

European Network of Homeless Health Workers (ENHW)



Issue N°13 – Spring 2011

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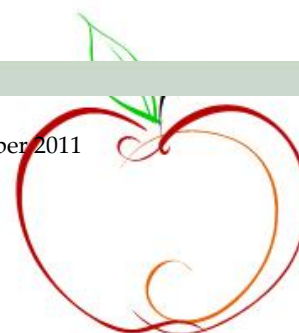
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Stefania Del Zotto, Policy Officer, FEANTSA

Dear Readers,

I am pleased to share with you the latest edition of the ENHW newsletter, which covers a wide range of topics. Articles include: the account of a woman's first hand experience and further research into the subject, which shows that "standard" services are one among many paths out of homelessness and alcoholism; findings and recommendations stemming from a study carried out in Barcelona on access to health services for people who are homeless; the results of research on undocumented children's access to emergency healthcare in the Netherlands, which highlights the need for better information sharing; an article on cross-sectoral working methods in the area of mental health and social exclusion in Belgium (in French); and an overview of a European project, of which the focus was ethics in the context of data collection by healthcare professionals.

In the resource section, you will find information on recent FEANTSA health-related papers; EWL's gendered analysis of poverty and social exclusion, as well as their position on women's health and violence against women; links towards a number of national and European resources of interest devoted to subjects ranging from tuberculosis, the impact of the crisis on mental health, Europeans' opinion on domestic violence or the consequences of increased cost sharing on access to healthcare for homeless patients in Germany; as well as information on relevant calls for proposals at EU level.

I would like to extend my warmest thanks to everyone who has contributed to the current issue and hope that it will stimulate further reflection and interaction.

For your information, this is the last edition of the ENHW newsletter that I edit. The time has come for me to take up new challenges and I will be leaving FEANTSA's office at the end of April 2011. My colleague Dalma Fabian, who is currently Housing Rights Watch Project Officer, will be taking over the health and social protection strand of FEANTSA's work in May, including coordination of the ENHW. Please do not hesitate to send her your comments, questions and contributions for the next issue of the newsletter at dalma.fabian@feantsa.org.

Let me take this opportunity to thank you for the cooperation and wish you and ENHW all the best for the future!

Sharing Experiences

There are many ways to recover from alcoholism

Dr. Patsy Staddon,

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There was a time when a feeling of worthlessness was my constant companion as I drifted from place to place, home to home, from house to flat to bedsit to squat to boarded-up basement. I did not lose hope that life would get better but I did lose the will to make significant changes. People think that if you have lost your job you at least have time on your hands, but they should try getting together a home, a safe place, no matter how small, with your own things in it, some way of keeping clean and organising and protecting your possessions, and at

the same time struggling to find the money to pay for bare essentials. Being homeless is a full-time occupation, even for those who manage not to use

substances to help, and even for those who do not have mental health issues.

It may sound strange but homeless was not a word I would have used. I always felt that this place was home, for as long as I stayed in it, and I was always upset when my 'tenancy' came to an end. The possessions I had with me, at first including furniture but later reduced to carrier bags, constituted 'home'. Today I cannot rid myself of pain whenever I see someone in a doorway with carrier bags; some of me still seems to belong there.

My road to life in a derelict basement was not an unusual one, as I now know. I used to self-medicate my depressions with alcohol, and this unfortunate combination eventually cost me my home, my husband and my children, as well as my job. There was never enough money at the end of the month to pay the rent and the bills because I had drunk it. I always thought things would somehow get better, and I left stuff with family and friends, to collect in the future (I thought, next month, but often it was never) while I went from job to job and town to town. After about ten years of this I started going to Alcoholics Anonymous (AA) where I met some really kind people and some who were far from kind, but I never felt I belonged. What they seemed to be saying was, do as we do, and then you will be able to live an ordinary life. But I did not want a life like theirs. I wanted excitement, challenges. I wanted to be myself, and at that time, I felt I frequently needed large amounts of alcohol to achieve that. I was often frightened, lonely and injured, but for me, any safety I found soon felt like a prison. AA did not provide the answers for me.

I was eventually befriended by two women who were dismayed at my basement 'apartment', and the extent of my injuries—I used to get beaten up a lot, but I also had a lot of accidents when I was drunk. They took me home with them and gave me their living room as a bed-sit. They did not ask me to stop drinking but instead took me with them to feminist political meetings, to lesbian clubs and pubs, and to women's discussion groups. To me, what was new was the way that no-one seemed bothered when I got drunk—not because they were big drinkers themselves, but because they did not have the idea that 'ladies' did not behave in that way. So shame stopped being a factor, I thought less and less about alcohol, and more and more about inequality and injustice. I had safety and friends but I also had freedom. What had changed was that I had stopped seeing my problems as being unique, and to do with my uselessness, and instead could see the many factors which combine to make some sorts of people (most women, many disabled people, many BME people) feel worthless. Then the day came when I decided (after very many years of problem drinking) I would stop drinking. I had had enough of scrounging from friends, losing my things, and being seen as worthless. I knew I was not worthless and I intended to prove it. I was 44.

