programmes targeting sex workers, drug users and ethnic minorities using empowerment strategies on different levels: individually, at organisational and community levels, but also in the area of political programmes and services. However, it cannot be seen as an isolated strategy. To overcome exclusion and barriers to access to health, it should be part of a comprehensive approach in order to change structural and legal provisions. Involvement in decision making and participation in all phases of planning, implementation and evaluation should be an integral part of empowerment strategies.

The Health Evidence Network, coordinated by WHO Europe, concludes in a review on evidence of effectiveness of empowerment to improve health: “In the light of the evidence and other information, empowerment strategies are promising in working with socially excluded populations. While participatory processes are the base of empowerment, participation alone is insufficient if strategies don’t also build capacity to challenge non-responsive or oppressive institutions and to redress power imbalance (...) The most effective empowerment strategies are those that build on and reinforce authentic participation ensuring autonomy in decision-making, sense of community and local bonding, and psychological empowerment of the community members themselves”. (Wallerstein, 2006) (43)

An important stipulation for successful empowerment processes is the fact, that empowerment ‘cannot be given’ by service providers or authorities. They can support and stimulate empowerment processes and provide ‘supporting spaces’, but initial actions have to be delivered by the people in charge themselves. A report of the process of empowerment of people who use illicit drugs in Vancouver states: “The empowerment process can be enhanced with funding and individual advocacy, but unless real control over valued community resources are handed over to users the empowerment process fails (...) We believe that users have as much capacity as the experts on drug use to assess their own needs” (Livingston, 1996) (44)

“Their personal involvement and their contribution represent a social capital that is either unrecognised or totally

underestimated but which however is worth counting on” concludes a Correlation report on that issue. The report addresses the need for a consultancy process of drug users at European level, the advantages of focus groups and peer support intervention at local level: “what best unites the experiences of empowerment in peer support between problematic heroin users is the trajectory of the life experienced: from the phenomenon and the marginalized practices of a stigmatised group to becoming resources for the local community; from unsatisfied and quarrelling clients to integral partners in a social and cultural movement.” (Grosso, 2007) (45)

The Scottish Drug Forum developed a model which focuses on social peer research to improve the quality of specialist drug services. “User Involvement volunteers are clear on why they have been recruited and what the purpose of the project is. Too often user groups are created and supported because ‘user involvement’ is perceived as a good thing to do – or be seen to be doing – and their work has no clear objective or direction.” (Lidell, Brand, 2007) (45)

The improvement of participation and empowerment on all possible levels is an integral element of all activities of the Correlation network. The aim is to integrate grass root organisations, peer and self help groups into conceptual debates and decisions, into the implementation of activities and the evaluation of results and to bottom up experiences from the street to policy level. Experiences showed, that this approach is complex and time consuming, so again rather a process than a fact. However, the network organised seminars and policy debates on that issue⁷ together with sex worker, drug user and migrant representatives, it supported the creation of an European drug user organisation and an European parent and relative alliance of drug users⁸ and implemented service user focus groups in nine different environments. In a reader on empowerment, experiences of the environment of drug user union are addressed. (Correlation, 2008) (45)

A survey, carried out by Correlation, collected information about existing self-organisation among drug users: “The main benefit from this research is that it shows that the profile of Drug User Organisations (DUO) world-wide (and the profile of the Drug User activist (DUA) that run the DUO) completely differs from the general image of drug users that has been imposed on society for decades. The research showed that DUO are capable of running a variety of services and have proved themselves to decision makers in their countries as reliable and capable partners and as an indispensable part of civil society. The next logical and inevitable step would be to develop and expand newly founded DUO unions and networks at international level, and proving decision-makers from all international institutions involved, that DUO should be considered not only as competent and equal partners, but also as indispensable experts in the drug-policy making process.” (Goossens, 2007) (45)

8. Conclusions

As shown in the different chapters of this articles, tackling the problems in regard to marginalisation, social inclusion and health is a broad, global and complex process with involvement of many stakeholders. Issues as human rights, major socio-economic developments, political climate and other aspects need to be taken into account. As mentioned before, many high level policy declarations, treaties and charters, programmes, projects and activities have been developed in the last decennia, a lot of research has been done, and there is sufficient evidence for adequate approaches.

On the other hand, major policy and economic developments like globalisation might cause more harm and disadvantages for people living in the margin. Therefore, efforts at local, national and international levels have to be continuously maintained and strengthened, in order to close the gap of (health) inequalities, to reduce stigmatisation and criminalisation and to include all members of a society. Human rights and the respect of human dignity and self determination should hereby play an essential role.

Therefore, integrated, multidisciplinary and holistic approaches, taking into account available evidence have the highest chance to make a difference and to have sustainable results in improving social inclusion and health for marginalised groups and populations.

Effective advocacy and lobbying strategies should be developed and continuously be improved in order

7 Correlation Empowerment seminar, Gruppo Abele, November 2006) , www.correlation-net.org

8 (see www.inpud.org <http://www.correlation-net.org/efdu/index.html>)

to influence the political debate and decision-making processes, with a strong focus on facilitating the empowerment and involvement of the people in charge to enable them to 'get their voices heard'.

So far, the network was able to contribute a little, tiny piece to the mosaic of knowledge and action in this field, due to the engagement and enthusiasm of hundreds of colleagues, experts, professionals, activists and policy makers all over Europe.

The positioning of the Correlation network in the broader field of other stakeholders, other networks and activities in order to provide added value, seems to require in the future:

- To stimulate innovative, multidisciplinary approaches, combining experiences from different fields
- o stimulate and to support the involvement and empowerment of the people in charge on all levels
- To transfer and to upgrade grass root initiatives to a policy level, taking into account the newest evidence base.

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