RÄTT TILL VÅRD
KONFERENSEN

Right to Health Care Summit

26th of November 2010

The report

"The Universal Declaration of Human Rights provides the foundations for the international right to the highest attainable standard of health (also known as 'the right to health'). This fundamental human right is in the major legally binding international human rights treaties that countries - like Sweden - have drafted and chosen to sign up to. It forms part of what is known as the International Bill of Rights.... The right to health is not just the preserve of international human rights systems. It is enshrined in the WHO Constitution, Declaration of Alma-Ata, Ottawa Charter for Health Promotion and other important documents agreed by the health community... Sweden has ratified numerous international human rights treaties that recognise the right to the highest attainable standard of health. In other words, Sweden is legally bound to do all it reasonably can to deliver the right to health. This fundamental human right is to be enjoyed by all - without discrimination - including undocumented people..... Undocumented people are among the most vulnerable and marginal in Sweden. They are precisely the sort of disadvantaged group that international human rights is designed to protect... Human rights are a check against the abuse of power by both dictators and democracies. In democracies, human rights are especially important as a way of protecting the most marginal and disadvantaged. In Sweden, respect for the right to health of undocumented people will help to stop a silent, hidden, grave injustice – an injustice that causes pain and threatens lives"
- Paul Hunt, 2010: UN Special Rapporteur on the Right to Health 2002-2008

Introduction

The Right to Health is a Human Right. Some elements in Sweden tend to believe that the meaning of this statement is open for debate. The United Nations take a different stance. In order to bring Sweden and Swedish legislation into conformity with our international obligations Sweden has to ensure that all people in Sweden have equal access to Swedish health care. Today, this is not the case.

Undocumented migrants are one of the most vulnerable groups of our society. Human Rights were designed to protect such groups. Current Swedish legislation does not entitle undocumented migrants to equal access to health care as Swedish citizens. On the 26th of November 2010, 36 agencies, representing almost all aspects of Sweden's civil society stood behind the first Right to Health Care Summit, a call for changes in the legislation.

It has been almost more than four months since the Summit. 2011 might become a year for change. The 31th of May a governmental investigation will present their proposal on how current legislation should be changed, in order to improve access to health care for undocumented migrants and asylum seekers. Whether this proposal will be extensive enough to meet the demands of the United Nations is yet to be seen.

180 registered to participate in the summit. It was streamed live and accessible on the Summit's homepage. Utbildningsradion (The Swedish Educational Broadcasting Company) filmed the Summit and later broadcasted it on the Swedish TV channel Kunskapskanalen (The Knowledge Channel). The project management is very pleased with how the event turned out. It required about a year of planning to bring an idea presented to the Right to Health Care Initiative in November 2009 to fruition. Hopefully the Right to Health Care Summit 2010 will be a catalyst in the Swedish debate on the subject of access to health care for undocumented migrants and asylum seekers.

This report is a summary of everything that was said during the intense Saturday on which the summit was held. Almost all the speakers have provided a short summary

of their speeches which are also included here. The project management would like to give special thanks to Margaret Gärding for the hard work with proof reading and for writing the summaries of the discussion following each speech. The aim of this report is to make the material from the summit available to all those who could not attend, and to all interested who do not know Swedish.

A warm thank you to everyone who contributed in different ways to making the Right to Health Care Summit 2010 such a success. Thank you. Good reading and remember that this Summit was held and this report written to ensure equal access to health care for undocumented migrants and asylum seekers as for Swedish citizens.

On behalf of the project management team,
Martin Gerdin

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Programme

The structure of the Summit was based on the four perspectives drawn up by Paul Hunt in his report Mission to Sweden, available from: http://www.vardforalla.se/files/vardforalla/paul_hunt_mission_to_sweden.pdf

08.00 – 09.00 Registration and coffee

09.00 – 09.15 Introduction

09.15 – 09.45 *Opening speech*
Anders Björkman – Professor and senior physician, Department of Medicine, Infectious Diseases Unit, Karolinska Institutet. Founder of Medicins du Monde clinic in Stockholm.
Anne Sjögren – Nurse, one of the founders of the Rosengrenska Network, now run in cooperation with the Red Cross.

09.45 – 10.30 *The perspective of medical ethics*
Gunilla Klingberg – Chairperson of the Swedish Dental Association
Thomas Flodin – Chairman of the Ethics Committee of the Swedish Medical Association.

10.30 – 10.50 Coffee

10.50 – 11.20 Testimony by **Boris Pendic –** Former undocumented migrant and now pharmacist student.

11.30 – 12.15 *The international right to health: protecting the disadvantaged and demanding accountability.*
Paul Hunt – Professor, University of Essex, UN Special Rapporteur on the Right to Health (2002-2008)

12.15 – 13.15 Lunch

13.15 – 14.00 *Access to healthcare in Europe: a right not respected*

Nathalie Simonnot – Deputy Director, Coordinator for National Programmes, Advocacy and Communication, Médecins du Monde

14.00 – 14.45 *The public health perspective: Can a chain be stronger than it's weakest link?*

Henry Ascher – Chairman of the Swedish Pediatrician's Working Group for Refugee Children

14.45 – 15.15 Coffee

15.15 – 16.00 *The humanitarian perspective*

Agneta Pleijel – Writer

Anna-Karin Eklund – Chairperson of the Swedish Association of Health Professionals

Lennart Molin – Assistant Secretary General of the Christian Council of Sweden.