I was in poor shape physically so after a couple of weeks I went to see a GP, who at once suggested a local treatment centre, assuring me I would start drinking again if I did not go. The centre provided a useful space to reflect, and to do things like painting, but the ideas that were presented, very strongly and didactically, by staff and service users alike, were quite different from those which had been helping me to recover. For example, in treatment I was expected to feel shame and remorse. I was to consider how I could make reparation. However I had come to recover by seeing external factors as being at least contributory to my downward path, and this awareness was what had given me the strength, and the anger, I needed to pull myself out. I was indeed sorry people I loved had been hurt, but blaming myself helped no-one. Another mistaken piece of ideology I was given was to avoid the places I had once drunk, even being told to cross the road when I saw a pub. But as a lesbian woman my social life was lived in pubs and clubs, and if I had followed this advice I would have been lonely indeed. This was a failure in the services to take into account different social mores. Perhaps it is true that men tease each other if they do not drink alcohol but this may not be the case for women. I have not been pressed to use alcohol even once.

Like many others I know, I seldom spoke out at that time, for fear of ridicule or worse. The treatment centre made extensive use of the powerful AA organisation to back up what it said. They ran groups on the premises and we were advised to attend not less than one a day. The overwhelming sense was that we were sinners but on probation. Disapproval is a powerful weapon; it often feels safer to keep quiet and get on with your life. However I was to find later, when my academic research involved me in private interviews with a wide range of women, that the majority had felt similarly disempowered by 'treatment' that emphasised the shame they already felt, rather than helping them to understand how they had reached this position in the first place. Such treatment has insufficient regard for individuals' differences and needs.

Along my road to full (now 23 years) recovery, most helpful to me was having access to a variety of spaces and people—friends I talked to, but also one alcohol counsellor who was prepared not to talk about alcohol but about how I could show my

children I was not a disgusting person. There were the keep-fit classes I joined as soon as I was strong enough, the painting group, the walk around England's coastal paths, and the continual stimulation of discussion and argument in local women's groups.

Nowadays, when I am talking to women who have or have had alcohol issues, we talk about tool-kits, where you keep a list of the different things that make you feel better, less unhappy, perhaps less like needing a drink. These can be very small things, like making yourself a hot drink, phoning someone, writing down what you will do tomorrow. But ideally the lists are varied and include action, reflection and interaction, which help very much in changing mood. One to one, same sex, non-judgmental support, which focuses on how one's life may be made happier and more fulfilling, seems to help more than anything. This was the case for me in my derelict basement and I have every reason to believe it is still the case today.

* Patsy Staddon was awarded a doctorate at the University of Plymouth in 2009, her PhD thesis was titled: 'Making Whoopee? An exploration of understandings and responses around women's alcohol use'. Findings are still in the process of publication. Other publications:

- Staddon, P. (forthcoming) 'Service user led research in the NHS: wasting our time?' *Critical Perspectives on User Involvement*, Barnes, M. and Cotterell, P. Polity Press;
- Staddon, P. (2011) 'No blame, no shame: towards a social model of alcohol dependency - a story from emancipatory research,' *Social Care, Service Users and User Involvement: Building on Research*, Carr, S. and Beresford, P., Jessica Kingsley Publishers.
- Staddon, Patsy. (2005) 'Labelling Out', in special issue of *Journal of Lesbian Studies*, 2005, vol.9, Issue 3. pp. 69-78. Also co-published in *Making Lesbians visible in the substance use field*, ed. Elizabeth Ettorre. New York: Haworth Press (ISBN-13:978-1-56023-616-0).

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Homeless population in Barcelona: profiles, health situation and access to health care services

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This article is a brief summary of a study the authors published in 2009 (see references at the end of the article).

According to the diagnostic counting carried out the night of the 12 March of 2008, there are approximately 1900 homeless people in Barcelona city in a day. The variation estimated for the whole year is of up to 3000 persons. We launched a study on the health situation of people who are homeless in Barcelona using an adapted ESCA (Survey of Health of Catalonia), with a sample of 611 polled persons.

The results give us a profile according to which 87,7% are men, and 12,3%, women. According to the place of birth, more than half is no Spanish (50,7%). A 28,1% was born in towns of Catalonia:

22,7% people who was born in Barcelona, and 5,4% in other places of Catalonia. 21,2% comes from different provinces of Spain. The average age is 44,5 years old and lives and spends the majority of their time in the street. Taking as a basis the place where they live, it is ascertained that 32,9% lives and sleeps in the street; 26,7% in night shelters; 26% in residences for homeless, 8,3% in temporary structure or non-conventional buildings and 5,6% at friends or accommodations in flats for social inclusion. The majority have been in that situation from less than 6 months (27,6%) to less than 3 years (46,9%), while 25,9% have been homeless for more than 3 years.

In the study we analysed three areas related to the health of the homeless people in Barcelona:

- their health
- their health perception
- the health care services they received.

We have ascertained that none of the three coincide: the health situation of people who are homeless is worse than what they said in the survey, but the services they receive is below their needs.

