

## Non-Communicable Diseases (NCDs): The Human Rights Factor

***The enjoyment of the highest attainable standard of health is one of the fundamental rights of every human being without distinction of race, religion, political belief, economic or social condition.***

—Preamble to the Constitution of the World Health Organization

### Section I. NCDs and Human Rights

#### Introduction

**“The UN High-Level Meeting on NCDs in September, 2011, provides an unrivalled opportunity to create a sustained rights-based global movement to tackle NCDs.”** *Priority actions for the non-communicable disease crisis.* The Lancet, Volume 377, Issue 9775, Pages 1438 - 1447, 23 April 2011.

Worldwide, NCDs currently represent 43% of the burden of disease and this is expected to rise to 60% by 2020. Left unchecked, it is estimated that NCDs will be responsible for 73% of all deaths by 2020. Most of this increase will be accounted for by emerging NCD epidemics in developing countries. There is now an increased understanding at the international and regional levels that health is not just an issue of development, but primarily a matter of human rights.

Member states have already determined that the UN Summit on NCDs will focus on “the four most prominent NCDs, namely cardiovascular diseases, cancers, chronic respiratory diseases and diabetes”, and the “common risk factors of tobacco use, alcohol abuse, unhealthy diet, physical inactivity.” We note that mental illness has been recognized in the Moscow Declaration on Healthy Lifestyles and Noncommunicable Disease Control, 29 April 2011 (“other NCDs such as mental disorders also significantly contribute to the global disease burden.”)

We certainly would expect the Outcome Document of the Special Summit on NCDs to reaffirm the human right to health and commit to bold targets for treatment and prevention of NCDs. To do less is a travesty of human rights justice and a threat to personal, social and economic well-being of countless societies and persons.

The Outcome Document that emerges from this UN Special Summit in September 2011 must reaffirm Member States' commitment to the full realization of human rights for all as an essential part of the global response to this NCDs epidemic. In particular, it must commit particularly to address the human rights-related barriers to access to services and justice for key affected populations.

The United Nations decision to tackle non-communicable diseases as a major part of its mandate is an international human dignity and human rights imperative. We now have a window of opportunity to reinvigorate efforts where they are flagging, encourage action where nothing has yet been done, and put into focus a scourge of humanity. Dignity and international human rights is critical in this timely and pressing summit.

"Human dignity" is the cornerstone of human rights. "Dignity" has a broad acceptability through usage and grounding in the Universal Declaration of Human Rights. The opening phrase of the Universal Declaration recognizes the inherent dignity of all members of the human family. Intellectual respect for the concept of human dignity has been shown from every corner. As "dignity" is the flagship of all health care endeavors, we can formulate our goals in terms of human rights.

The human rights approach is concerned with population groups most exposed to human rights violations. The identity of those whose rights are denied or at risk becomes an important factor determining why and when the right to health is not being realized. We shall isolate women and children and indigenous populations in this report, but inter alia, the principles are applied to all other at risk populations.

## **Health as a Human Right**

Health as a fundamental human right is found in a multitude of international and regional instruments. The International Covenant on Economic, Social, and Cultural Rights makes the obligation clear for all States Parties to the Convention. Article 12.1. recognizes the right of everyone to the enjoyment of the highest attainable standard of physical and mental health... and in 2d) the creation of conditions which would assure to all medical service and medical attention in the event of sickness. The core obligations of signatory nations are: to pursue goals of access to health facilities; to provide essential drugs; and to pursue a national public health strategy.

The practical implications of the human rights values of dignity and non-discrimination result in a set of working principles that form the basis of a human rights approach. The treaty bodies and United Nations experts have clarified the importance of seven such principles: accountability, participation, transparency, empowerment, sustainability, international cooperation and non-discrimination. These principles have particular application when examining a human rights-based approach to addressing NCDs.

The human right to health is the right to the enjoyment of a variety of facilities, goods, services and conditions necessary for the realization of the highest attainable standard of health. It provides a universal normative framework to design and assess health-care and health determinants in relation to NCDs. Other human rights which guide and support actions to address NCDs include equality and non-discrimination and the right to information, education and participation.