16.00 – 17.00 *Panel discussion*

Ingemar Engström – Chairman of the Delegation for Medical Ethics of the Swedish Society of Medicine.

17.00 – 17.15 Closing remarks

The perspective of medical ethics

Gunilla Klingberg

Dental care for asylum seekers and other undocumented persons

There is limited knowledge regarding the oral health status of asylum seekers and other undocumented persons. However, it is plausible that these individuals have more oral health problems than Swedish residents. The living conditions of asylum seekers and undocumented persons may also increase the risk of oral disease, and this alone is an ethical dilemma.

According to the principle of justice every person should have equal right to access the same kind of dental care regardless of age, gender, social position, education, religion etc. This should form the basis for all dental care. However, dental care differs from medical care as the adult patient in Sweden finances a rather large proportion of the cost for dental care herself/himself. Dental care in Sweden is subsidized through the social welfare system. The financial support is based on the treatment of each individual patient and the dentist receives reimbursement from Försäkringskassan (Swedish Social Insurance Agency) based on the patient's 10-digit personal number (this is an identity number where the first 6 digits are the individual's date of birth). The financial support is the same regardless of whether the dentist is a private practitioner or employed within the public dental service. Dental care is regarded as costly by many people, and a high number of people refrain from seeking dental care. This implies that the individual's social and socioeconomic status impacts on the person's use of dental services and in a more long-term perspective possibly also on oral health. People with Swedish residency permits may seek financial support from the social services if they cannot cope with the cost for dental care. This is not possible for asylum seekers or undocumented persons. Asylum seekers are provided emergency dental care at reduced price. Undocumented persons are not covered at all, but in practice they have the right to emergency dental care under the same conditions as asylum seekers. But what is emergency dental care? Who is to define this? An ideal situation would be if dental care could be provided free of charge to asylum seekers and other undocumented persons, but this would give these persons a more favorable situation than Swedish residents.

For children, the system in Sweden provides full dental treatment free of charge up to the age of 19. According to the UN Convention on the Rights of the Child also children (under the age of 18) with status as asylum seekers or as undocumented persons are encompassed by the same dental care. The overriding point in the Convention is that children have rights. The child has the right to health care, to be respected and also to be protected against health hazards, unfair treatment etc. Children seeking asylum or being undocumented are particularly vulnerable. Either they live in families that may be under severe psychological pressure, or they may even lack family in Sweden having arrived here as unaccompanied refugee children. The dental care system in Sweden today lacks an administrative system to ensure that children belonging to the group asylum seekers and other undocumented persons are reached. This is problematic as dental care is important for young people in order to promote good oral health in a lifelong perspective. Society also puts great efforts into different preventive strategies targeting the young population. It is unknown if these measures reach asylum seekers and other undocumented persons.

Prerequisites for providing dental health care on the same conditions as for other residents:

- need for epidemiologic survey on oral health in asylum seekers and other undocumented persons in order to evaluate oral health and dental treatment needs
- acknowledge the oral health needs for asylum seekers and other undocumented persons
- asylum seekers and other undocumented persons should not be restricted to emergency dental care,
- provide a financial structure to ensure that all asylum seekers and other undocumented persons have the right to dental care on the same conditions as other residents
- asylum seekers and other undocumented persons that are children must be ensured comprehensive dental care on the same terms as other children in Sweden
- clear guidelines, including financial reimbursement, should be available to dentists making it possible for any dentist to meet and treat asylum seekers and other undocumented persons.

Thomas Flodin

The medical profession is characterized by a long and demanding scientific education and by basic professional values, medical ethics. The foundation of medical ethics can be traced back to the days of Hippocrates some 2 500 years ago. The responsibility of physicians to provide medical care on the basis of clinical need and never discriminate patients is a central element of medical ethics.
As resources in health care are not unlimited prioritizations must be made. Decisions regarding prioritizations need to be based upon well known and well informed principles The Swedish Parliament decided in 1997 that one principle should be paramount when making prioritization decisions. That is the principle that all human beings have equal value and equal rights, regardless of their personal characteristics or their standing in society (människovärdesprincipen). To accord some patients a lower priority than others because of their legal status is clearly not in accordance with this fundamental principle.

The equal right of all patients to receive medical care is at the core of both international and national documents of medical ethics. The World Medical Association (WMA) Declaration of Geneva, which is directed to the world´s physicians, states: "I will not permit considerations of age, disease or disability, creed, ethnic origin, gender, nationality, political affiliation, race, sexual orientation, social standing or any other factor to intervene between my duty and my patient". In the WMA Declaration of Lisbon on the rights of the patient, it is further clarified that "every person is entitled without discrimination to appropriate medical care". The Swedish Medical Association has its own set of ethical guidelines. In these it is stated that the physician must always abide by the principle of every person´s equal value and may never discriminate against any patient. Swedish legislation regarding medical care for asylum seekers and undocumented migrants is in opposition to these basic ethical principles. This needs to be corrected.