We would like to highlight the following research results:

- 79,2% of homeless people has chronic disorders -from one to three, and more than three-: among men the prevalence is of 77,9% and among women of 87%.
- There is a close relationship between morbidity / chronic disorders and time spent in homeless situation.
- The illnesses or more frequent disorders are: the muscle skeletal (67,6%); cardiovascular (57,2%); mental morbidity (49,1%). Drug addiction -alcoholism (28%) and other drugs (18,2%)- follow.
- About mental morbidity-stress, anxiety, anxiety and fear-, and, too, about the neurological chronic illnesses and muscle skeletal chronic illnesses, evidence shows the close relationship between not having a home and the quality and number of effective times of sleep. Given that, it seems that the situation of homelessness facilitates the increase of the mental morbidity and consequently, the mental illness. Neurological and muscle skeletal illnesses too.
- The mental morbidity is the disorder that is addressed most frequently, especially through the use of medicines to lighten the insomnia.
- Relating to morbidity, use of medication and health services, it appears that usually there is a lack of correspondence between morbidity and treatment. Also, the homeless population usually access health care services in a situation of emergency -critical or of risk -, and not at a stage of medical treatment or prevention.
- 77,8% of the persons with diagnosis of cardiovascular chronic illness is not treated for that condition.
- 50,5% of the total number of homeless persons with chronic musco-skeletal disorders (255 persons), does not receive the pharmacological treatment prescribed by the doctor.
- 45% and 35,7% of the persons that need medication for, respectively, HIV/SIDA and for diabetes, stated that they do not take the medication.
- Only 31% of the total number of homeless persons has been visited by a health care or socio-sanitary professional and had to wait for an average of four days. It is necessary to relativize this average, as it includes visits in situation of emergency, which are very

numerous. Without them the average waiting time would be much higher.

- Finally, it is necessary to insist on the concept of "inequality in health": the risks or vulnerability that some groups of the population are faced with, especially in the use of services or in terms of health care coverage, shows that homeless people have to face severe situations of inequality in relation with severe implications affecting their health expectations, and possibility survival.

Proposals

Below you will find the most relevant proposals from the report:

1. The right to the health can't be dissociated from housing, a decent work and income. It is necessary to have determined policies on the subject of accommodation for everyone in the homeless population. Without stability, it seems impossible for people to access social and in particular in health services on a continuity basis,. It should not be forgotten those suffering from mental health problems. We refer to transversal policies about housing, work, health and social activation.
2. The health care system should be more accessible to homeless people, and it should facilitate access to programs of prevention and of rehabilitation. We suggest the idea that to do so additional actions with respect to those that are implemented with the general population.
3. It would be convenient to revise or to implement the channels and necessary protocols to correct the divergence among the morbidity of the study's target group and the health care they receive, also during medical treatment.
4. Also we suggest concrete protocols, with the aim to resolving and/or addressing some of the problems, which have been identified:
 - The research of common issues in the area of health, in the context of specific policies, goals, conditions and specific interests, and in the social activation area, to allow for a common language, goals and work with homeless people.
 - The possibilities of the integration of the primary health care provision as a natural

and efficient door of entry into the medical treatment for homeless.

- Discharge from emergency services for people who are homeless: coordination between health and social services to give continuity to the medical work.
 - A work based on the personal story and path of the person taken care of: only one clinical/social history of the person, independent from the moment, the organization or institution and the area (social or of health).
 - The follow-up of the person by only one professional acting as a case manager.
5. The health area needs an external ally that, due to the health situation of the person and his/her personal context, backs up the person in his/her health needs. Because of that, it is necessary to guarantee formally ways to improve the cooperation among the set of entities, institutions and organizations, and coordination in the medical treatment follow-up of cases. Also, it is necessary to harmonise criteria or protocols of care and follow up, as unified data bases, among others. Let's not refer only to the entities and organizations of

the social area: also, and especially, there is a need for a basic formal link and coordination between the social and the health services, that allows for the treatment and follow-up to operate with the same possibility of success than for the general population.

References

- "Les persones en situació de sense llar de Barcelona: perfils, estat de salut i atenció sanitària"; Uribe, J., Alonso, S.; Fundació Jaume Bofill, 2009, Barcelona. The book is available in Catalan at: <http://www.fbofill.cat/index.php?codmenu=11&publicacio=507&submenu=false&SC=12012007040643&titol=&autor=&ordenat=&tags=>.
- The book has been translated into Spanish as: Personas en situación de sin hogar en Barcelona: Perfiles, estado de salud y atención sanitaria; Uribe, J., Alonso, S.; Labor Hospitalaria, núm. 295-296, monográfico, 2010, Barcelona.

* For further information or if you would like to receive the Spanish PDF version of the study, please write to Joan Uribe: juribe@ohsjd.es.

Results of a study on undocumented children and access to emergency healthcare in the Netherlands

Marjan Mensinga

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In the Netherlands there are between 100.000 and 150.000 undocumented migrants. According to estimates approximately 30.000 of them are children. Research points out that those children are more vulnerable to risks at their well being and that they show more mental problems.

According to the Dutch Aliens Act, undocumented people have the right to (medical necessary) healthcare, to education for children until 18 year as well as the right for legal assistance.