The right to health has been enshrined in numerous international and regional human rights treaties as well as national constitutions. International fora have entertained the notion of realizing the human right to health – the Earth Summit Rio, International Conference on Population and Development in Cairo, World Summit for Social Development in Copenhagen, Habitat II conference in Istanbul and so on.

## **Section II. Implementation**

### **Progressive Realization and Capacity Building**

International human rights treaties and their interpretation by human rights bodies have made clear that many of the obligations States must undertake to increase the right to health are of immediate effect: “a State Party cannot, under any circumstances whatsoever, justify its non-compliance with the core obligations ... which are non-derogable”. The right to life and other civil and political rights, and the right to non-discrimination, are not subject to progressive realization.

Health care and disease control can only be realized in widely divergent countries according to capacity. Much of the right to health is considered a right of ‘progressive realization’ under international law. All nations are expected to take positive steps towards increased services and require States to take steps to achieve those rights to the maximum of their available resources. It distinguishes the inability from the unwillingness of a State Party to comply with its right to health obligations.

Changes do not take place overnight ... human health rights require monitoring, commitment and preparation. Issues of compliance and enforceability are always an elusive element in human rights. A U.N. reporting mechanism, already in use, can be a mechanism by which governments are reminded of their non-communicable disease control and treatment obligations.

A human rights based approach in addressing NCDs will support analyses and actions of those needing to claim their rights to health, and will underscore the requirements of States Parties to meet their obligations. International non-government bodies, from the non-communicable disease associations and organizations through to the pharmaceutical industry and private corporations, will note their responsibilities.

If we suggest that the four major chronic diseases are responsible for 60 per cent of the world's deaths, then 80 per cent of these deaths are happening in the poorest populations of the world. Non-communicable diseases are imposing a much greater burden on the poorest countries than on richer economies and must be tackled as a development issue too.

## **Transparency and Accountability**

Borne by the interest in the right to health, there is a growing demand for transparency and accountability. In international human rights law, those with rights require those with obligations, mostly governments, to be forthright and accountable. Without transparency, there cannot be meaningful accountability or participation. The State is obligated to provide transparent accountability processes to enable citizens to participate fully in the review and refocusing of public policies. Health strategies are to be devised and reviewed “on the basis of a participatory and transparent process.” The Special Rapporteur on the right to health emphasizes that all mechanisms must be “effective, accessible and transparent.”

Accountability is one of the most important features of human rights. Human rights provide an internationally recognized legal framework under which governments have concrete obligations relevant to NCDs. Accountability is at the core of the enjoyment of all human rights and has two main components: addressing past grievances and correcting systemic failure to prevent future harm. The Special Rapporteur on the right to health has defined accountability as “ensuring that health systems are improving, and the right to the highest attainable

standard of health is being progressively realized, for all, including disadvantaged individuals, communities, and populations.”

Attempts continue to be made clarifying the duties and roles of the private sector in the right to health. Under international human rights law, the government is under the obligation to protect the right to health and thus must regulate non-state actors – corporations and private interests – to respond in a way consistent with this right. This raises the question as to how far the state can regulate. In NCDs the private sector is a significant player, including the tobacco, food, sugar, and alcohol industries. This means that it is an obligation of government to protect human rights by regulating the private sector so that it acts in conformity with human rights. The glaring example is the tobacco industry which cannot be assumed to respect the right to life – the most fundamental of all human rights – when the tobacco it produces kills a third to a half of all those who use it. This is but one example.

Regarding diet and nutrition, pressures are mounted for the development of international legal standards, following the 2004 Global Strategy on Diet, Physical Activity and Health to address non-communicable diseases. In order to enable consumers to have the right to an informed decision, information re the labeling of ingredients and any health risks, as well as health claims, support the right to information by those who demand healthier choices.