At its General Assembly in Vancouver in October 2010 the WMA adopted a statement concerning medical care for refugees, including asylum seekers, refused asylum seekers and undocumented migrants. The WMA states that: "Physicians have a duty to provide appropriate medical care regardless of the civil or political status of

the patient, and governments should not deny patients the right to receive such care, nor should they interfere with physicians' obligation to administer treatment on the basis of clinical need alone". Furthermore, the WMA recommends that "National Medical Associations and physicians should actively support and promote the right of all people to receive medical care on the basis of clinical need alone and speak out against legislation and practices that are in opposition to this fundamental right."

On the basis of fundamental and widely accepted ethical principles the physicians of Sweden firmly hold that every person´s equal right to medical care needs to be protected by law as soon as possible.

The international right to health: protecting the disadvantaged and demanding accountability.

Paul Hunt

The Universal Declaration of Human Rights provides the foundations for the international right to the highest attainable standard of health (also known as 'the right to health'). This fundamental human right is in the major legally binding international human rights treaties that countries - like Sweden - have drafted and chosen to sign up to. It forms part of what is known as the International Bill of Rights.

Until 2000 it was not clear what the right to the highest attainable standard of health meant. In that year, a group of international experts agreed a document, called General Comment 14, which sets out in some detail what is understood by this human right. These experts were chosen by governments but, once appointed, were independent. They drew upon international human rights, as well as health good practices. They benefited from the expertise of the World Health Organization and civil society organisations. The right to health provisions of most international treaties are only a few sentences, whereas General Comment 14 has 65 paragraphs. It transformed the right to the highest attainable standard of health from a slogan to something that can make a constructive, concise contribution to health-related policies, programmes and practices.

Briefly, the right to health encompasses medical care, as well as access to safe water, adequate sanitation, a safe working environment, access to health-related information and education, and other critical pre-conditions of good health. Moreover, it places an obligation on governments to address discrimination and inequality. The right to the highest attainable standard of health requires governments to enhance access for disadvantaged individuals, communities and populations; in other words, it has a social justice component. It also requires governments to put in place arrangements that facilitate the active and informed participation of those affected by health-related policies, programmes and practices. Crucially, the right to the highest attainable standard of health is subject to

progressive realisation i.e. no government is expected to realise it overnight – or even in ten years – but to progressively work towards its realisation. This means we need indicators and benchmarks to measure whether or not progress is being made. However, the right to health is subject to resource availability, in other words, more is demanded of Sweden than Chad. Monitoring and accountability are crucial elements of the right to the highest attainable standard of health. Too often, the same body is responsible for delivering and regulating health-related services, as well as holding those responsible to account; from the right to health perspective, this is problematic. At the core of the right to health is an equitable, integrated, responsive, effective health system that is accessible to all and of good quality.

Importantly, some elements of the right to health are *not* subject to progressive realisation – one such element being non-discrimination. For example, a country cannot say 'we will favour one ethnic group now but, over the next ten years, we will progressively extend our health services to all ethnic groups.' Progressive realisation does not extend to discrimination!

The right to health is not just the preserve of international human rights systems. It is enshrined in the WHO Constitution, Declaration of Alma-Ata, Ottawa Charter for Health Promotion and other important documents agreed by the health community.

Between 2002-2008, I served as the UN Special Rapporteur on the right to health - an independent human rights expert accountable to the United Nations General Assembly and Human Rights Council. My responsibility was to advise States and others on how to realise the right to the highest attainable standard of health. In this capacity, I wrote some 30 UN reports, including reports on the right to health in a number of countries.

In January 2006, I visited Sweden at the invitation of the Government. As my report to the United Nations records, I found a health status, life expectancy and standard of living that are among the best in the world. The Swedish health system is recognised as one of the nation's vital social institutions and it attracts considerable resources. On the whole, Sweden has a fine record of respect for human rights and democratic principles.

However, my UN report also draws attention to some right-to-health problems. When I visited, for example, data suggested that mental health in Sweden was deteriorating. Comprehensive harm reduction programmes - for intravenous drug users - were not available throughout the country. The Sami's special status as the indigenous people of Sweden had not yet translated into specific health initiatives. And my report also drew attention to the alarming health situation of undocumented people in Sweden.

Sweden has ratified numerous international human rights treaties that recognise the right to the highest attainable standard of health. In other words, Sweden is legally bound to do all it reasonably can to deliver the right to health. This fundamental human right is to be enjoyed by all - without discrimination - including undocumented people.

Undocumented people are among the most vulnerable and marginal in Sweden. They are precisely the sort of disadvantaged group that international human rights is designed to protect. Nobody would suggest that an undocumented person, who is charged with a criminal offence, should be denied her or his human right to a fair trial. Equally, a sick undocumented person should not be denied their human right to medical care without discrimination.

When undocumented people are asked to pay medical fees that are not required of others who are living in Sweden, this is a discriminatory obstacle to their enjoyment of the right to the highest attainable standard of health. Invariably, they cannot afford the fees and so they do not have the medical care they need. The tuberculosis is untreated. The chemotherapy is missed. The antenatal care is neglected - endangering mother and baby.