Research shows that undocumented migrants, but also health professionals in hospitals, know very little about the Aliens Act and the international rights of children.

In 2008/2009 Pharos, UNICEF Netherlands and Defence for Children International (section Netherlands) conducted a research on the access to hospital care for undocumented children. The purpose of the research was to find out what the sticking points are when trying to get access to healthcare in hospitals and if their access changed due to the introduction of the new regulation.

Until 2009 hospital care in the Netherlands was not financed by an official administration. Hospitals had to make agreements with the health insurances in order to make them pay for (Dutch) people who were not insured and/or didn't pay their bills. In 2009, a new regulation was introduced. It foresees that an official administration pays hospitals (whom they have contracted) a certain amount of money for the treatment of undocumented migrants.

Literature search

Dutch literature searches reveal that little research has been done on undocumented children in

hospitals. It also shows that undocumented migrants are in general scared to go to hospitals. They think the police will wait for them at the hospital. They also fear that they will have to pay a high hospital bill afterwards, as undocumented parents and hospital professionals are often unaware of the right of undocumented children to get medical help, irrespective of the fact that they can pay the bill or not. Sometimes undocumented parents and their children are refused access to the hospital at the reception because they can't pay beforehand nor show some identification. In some cases the reception clerk refuses to contact a doctor to assess whether it is a medical emergency or not. In fact, emergency aid should be given always. Also the literature search showed that the right to healthcare for undocumented migrants is embedded in several (inter)national laws and treaties but that the knowledge of these treaties in actual practice at hospitals is very limited.

Method of research

Twenty-three undocumented children and young people between four and twenty-one year old were interviewed at two times, in 2008 and in 2009 before and after the introduction of the new regulation. We talked to the mothers of young children of less than 12 years.

Fifty hospitals all over the Netherlands were invited to participate in the research. Thirteen hospitals responded. Eight of them are located in four big cities (Amsterdam, The Hague, Rotterdam and Utrecht). The other hospitals were located in other parts of the country. At the hospitals we interviewed 49 professionals, including medical doctors at the emergency room, social workers, financial staff members and reception clerks. Professionals were also interviewed twice in 2008 and in 2009, before and after the introduction of the new regulation.

During the interviews we informed the professionals informally about the rights and duties of undocumented migrants. We also submitted an informal protocol to be discussed, a 'what-to-do with undocumented migrants' document which was available at the reception of one of the hospitals.

Results

Our research shows that undocumented children and their parents are not familiar with their rights

related to healthcare, nor their duties (they have to pay for care given). At both times (2008 and 2009) undocumented children and their parents declared to be afraid of the police and of the fact that hospital professionals will inform the police that they are there. This is why parents wait a long time before they go to the hospital with their sick child.

Undocumented parents are willing to pay for healthcare services, but since healthcare is expensive they are often unable to pay the bill. In 2008, some of the parents were faced with difficulties at the hospital reception. Reception staff forced them to pay first. When they couldn't they were sent away. During the second interview in 2009, it appeared that the parents were sent to the (health insurance) contracted hospitals by the official administration.

When the children got treatment at the hospital, they received the same (level of) care as other people.

Until 2009 the professionals in the thirteen hospitals all gave emergency help. Medical aid, which could be postponed, had to be paid first by the undocumented migrants. If that was not possible, they were sent away by the reception staff. One hospital developed a protocol on how to deal with undocumented migrants. According to the reception staff the fact some undocumented migrants did not know that they had to pay for healthcare posed a major problem. Some of the undocumented migrants seem to think that healthcare is a human right that should not be paid for if one is unable to do so.

Most professionals were not informed about the rights of undocumented children. Medical doctors often didn't know they had to help children in all circumstances, even if their parents couldn't pay the bill. Two doctors (out of thirteen) only provided care to undocumented children after their parents paid. However all doctors gave emergency healthcare.

After the introduction of the new regulation in 2009 access to hospital has improved according to the professionals. Emergency care generally poses no problem but care, which can be postponed, has to be referred to a contracted hospital. According to reception staff many undocumented migrants still don't know their rights and duties. Some undocumented migrants became angry when they heard they had to pay. They heard about the new regulation and thought healthcare was for free now.

All reception staff had a protocol on how to deal with undocumented migrants. The health professionals all knew about the rights of undocumented children. Doctors all provided care in all cases or they referred the patients to contracted hospitals.

Conclusions

- Undocumented children and their parents are not well informed about their rights and duties concerning access to healthcare in hospitals.
- Regardless the 2009 regulation undocumented children and their parents remain scared of police. They think staff has to inform the police when they come to the hospital.
- Parents of undocumented children are afraid they cannot pay the bill of the hospital. This, together with fear for the police, makes parents wait a long time before they go to the hospital with their sick child.
- During the first interviews in 2008, most hospital professionals were not or insufficiently informed about the rights and duties of undocumented children.

- During the interviews in 2009 professionals were all sufficiently informed.
- Two doctors (out of thirteen) only helped the undocumented children after payment. In 2009 this problem was solved and all doctors helped without asking for advance payment.
- Emergency care was given in all circumstances.
- In 2008 only one hospital showed a protocol in case an undocumented migrant came to the counter of the hospital.
- In 2009 all thirteen hospitals had a protocol for hospital admission of undocumented migrants.

Talking about an admission protocol and the rights and duties of undocumented children during the interviews has helped health professionals to get informed. As a result, undocumented children who need to get hospital healthcare benefitted from the information provided by the researchers about the admission protocol.

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At the crossroads between mental health and social exclusion – reflection and innovative practice in Belgium and Europe (article in French)

In the following article Sébastien Alexandre explains SMES Belgium's approach and gives an overview of the way they work.

A l'intersection de la santé mentale et de l'exclusion sociale, le développement de réflexions et de pratiques innovantes en Belgique et en Europe

Sébastien Alexandre

Coordinateur, SMES Belgique*

Le SMES-Belgique et ses corollaires européens, réunis au sein du SMES-Europe, interviennent intensément dans le « no man's land » de l'intersection entre social et santé mentale. Ils sont reconnus pour cela ! En mai 2010, le SMES-Belgique a eu l'honneur de recevoir le Prix Fédéral de Lutte

contre la Pauvreté, remis par le Secrétaire d'Etat à l'Intégration Sociale, Mr Philippe Courard.

Que manifeste donc l'obtention de ce prix prestigieux ? Deux choses, au moins.

Ce prix souligne tout d'abord qu'il faut, encore et toujours, insister sur le fait que problématiques sociales et de santé mentale se cumulent et se complexifient l'une et l'autre. Si l'accès à certains dispositifs sociaux est d'autant plus difficile, lorsque la personne souffre de problématiques de santé mentale, c'est aussi vrai dans l'autre sens : l'accès à des soins de santé mentale est d'autant plus difficile pour les personnes en situation de grande précarité. On pourrait alors imaginer davantage de concertation, entre professionnels du social et de la santé mentale : chacun resterait dans son champ d'action, mais interviendrait de concert avec des professionnels de l'autre champ, pour des situations problématiques tant du point de vue social, que de

la santé mentale. Cela sous-tend, déjà, des perspectives intéressantes.

Néanmoins, le SMES développe son action un cran plus haut. Et c'est justement ce cran supplémentaire, cette volonté de construire « un pont plus loin », qui a été reconnu comme valeur ajoutée par le Prix Fédéral de Lutte contre la Pauvreté.

Parce que travailler de concert est une chose... Intervenir ensemble et à l'intersection du social et de la santé mentale, en est une autre.

Le SMES tente en fait de développer une action socio-santé mentale. Ce n'est plus uniquement du social, ni de la santé mentale : c'est les deux, le mixte, et le décroisement.

Au SMES-Belgique, c'est par exemple un dispositif d'interventions, mêlant professionnels du social et de la santé mentale dans la volonté d'un échange de points de vue et d'un partage d'expériences. Ensemble, ils construisent un savoir commun et intersectoriel. A partir de situations concrètes, ils échangent dans la logique du « 1 + 1 > 2 ».

Au SMES-Belgique, c'est aussi la cellule d'appui aux intervenants se sentant dépassés et bloqués, face à des situations où la précarité sociale se conjugue avec la précarité mentale. La cellule intervient donc en soutien, et non pas en remplacement. Elle détient un certain savoir et une certaine pratique, mais l'intervenant est le premier en contact avec la personne. Tout l'enjeu est alors de soutenir ce lien, éventuellement en le revisitant et en l'étoffant de nouveaux intervenants du social ou de la santé mentale.

La cellule développe donc un *outreach*, mais un *outreach* particulier. Un *outreach* qui répond bien à la traduction « d'aller à la rencontre », mais qui est une aptitude, avant d'être une pratique ou une méthode. Un *outreach* qui permet à la personne la sortie de l'institution et l'accès à l'aide et aux soins là où elle se trouve. Un *outreach* veillant à préserver ou reconstruire le réseau de la personne, que ce réseau

soit celui de ses proches ou celui des professionnels et des institutions avec lesquels elle est en contact.

Concrètement, la Cellule d'Appui aux intervenants constitue par excellence le dispositif mettant en pratique au jour le jour cet *outreach* particulier. Ses membres ne cherchent pas à se substituer aux intervenants précédemment impliqués dans la situation de telle ou telle personne. Au contraire, ils offrent un appui, un soutien, en permettant une relecture de la situation, souvent en intervenant directement auprès de la personne, mais toujours en gardant l'objectif de (re)constituer le lien entre la personne et les intervenants pertinents, que ces derniers soient ou non déjà inscrits dans la situation.

C'est donc un *outreach* de complémentarité, veillant à ne pas être un *outreach* de remplacement. C'est un *outreach* conservateur de liens, alors que l'intervention dans le milieu de vie de la personne court parfois le risque de se substituer aux intervenants précédents. C'est donc un *outreach* différent, non seulement sur les déclinaisons, mais aussi sur les principes.