There are many reasons for not discriminating against undocumented people - ethical, humanitarian, public health and economic. There is also a human rights argument for non-discrimination – an argument that I endorse and share with two UN committees of independent human rights experts.

Human rights are a check against the abuse of power by both dictators and democracies. In democracies, human rights are especially important as a way of protecting the most marginal and disadvantaged. In Sweden, respect for the right to health of undocumented people will help to stop a silent, hidden, grave injustice – an injustice that causes pain and threatens lives.

Access to healthcare in Europe: a right not respected

Nathalie Simonnot

Introduction

Doctors of the World's European Observatory on Access to Healthcare[1] led a survey in 2008 with 1,218 adults without a residence permit who participated in a quantitative survey or provided their testimonies to our teams in 31 towns in 11 European countries (Belgium, France, Germany, Greece, Italy, Netherlands, Portugal, Spain, Sweden, Switzerland and the United Kingdom).

The myth of immigration for health

The undocumented migrants (UDM) interviewed came to Europe mainly to flee poverty, war, danger or restrictions on their freedom and to ensure a better future for their children. They did not come to Europe to get treatment or to take advantage of European health and welfare systems.

- 56% said that their migration was linked to economic issues. Very often they said that they had come for political, religious, ethnic, sexual orientation reasons or to escape from war (26%) - these are reasons that, theoretically, give the right to asylum.
- Only 6% of people cited health as one of their reasons for migration. However on the day of the survey, 15.7% of the whole sample were suffering from a chronic health problem that they knew about before they emigrated (these people were most commonly from the European Union or North Africa).

We do not, therefore, see in this survey the "pull factor" of migration for healthcare that is highlighted in some political discourses. It is also clear that the frequency with which health reasons are cited as a reason for migration for each host country is not necessarily correlated with whether or not the legislation is favourable towards access to healthcare for undocumented migrants in that country. After France (a country where legislation is rather favourable), respondents were most likely to cite

[1] Doctors of the World European Observatory, "Access to healthcare for undocumented migrants in 11 European countries", Chauvin P., Parizot I., Simonnot N., September 2008 : http://www.doctorsoftheworld.org.uk/lib/docs/121111-europeanobservatoryfullreportseptember2009.pdf
in Swedish: Tillgången till vård för papperslösa I 11 europeiska länder http://www.lakareivarlden.org/files/Rapport.pdf

health as one of their reasons for migration in Greece and in Sweden, even though there is no possibility to get healthcare costs covered in either country.

Legal aspects in Europe

All countries do provide « access to healthcare » for undocumented migrants (UDM) under the condition that they have to pay (in most countries) integrally all costs. This is strictly impossible in reality as UDM do not have enough money. In 5 of the 11 countries, laws provide for coverage of part of the costs for UDM who cannot pay through individual health coverage (Belgium, France, Italy, Portugal and Spain).

In Netherlands (NL) and UK, it depends on the health professional. In NL s/he has to decide whether the patient has money or not (instead of working on the diagnosis in 10mn…). In UK the GP decides whether or not to include the patient for primary care. For secondary care = « immediately necessary care should be provided but … paid for.

In 4 countries Germany, Greece, Sweden and Switzerland, access to healthcare is more or less restricted to emergency care with little to no access for frequent or chronic pathologies.

Even in countries where laws exist, administrative barriers, complexity of the system, costs, care denial, fear of being denounced, ignorance of laws and rights considerably limit access to healthcare.

European citizens: undocumented migrants when they are poor…

Let's highlight a widely unknown situation: European citizens now need to "have sufficient resources for themselves and their family members not to become a burden on the social assistance system of the host Member State during their period of residence and have comprehensive sickness insurance cover in the host Member State". Otherwise they lose their right to remain in European countries since the 2004 European Directive on free movement within the Union (2004/38/CE, April 29th 2004, art. 7) came into force. In Belgium and France specific laws for undocumented migrants now also apply to European citizens. In other countries like Germany, Netherlands or Italy, poor Europeans have to pay the full cost.

Undocumented migrants: poor living conditions, poor health

Harmful living and working conditions lead to poor health.

Many of the interviewees live with, or have experienced, violent situations before, during or after their migration. 59% of respondents reported having been subjected to at least one type of violence and 40% have experienced several types of violence. More than half (52%) of people surveyed are sleeping rough, living in insecure accommodation or in a short-stay or medium-term shelter. A third (34%) of respondents consider their housing conditions as dangerous or harmful for their health and/or their children's health. Half of undocumented migrants are working; of these, 37% work more than 10 hours a day. 52% of respondents said that they feel lonely or very lonely. In addition, 59% of parents do not live with any of their children under 18 years old.

Only 47% of people interviewed say that they are "frequently" or "very frequently" able to count on someone for moral or emotional support.

34% of men and 23% of women perceived their state of health to be bad or very bad. This is much higher than in the general population, whichever national or European population we compare with.

The most common health problems are musculoskeletal problems, psychological (stress, somatic problems, depression) and digestive conditions. 32% of people surveyed are affected by at least one chronic health problem.

Of the 1,371 health problems identified in the survey population, 72% were not at all treated or poorly followed up.