Le SMES-Belgique a exploré d'ailleurs ces déclinaisons et ces principes à l'heure de l'Année Européenne de Lutte contre la Pauvreté. Il l'a fait en partenariat avec le SMES-Europe, au moyen de temps de travail organisés aux alentours de la « Focus Week » - qui a eu lieu en octobre 2010 et comprenait le Participatory Forum et le Congrès de Santé Mentale Europe - et de la « Conférence de Consensus sur le Sans-Abrisme » les 9 et 10 décembre 2010. Ces échanges seront résumés dans une publication à venir, vers la fin de l'année 2011.

* N'hésitez pas, pour toute question, à visiter notre site Internet www.smes.be ou contacter Sébastien Alexandre à l'adresse coordinationreseau@smes.be. Pour des informations concernant SMES-Europe, veuillez vous référer au site : <http://www.smes-europa.org/>.

The European Healthcare Professionals' Guide to Confidentiality and Privacy in Healthcare according to the EuroSOCAP Project

Rosa Ordóñez

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EuroSOCAP (European Standards on Confidentiality and Privacy) is a European Commission sponsored project (2003-2006), which aimed to provide ethical guidelines on confidentiality and privacy in the healthcare framework. The project's starting point had to do with the so-called knowledge or information-based society, which generates an enormous amount of

data that can lead to potential multiple uses and is stored in databases to be automatically processed, thus making it impossible to foresee all the potential uses of said information. In this context, the control that citizens may exercise on the information collected about them raises a difficult challenge, that could call into question the individuals' right to privacy. Amongst other, privacy is associated with the control of the information that concerns us.

The diversity of uses that can arise from computerized medical history and the variety of professionals who can become involved in its preparation (health personnel, administrative personnel, experts in new technologies) requires us to handle them with care to prevent the risk of a breach in the patients' privacy or confidentiality, which entails acting with caution when treating confidentiality in healthcare, information systems and documents.

There are a number of patient groups who are at greater risk than others of suffering a breach of confidentiality, which we will identify as vulnerable patients. This is a population to which the EuroSOCAP Project has paid special attention given their greater need for protection compared to other patients. The right to autonomy, patient protection against possible damage and compliance with the law are fundamental principles in the ethics of the healthcare professions. When noting that specific individuals or groups of patients have conditions that make them vulnerable, our objective is to ensure compensation to the possible breach of their right to autonomy, dignity or integrity that may be limited due to the illness. In reality it is not so much the people who are vulnerable but rather certain aspects of their situation, of their characteristics or their circumstances that make them vulnerable. For example patients who are not in a position that enables them to freely choose between various alternatives, patients who do not understand the information provided, patients who cannot use the information in a realistic or logic way or patients who do not understand the nature of the disease or disorder they suffer from. The personal autonomy in connection with the intimate and personal aspects related to health is expressed in the form of informed consent, and one of the characteristics of vulnerable patients is the difficulty we face with them to obtain a valid and informed consent.

In the project we discussed a way of compensating the difficulty to obtain a genuine consent and

prevent psychological and moral damage to patients through increased protection for vulnerable groups, but that is not always simple and there are occasions where the healthcare professional may be trapped in an ethical dilemma. That would be the case of prison doctors for instance. The vulnerability of prisoners derives from their situation of captivity and the prevailing conditions inside the prisons (in some more than others) throughout the world, such as violence, intimidation, negligence and lack of respect for fundamental human rights. A prison doctor may face a contradiction between his or her obligations to the patients and their obligations with the authorities of the prison. Their fundamental duty is to protect the patient but they are also obliged to disclose certain incidents affecting the order within the prison. In addition, if they reveal certain information to their superiors the patient may suffer reprisals or be punished. In prison the priority is to maintain control and security, not prisoners' health, so it is common for prison doctors to be faced with conflicts of interest between patients' interests and the prison administration need for control.

The health decisions that affect vulnerable populations and involve ethical aspects were extensively discussed in the framework of the project before drafting the recommendations, guides and guidelines on confidentiality. A person in a vulnerable situation may be less able to claim his/her rights, as is the case for example for people who are homeless, who require an attitude of greater protection from health professionals.

The awareness of patient vulnerability by healthcare professionals requires that they are able to identify groups in which there are significant power inequalities in comparison to the rest of the population, allowing them to avoid discriminatory practices and to be more sensitive to the potential consequences of inability to make balanced decisions. Some immigrants for example - including asylum seekers, temporary workers or those who are in an irregular situation - are unable to fully exercise their rights and therefore belong to one of the vulnerable groups that can more easily suffer discrimination in healthcare.

The perspective of the different vulnerable groups has been a central consideration for the EuroSOCAP's team in its reflection on the duty of confidentiality, also taking into account justified exceptions where a professional can or should disclose information on patient's health. A part of

the team's deliberations was focused on the requirements to be met in the possible and various uses and disclosures of information concerning the health of citizens.

More detailed information can be found in the European Guidelines on Confidentiality and Privacy in Health Care at www.eurosocap.org, including the estimates related to the protection, use and disclosure of patient information in various contexts such as audits, multidisciplinary work and inter-institutional work, information disclosure for purposes not directly related to healthcare, legal obligations of disclosure, etc.

The EuroSOCAP project's team consisted of 20 professionals from 11 European countries, including doctors of different specialties, psychotherapists,

legal experts and ethics specialists. Roy McClelland, psychiatrist and professor at the School of Medicine of the Queen's University in Belfast was the coordinator of the project. The team members, belonging to different EU countries, contributed a series of reports reflecting the specificities of laws on privacy, intimacy and confidentiality in their respective countries, and when they drafted the European Guidelines they took into account a variety of aspects from the ethical and deontological codes of each legal framework.

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Resources

FEANTSA health-related resources

FEANTSA has recently published different papers relating to health and homelessness, which are available online:

- [Policy Statement on Health Care Entitlements for People who are Homeless](#) (available in EN and FR)
- [Briefing paper on Health Care Entitlements for Homeless People in 10 European countries](#)
- [Contribution to the consultation on an EU Strategy for combating violence against women 2011- 2015](#)

Please do not hesitate to circulate the information to colleagues who might be interested and to contact us, should you have any question.

For your information, the next FEANTSA thematic magazine is devoted to health and will be available in the coming weeks at the following address: <http://www.feantsa.org/code/en/pg.asp?Page=35>. If you wish to receive a paper copy, or if you would like to receive other FEANTSA publications, please contact suzannah.young@feantsa.org.

The realisation of women's rights and gender equality requires action across policy fields: some activities of the European Women's Lobby

Cécile Gréboval

Secretary General, EWL *

Inequalities between women and men still exist in all areas of society in Europe, ranging from the under-representation of women in decision-making (65% men Members of the European Parliament and an average of 76% men in national parliaments), to the fact that an estimated one in five women has been a victim of domestic violence and that women earn an average of 17.4% less than men in the

European Union. The progress towards equality between women and men therefore requires consistent action across all areas.

The European Women's Lobby (EWL) was founded in 1990 in order to address these issues at the level of the European Union's institutions. Together with its 2500 member organisations from 30 countries, the EWL works for the advancement of equality between women and men as well as the integration of gender equality perspective in all areas of European Union policy.

EWL Position Paper on Women's Health in the EU

In 2010, the EWL focused part of its efforts on the area of health and, in June 2010, published a Position Paper on 'Women's Health in the EU'. The need for such a document stems from the fact that national and European health policies still fail to properly address women's specific health needs and to integrate a gender perspective.

In addition to biological sex, the social construct of *gender* influences the extent to which women are able to have control over the circumstances affecting their health and quality of life. Existing research points to gender inequalities in health status, health-related behaviour, access to health and treatment. Inequalities between women and men include lesser access to resources (including unequal pay and pensions), heavier workload as women combine a greater share of paid and unpaid work, male violence against women, services and treatments which are not adapted to women's needs, and sex-based or multiple discrimination. Unequal access to resources coupled with other social factors produce unequal health risks and access to health information and services for women and men. In addition to this, age, ethnicity, disability, sexual orientation or identity, resources, education, legal, social and marital status, position in the labour market, place of residence, the level of gender equality in society and other attributes influence women's health needs and access to health.

The EWL Position Paper looks at the gender dimension of women's health, highlighting women's health risks and needs and the particular barriers and inequalities women face. The Position Paper argues for a dual approach of specific measures for women *and* gender mainstreaming in health policies, and presents recommendations for the European Union and its member states. The EWL paper puts particular focus on the health needs of different groups of women, which need to be researched and addressed through targeted measures and the involvement of women in policy making. The paper puts health issues in the broader context of violations of women's human rights, including male violence against women, and of socio-economic barriers faced by women.

In December 2010, The European Women's Lobby has adopted and published a Position Paper entitled 'Towards a Europe free from all forms of male violence against women' which comprises the position and recommendations of its membership

on the serious issue of male violence against women in the EU.

The need to address the feminisation of poverty and social exclusion

The issue of women's poverty has always been an integral part of the European Women's Lobby's work on employment and social policies, and the EWL is an active member of the Coalition of Social NGOs for the European Year 2010 for Combating Poverty and Social Exclusion. Women's at-risk-of-poverty rate stands at an average of 17% across the EU today, two percentage points higher than that of men. In every age group, more women are likely to be living in poverty than men. Despite relative economic prosperity, this rate has not significantly decreased over the last five years.

Unequal positions in the labour market, in political systems, in legal codes including divorce, dependency status in social protection systems, limited pensions, lack of quality affordable child care and the gender pay gap put European women at a greater risk of poverty than men. Women are also part of every group at risk of poverty and social exclusion, and in most cases, they are affected more strongly. For example, only 56.3% of European women with disabilities are employed (compared to nearly 75% of men) and women in rural areas experience higher unemployment: 10.6%, compared to men's 7.9%. 22% of women over the age of 65 are at-risk-of-poverty.

Poverty and social exclusion lead to severe gender inequalities, inadequate incomes, poor housing and homelessness, poor access to health, including reproductive health, and other social services, lack of child-care services, poor work options and opportunities, as well as male violence against women, including prostitution and trafficking.