Non access to health care for such vulnerable people who have suffered before arrival in Europe and are now suffering in our countries is a breach of public health policies.

HIV / AIDS: denial of rights to undocumented migrants in Europe

Lack of information and knowledge on the availability of screening and treatment is the main difficulty found by Doctors of the World/Médecins du Monde (MDM) for access to prevention and care of HIV / AIDS for undocumented migrants in countries where such access exists.

This result is based on the 2 surveys carried out for the European Observatory in 2005 (in 5 countries) and 2008 (in 11 countries). Face-to-face interviews on medical and social aspects were conducted among 1960 undocumented persons attending MdM's programs – selected through random sampling in each program.

The results show that most people are not aware of free testing opportunities (in countries where they exist): in 2005 as well as 2008, more than 60% of interviewed undocumented migrants did not know about this possibility.

Over a third of the undocumented persons have wished to be screened. Among them, 72% have actually had the test carried out. The figure is lowest in the United Kingdom and Sweden, 2 countries where no coverage of treatment costs is legally provided for undocumented migrants. The overwhelming majority (83%) of those who did not wish to have a test said it was because they did not feel concerned, even though the average age of undocumented respondents is 36 years old. Regarding free access to treatment (in countries where this is possible), 51% did not know about it and 13% reported erroneously that this access was not free.

These data show how specific information and prevention inputs could be beneficial for populations living in poverty, especially the undocumented migrants. Appropriate and personalized assistance would help ensure effective access to treatment. These results show that all European countries should provide effective access to free testing and treatment for those most vulnerable, this includes the undocumented migrants.

Barriers in accessing healthcare

70% of the population surveyed have experienced obstacles when they tried to access healthcare: 68.9% of people cite the complexity of the health system and

administrative problems (finding documentary proof, abusive demands, being sent from one office to another…), mostly in Belgium, Sweden and the United Kingdom.

59.4 % mention the cost of consultations and treatment.

60% said that they have to limit their movements or activities because of fear of being arrested.

14% said that they were refused healthcare the last time they were ill. The rate is highest in the Netherlands affecting 1/3 of respondents, followed by the UK and Sweden (1/4 of respondents in each case). The rate is around 15% in Spain and Belgium. The Greek MDM team explains that many undocumented migrants do not even try to access mainstream services because they know that they won't be accepted.

36% of respondents were personally victims of racism during the last year. For one fifth of them, this had happened in a medical establishment (in Sweden, the United Kingdom and Greece in particular). Of all respondents, those from Africa, including North Africa, were most at risk of being victims of racism.
41% of interviewees gave up on seeking healthcare for themselves during the last 12 months (this rose to 68% in Sweden). 29% had even given up seeking healthcare for their children, most commonly for medical consultations and vaccinations. People whose healthcare costs are not covered have given up on seeking care three times more often than those who have access to health coverage. This illustrates the importance of financial constraints.

The fundamental human right of accessing healthcare is still denied in Europe.

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Right to Health in a Public Health Perspective: Can a chain be stronger than it's weakest link?

Henry Ascher

In contrast to the health of individuals, which deals with the interplay between the individual and society, public health is about the general state of health in a population. However, the general state of health greatly affects the health of individuals. This knowledge is well known since a long time. Already in the 18th century Sweden had a public health policy, long before the first policy for the medical care developed. The general health situation in Sweden has changed in a most revolutionary way in the last 100 – 150 years. In spite of extraordinary advances in the medical care, from vaccinations and antibiotics to dialysis and transplantations, the overwhelming part of the progress in public health is an effect of broad socio-political actions. It involves actions such as better housing, safer working conditions, free school lunches and child allowances. Even if some marginalized groups were excluded from the welfare system, the ambitions were to include all on equal terms.

This broader view on health is acknowledged in the human rights documents about the right to health as well as in important WHO documents. The Ottawa Charter declares that "The prerequisites and prospects for health cannot be ensured by the health sector alone" but "demands coordinated action by all concerned: by governments, by health and other social and economic sectors, by nongovernmental and voluntary organization, by local authorities, by industry and by the media. … Professional and social groups and health personnel have a major responsibility..." The Ottawa Charter points out that peace, social justice and equity are among the fundamental conditions for health.

In the Bangkok Charter the increasing inequalities within and between countries are regarded as a critical factor that now influences health. ”The vulnerability of children and exclusion of marginalized, disabled and indigenous peoples have increased" and

is described as a challenge. The charter emphasizes health promotion as a "process of enabling people to increase control over their health and its determinants, and thereby improve their health" and that this is essential in public health and "contributes to the work of tackling communicable and non-communicable diseases and other threats to health". The strategy for progress "requires strong political action, broad participation and sustained advocacy". It includes that all sectors must act to ”advocate for health based on human rights and solidarity” and ”regulate and legislate to ensure a high level of protection from harm and enable equal opportunity for health and well-being for all people".

Important determinants of public health are factors such as the general welfare and its distribution as well as life style factors, including a healthy diet and physical exercise. In contrast, undocumented migrants are among the most vulnerable groups living in Sweden. They virtually lack every form of control over their health and its determinants, to use the Bangkok Charter language. They have no access to any form of general welfare. They live under deprived conditions, usually in poverty and with bad, often crowded, housing conditions. They commonly live in fear of being discovered and deported and are excluded from the society. All these problems often add to past traumatizing experiences and memories.

Grass root volunteers and practitioners have witnessed about appalling living conditions for undocumented migrants including the health situation. However, only a few studies on the health of undocumented migrants in Sweden have been published. Those are done as interview studies on voluntary clinics for undocumented. Between 70 and 82 % of undocumented migrants reported difficulties in receiving health care, primarily because of fear of being caught or that they will be refused health care. A too high cost was an obstacle for 28 %. More than two out of three had refrained from seeking health care during the last 12 months. In one of the studies, two out of three undocumented migrants reported that their physical health had been worse during the time as undocumented and the same number reported that their psychological health had been worse. In one study 32 % of the patients included were evaluated to suffer from chronic conditions demanding treatment and in 20 % the treatment was evaluated as absolutely necessary.

Children generally constitute a vulnerable group in a public health perspective. Children of a marginalized group such as undocumented or, even still more, rejected asylum seekers, are at an extra risk. Undocumented children of former asylum seekers have access to health care and dental care on the same conditions as Swedish children. In practise, however, there are several obstacles. The families are often too afraid to dare to seek help. The knowledge about their right to health in the healthcare system is also limited which leads to that they, in many cases incorrectly, are refused health care. Further, even if the children receive health care, the families have to pay the full cost for medicines and other treatments, which in many cases is impossible. Other categories of undocumented children, as well as the parents and other adults, have a right only to emergency care and they need to pay the full cost themselves. Studies on undocumented children have shown that the family is the most important determinant of the health of the child. Children worry very much about the health of the parents and are severely affected if they witness how their parents are broken down and denied help. The exclusion of undocumented adults from access to health care thus has a great impact on the physical and psychological health of their children.

But even if the health effects of being undocumented and excluded from the access to health in Sweden in the few studies done looks grave, does that really affect the public health? Is that not more of an individual health problem not affecting the society as such? Even if Sweden of today is an extremely individualistic society, we have to realize that the health in marginalized unprivileged groups is affecting the overall public health of the society, including the most affluent parts of the society. This is perhaps most clearly visible in the area of infectious diseases. Even if we should be careful about exaggerating the risk and strengthen the picture of "the contagious aliens", the development of antibiotic resistant bacterial strains, resistant tuberculoses, HIV, as well as epidemics like swine flu and bird flu are a global threat to all parts of the world and all parts of society. If we want to take control, we cannot keep our eyes shut to an important and extremely vulnerable part of the population, often living in bad and crowded housing conditions where infectious diseases can

spread rapidly. Exclusion of them from the health system, including preventive care, leads to risks for the whole population. If, as just one example, a pregnant woman is denied access to maternal care and early HIV test, the risk for transmission to the baby if she is HIV positive increases 10 times.

Traumatized undocumented migrants constitute not only a group with severe individual sufferings. From many aspects they are also a public health concern. Many studies show that chronic trauma reactions, such as post-traumatic stress disorder, are contagious. The suffering affects the surrounding and the symptoms are spread. Exclusion from the right to examination, treatment and rehabilitation, risks leading to health problems in the surrounding, including the children, family and helpers. Failure to ensure a proper documentation of the trauma, which today is the consequence of the limited access of health care for both asylum seekers and undocumented migrants, risks leading to an insufficient basis for the asylum application. This is in violation of Sweden's international obligations as well as the medico-professional ethics.

A huge number of public health studies have shown the benefit of prophylactic and early treatment, both in terms of suffering and costs. A few reports on the economic effects of reducing the limitations for asylum seekers and undocumented migrants have verified this effect: the costs for a generous policy in Skåne was far lower than budgeted and in Stockholm County, the costs were reduced when the restrictions were abandoned. Restricted access to health care also risks leading to long-term effects negative for the individual and the society, independent of whether the migrant later will be sent back or eventually receive a residence permit.

Professor Michel Marmot, responsible for the important WHO project Closing the Gap within a Generation, as well as Richard Wilkinson and Kate Picket in their book The Spirit Level and many others, have shown that societies with a high level of inequity do worse than societies with a high level of equity in all types of health outcomes, quality of life outcomes and social outcomes. Even the most affluent groups did worse in societies with a high level of inequity. These data demonstrate

that restricting the access to health for a marginalized, isolated and vulnerable group, such as undocumented migrants, does have wide effects on public health for the whole society. The chain is not stronger than its weakest link. Health care for everyone on the same basis is a cheap, cost-effective and efficient way to improve the public health for everyone in Sweden.

The Humanistic Perspective – why so hard to accomplish?

Agneta Pleijel

In spite of our undersigning of international conventions for refugees and asylum seekers – fleeing from political, racial and ethnic persecution many applications are rejected despite horrendous threats if they return. 20 – 30.000 persons hide illegally, deprived of health care and schooling. There is a blatant neglect of children´s rights. An abyss exists between words and reality. Do we have to accept it? I focus on the most vulnerable: children, especially those with refusal syndrome (”apathetic”), very old persons and disabled, which include women that have been severely harassed.