In order to address the issue of women's poverty and social exclusion, the EWL has been calling for a set of actions to be taken, including for example insuring more visibility for the issue, which means revising the household unit measure used to determine income-related poverty assuming that resources are distributed equally within households; establishing a minimum income for all; and individualised rights with regards to taxation and social protection entitlements.

References – EWL papers:

- [Women's health in the European Union](#)
- [Towards a Europe free from all forms of male violence against women](#)

* Today the EWL's work covers 30 countries (27 EU Member States and 3 candidate countries) and includes 21 European-wide organisations. The EWL Secretariat is based in Brussels. For more information visit: www.womenlobby.org or contact: ewl@womenlobby.org.

Resources: recent articles, reports and other publications of interest

National level:

- Article on legal provisions relating to housing and mental health in Belgium (in French): Nicolas Bernard, « Le logement et la santé mentale au prisme de la loi », in « Les Echos du logement », n°2, 2010, p. 14 – 26 : http://mrw.wallonie.be/dgatlp/dgatlp/Pages/DGATLP/Dwnld/Echos/EchosLog10_2.pdf
- Paper on the impact of increased cost sharing on access to health care for poor and homeless patients in Germany (in German): BAGW, "Auswirkungen zunehmender kostenbeteiligung und eigene verantwortung auf die gesundheitsversorgung wohnungsloser und armer patienten", available at: <http://www.bagw.de/index2.html>
- Joint NGO Report to Office of the High Commissioner for Human Rights on issues in relation to health and housing in Ireland: [see details](#)
- Study on alcohol abuse and homelessness among Eastern European migrants living in London, available on Homeless Pages: <http://www.homelesspages.org.uk/node/24380>

European level:

CEDEFOP publication on "Quality assurance in the social care sector, the role of training": <http://www.cedefop.europa.eu/EN/publications/16821.aspx>

European Commission:

- Materials thematic conference on mental health, stigma and social exclusion (November 2010): http://ec.europa.eu/health/mental_health/events/ev_20101108_en.htm

- EU compass on mental health, including database of good practice examples: http://ec.europa.eu/health/mental_health/eu_compass/add/index_en.htm

Eurobarometer Special Surveys (2010):

- Mental health: http://ec.europa.eu/public_opinion/archives/ebs/ebs_345_en.pdf
- Domestic violence: http://ec.europa.eu/public_opinion/archives/ebs/ebs_344_en.pdf
- Poverty and social exclusion: http://ec.europa.eu/public_opinion/archives/ebs/ebs_355_en.pdf
- Europeans and the crisis: http://ec.europa.eu/public_opinion/topics/eb741_parl_en.pdf

European Monitoring Centre for Drugs and Drug Addiction recent publications:

- [Treatment and care for older drug users](#)
- [2010 Annual report on the state of the drugs problem in Europe](#)
- [Guidelines for testing HIV, viral hepatitis and other infections in injecting drug users](#)
- More information available at: <http://www.emcdda.europa.eu/news/home>

ECDC - WHO – joint report on tuberculosis:

http://www.ecdc.europa.eu/en/press/news/Lists/News/ECDC_DispForm.aspx?List=32e43ee8%2De230%2D4424%2Da783%2D85742124029a&ID=418&RootFolder=%2Fen%2Fpress%2Fnews%2FLists%2FNews

EPHA's [European Charter for Health Equity](#)

HUMA-Network: European Declaration of health professionals towards non-discriminatory access to health care: see [relevant link](#).

PICUM: Report on Violence and Exploitation of Undocumented Migrant Women:

<http://picum.org/en/publications/conference-and-workshop-reports/25474/>

World Health Organisation (WHO) Regional office for Europe, recent reports potentially relevant to health and homelessness:

- [Impact of economic crisis on mental health](#) (2011)

- [Poverty, social exclusion and health systems in the WHO European Region](#) (2010)
- [Socio-environmentally determined health inequities among children and adolescents. Summary of outcomes, background papers and country case studies](#) (2011)
- Other reports can be found at: <http://www.euro.who.int/en/what-we-publish>

Health Calls for proposals

The Executive Agency for Health and Consumers has published the 2011 calls for proposals relating to

health (deadline: 27 May 2011), relevant information is available at the following address:

<http://ec.europa.eu/eahc/news/news.html>

Events

European Public Health Association (EUPHA)
Conference on public health and welfare – welfare development and health
Copenhagen, Denmark
10-12 November 2011

More information available at:

<http://www.eupha.org>

FEANTSA is supported financially by the European Commission
The views expressed herein are those of the author(s) and the Commission is not responsible for any use that may be made of the information contained herein.



The FEANTSA ENHW Newsletter is supported by
the European Community Programme for Employment and Social Solidarity (2007-2013).

This programme was established to financially support the implementation of the objectives of the European Union in the employment and social affairs area, as set out in the Social Agenda, and thereby contribute to the achievement of the Lisbon Strategy goals in these fields.

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- monitoring and reporting on the implementation of EU legislation and policies in employment, social solidarity and gender equality policy areas;
- promoting policy transfer, learning and support among Member States on EU objectives and priorities; and
- relaying the views of the stakeholders and society at large.

For more information see: <http://ec.europa.eu/social/main.jsp?catId=327&langId=en>.



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