Anna Karin Eklund

The Humanistic Perspective means always putting human rights first, always acknowledging that all human beings have the same value and share the same rights. This is a standpoint which demands action. When our personal values are connected to our actions, we contribute to the common standpoints and values of our society.

The Swedish Association of Health Care Professionals is a professional organization for 110 000 nurses, midwives, radiographers and biomedical scientists. In our professions, we meet people every day, and we are always "at your service". The need for care is universal and respect for human values is in the nature of all health care professions.

As a health care professional, I have to meet every person as a unique, autonomous individual. I have to offer the best possible care, based on the person's needs, never based on the person's economic status or if he/she can show me any identification documents.

Describing the individual as an authority on health care gives us a new outlook to strengthen the humanitarian perspective. Each person seeking health care should be

met with respect and recognition of their autonomy and integrity.

People living in Sweden without approval from Swedish authorities, are marginalized and exposed to extreme vulnerability. This means that that their right to health is undermined and that they actually risk their lives because of the danger of not being able to receive health care in time or being refused health care.

Health care is a “safe zone” in society that we have to stand up for. As health care professionals, we cannot accept that the boundaries of this zone are being broken down. And as human beings, we have to show solidarity to our neighbour. Being prepared to share our common available resources also means upholding the humanitarian perspective, contributing to every person’s right to health.

Lennart Molin

The border-line between good and evil goes through human beings and not between them. We are all both good and evil, and so are our deeds. Therefore it is problematic to talk about good people and even more about evil people, because we are both and cannot claim otherwise.
This is why we cannot base our dignity as human beings on what we do or do not do. We cannot earn our dignity. We have it only because we have received life and cannot change the fact that we are born without choosing to be born. Life is to all of us a free gift that we can use to serve others or to obtain from it.

In the choice of serving or not serving others we also make a decision on who we will become as persons. We will be different if we decide only to fulfill our own personal needs compared with if we decide to be open to the needs of others. In the Ubuntu tradition - i.e. in South Africa - there is a conviction that we become who we are through other human beings. We are created <u>in</u> mutual relationships as well as we are created <u>for</u> mutual relationships.

The humanistic perspective must mean that we shall not make distinctions between rich and poor, between strong and weak, or between people with or without papers. Everybody has the same dignity. Therefore the right to medical care must be based on needs and not on education, work skills, race or citizenship.

This is easy to say but hard to accomplish. Therefore we must be clear on this point: Humanism is to safeguard and defend human life despite that we constantly fail to be so good and human as we would like our reputation to be.

Summary of key points emerging in the discussion

Margaret Gärding

The following issues were discussed and clarified after the presentations and during the panel debate: The critical document that the undocumented migrants lack is the social security number. The demand for undocumented migrant' rights to health does not entail a stand on the right to asylum – it is the confirmation of a human right i.e. the right to health care for all that need it. Initially health care for undocumented migrants was provided by individuals on a voluntary basis or organised through civil society organisations. Today the public health care services are also involved. However civil society clinics often have to function as a bridge to the public health services as undocumented migrants often fear authorities and are also afraid of disclosure. A common assumption is that if undocumented migrants do not receive health care they will leave Sweden. Experience shows that this is not so – an example was given of a women who was diagnosed with breast cancer and was prepared to risk dying of the untreated breast cancer rather than returning to the country she had fled from. The negative impact on the individual of being an undocumented migrant was discussed – the complicated bureaucratic procedures and the inhuman demands placed on parents and especially children. Lack of access to health care is stressful for undocumented migrants and exacerbates already existing trauma and the challenges of being undocumented. The general vulnerability of undocumented migrants was also touched upon. This includes the fact that they cannot have the violence they have been subjected in their country of origin verified and documented through medical examinations and certificates if they do not have access to health care. Furthermore if their rights are violated in Sweden – their fear of the authorities and their legal status means that they cannot turn to the authorities for justice and redress. A dilemma regarding dental care for undocumented migrants is that dental care is expensive for all. Some dentists are helping to provide free dental care but this is an area needing to be developed further. It is quite clear that we need mechanisms to monitor the adherence of the Swedish Government to international declarations on the access to health as a human right also for

undocumented migrants and to find ways of holding the government accountable. A significant challenge here is that while Sweden has ratified the different declarations some have not been integrated into Swedish law. We need active and informed participation of the undocumented migrants themselves so the issue of disseminating information about their rights is paramount. There was a general agreement on the need to uphold a humanistic approach in the issue of health care for undocumented migrants and that health policies must remain independent of migration polices. The terms of reference for the ongoing investigation of the health care for undocumented migrants were discussed – especially as they include migration policy considerations. The issue of where the health care professionals primary loyalty lies *vis a vis* undocumented immigrants was discussed. Do health care professionals have a duty to comply with requests by authorities for information that entails disclosure to facilitate expulsion? Who are health professionals accountable to – is it their superiors in the health care structures or state authorities? There was a consensus around the view that the primary loyalty was to the patient. References were made to some of the challenges in the Swedish society regarding the protection of the human rights of undocumented migrants. One is the issue of xenophobia and especially the fact that the Swedish Democrats are now in parliament. The other challenge is that historically people's rights have been discussed within the context of citizenship rather than human rights as such. Allusions were also made to the fact that internationally Sweden has been and is the champion of human rights – and that perhaps Sweden should also put efforts into making these human rights a reality for the most vulnerable in their own society – among these are the undocumented migrants. Not living up to this weakens the fibre of the whole society as it impacts on all vulnerable groups. There was strong support in the different contributions for the responsibility to uphold human rights – in this case ensuring health care for undocumented migrant – both as fellow human beings and as professionals. This was aptly captured by the quotation of the words of Anne Franck: "Nobody should wait a single moment before starting to improve the world" quoted by one of the speakers.

Summary of key points emerging in the conference

Ingemar Engström

We need a clear differentiation between health care policy and migration policy and the roles inherent in each. Health care practitioners must uphold their professional responsibility. There appears to be a discrepancy between reality and what should be done regarding health care for undocumented migrants. The facts of the matter are that undocumented migrants have an extensive need for health care, yet they seldom seek it. Key deterrents for undocumented migrants needing health care are fear and lack of trust. Medical tourism is relatively rare. The inadequate health care for undocumented migrants has a negative impact on the national public health. It is illogical to give priority to emergency health care instead of early inputs. There is no evidence of push and pull factors. There are also different subgroups among undocumented migrants and while their respective needs may differ they all share a need for medical care. The choice of terminology for these different subgroups may have an impact on their rights and ethical considerations in meeting their health care needs. Other legal aspects of significance here are the Swedish Health Laws ensuring equity in health care for the entire population; special laws protecting the individual's rights to health care; expressed government priorities and commitment to the human rights principles.

Challenges in health care for undocumented migrants include lack of clarity in the use of the different concepts, the risk for arbitrary decisions by individual care givers; dependence on the patient's ability to pay; limited access to medicines and threats to patient safety and issues of confidentiality. Medical ethics are clearly guided by the ethical principals stipulated in the Geneva, Lisbon and WMA declarations. Priority is given to what is best for the patient based on science and tested experience with the patient's need as the point of departure. Political considerations and administrative practices undermine medical ethics. General ethics entail adhering to moral principles, avoiding degrading treatments and upholding the principles of human dignity and mutuality. All health personnel are obliged to abide

by professional ethics. However the lack of clarity on the rights of undocumented migrants is a source of moral stress for health professional in Sweden. When demands by the authorities go against the ethical principles, they are faced with the challenge of disobeying their superiors to uphold their professional ethics. Upholding ethical standpoints and adhering to the principle of responsibility is threatened.

Some of the challenges that are specific to Sweden are that in Sweden it is uncommon to have human rights as a base for action – the focus is more on the individual's rights as a citizen rather than human rights. Furthermore, human rights are related to a residential address which undocumented migrants lack. The right to health and the implication of this concept is not established and widely known in the Swedish society.

Closing remarks

Martin Gerdin

The Right to Health Care Summit 2010 was the first of its kind with primarily two aims: to make the struggle of undocumented migrants visible to the public and to create a common platform for all people involved in working with undocumented migrants. As project management we consider both aims partly accomplished. The conference was mentioned in print in Läkartidningen, Dagens medicin (Two medical journals) and Östgötakorrespondenten (a newspaper) among others. Kunskapskanalen (The Knowledge TV Channel) filmed the conference and it has now been broadcasted. Apart from these, no major media at national level chose to write about the Summit despite the information given to them - which must be considered a disappointment. We did succeed in creating a common platform, a natural way of meeting others engaged in work with or in other ways touched by the issue of undocumented migrants. The only drawback in this aspect was the absence of politicians – despite the invitations that were extended to them.

The invited speakers made it clear why providing health care for undocumented migrants is not only a gesture of goodwill but something we are bound to do by international law. The right to health care is a human right, defined by the UN as the right to the highest attainable level of health. This means, in the Swedish context, that Sweden is obliged to change current legislation and to offer undocumented migrants health care on the same terms as Swedish residents. Nothing less should be accepted.

The conference was co-organized by 36 organizations. This shows that there is a strong movement in the civil society working for giving undocumented migrants the right to health care. The Right to Health Care Summit 2010 is a product of the persistent struggle by all of these 36 organizations. It is one way to create awareness, to turn the spotlight on the issue and to influence policy makers and legislators Nevertheless, the experiences from the Right to Health Care Summit 2010 show that

it is possible to merge the wills of many to create a product representing a struggle for a common cause. The future will be the judge of whether this was enough.

“The World Medical Association (WMA) Declaration of Geneva, which is directed to the world´s physicians, states: “I will not permit considerations of age, disease or disability, creed, ethnic origin, gender, nationality, political affiliation, race, sexual orientation, social standing or any other factor to intervene between my duty and my patient”.

- Thomas Flodin, 2010: – Chairman of the Ethics Committee of the Swedish Medical Association

“The Ottawa Charter declares that “The prerequisites and prospects for health cannot be ensured by the health sector alone” but “demands coordinated action by all concerned: by governments, by health and other social and economic sectors, by nongovernmental and voluntary organization, by local authorities, by industry and by the media. Professional and social groups and health personnel have a major responsibility...”

Henry Ascher, 2010 – Chairman of the Swedish Pediatrician's Working Group for Refugee Children