### **Section III. Particular Issues**

#### **The Right to Pain Control**

Under the right to health, countries are obliged to ensure access to health services for all patients, including those with incurable or terminal illnesses. Yet, in much of the world access to palliative care and pain control is very limited because health policies do not promote palliative care, drug regulations interfere with the availability of medications like morphine, and healthcare workers are inadequately trained in palliative care. To comply with the right to health, countries must ensure that health policies address the needs of patients who can no longer be cured; that healthcare workers receive adequate training and that essential medicines, including opioids like morphine, are available to all who need them.

The World Health Organization considers access to controlled medicines such as morphine a human right. It is virtually non-existent in over 150 countries.

The WHO estimates that between 30 and 86 million people annually suffer from untreated moderate to severe pain. A majority of these fall under the NCDs' umbrella.

## **The Right to Health and Poverty Reduction**

Most poor people in many poor countries remain poor at least in part because their political institutions are inefficient, or venal, or rapacious, or absent altogether - *or have no inclination to recognize the human right to health.*

Health is a fundamental human right which is integral to poverty reduction and development. In recent years the human rights community has also given greater attention to poverty as a human rights problem. Much of the work on poverty and human rights has addressed how to design, implement, and monitor a poverty reduction strategy through a human rights-based approach rather than assessing the impact of poverty on human rights.

## **Human Rights and the Social Determinants of Health**

The right to health goes beyond access to health care. NCDs are affected by a number of underlying social, economic, cultural and political determinants of health and structural barriers. A human rights-based approach provides a practical way to address the social determinants of NCDs, including poverty, gender equality, ethnicity, economic exclusion, non-discrimination and other socially determined barriers.

Although improving, to date there has been too little interaction between the health and human rights communities and the social epidemiology and social medicine communities. They are the two sides of the same coin.

The social determinants of health research has frequently under-acknowledged the potential contributions of a human rights paradigm. On its side, the human rights approach may require a deeper relationship with the considerable research indicating the impact of social determinants of health, impacting on the realization of the right to health.

The social determinants of health are the conditions in which people live and which affect their health status. A human rights direction tends to identify the state's obligations and assess the extent to which they are being fulfilled. The

findings of the social medicine and social epidemiology communities, suggest that societies cannot improve the health status of their populations and reduce significant health inequalities solely or primarily by increasing the resources devoted to medical services. A more creative interconnection between health and human rights would build on work in social epidemiology.

The emerging “health rights movement” should forge stronger alliances with the public health community. The health rights movement brings with it the skills of the international human rights movement including advocacy, litigation, social mobilization and societal transformation skills.

The public health community has the authoritative tools of epidemiology, which are revealing causal links not only between smoking and death, but also between unhealthy diets and a range of chronic diseases, cancer, diabetes and other conditions linked to obesity.

The human rights and public health communities can generate stronger leadership from governments and international organizations to address NCDs through a human rights based approach, cognizant of the social determinants.

#### **Section IV. Vulnerable Populations: Women, Children, Indigenous**

##### **Human Rights - Women’s Health and NCDs**

NCDs represent the biggest threat to women’s health worldwide, increasingly impacting on women in developing countries in their most productive years. The costs of NCDs to families and societies are high and escalating, in terms of healthcare and lost productivity.

Extensive discrimination against women continues to exist. In situations of poverty women have the least access to food, health, education, training and opportunities for employment and other needs. Obvious is the lack of rights and a continued discrimination of women in the access of healthcare. There is a growing concern about the effects of diseases affecting productivity and development of women and their families.

The right to health, including sexual and reproductive health, encompasses both the freedom to control one’s health and body as well as the right to enjoy a variety of facilities, goods, services and conditions necessary for the realization of the highest attainable standard of health.

Governments have undertaken legal human rights obligations to combat gender inequalities. The key international agreement on women's human rights is the Convention on the Elimination of All Forms of Discrimination against Women (also described as the international bill of women's rights). Ratified by 185 UN Member States, the Convention encompasses a global consensus on the changes that *need* to take place in order to realize women's human rights. Women's rights continue to be recognized on paper and through many fora. There is an apparent disassociation between Women's Rights and NCDs' prevalence.

Failure to act on NCDs will undermine development gains made to date, including progress made on women's empowerment. NCDs are financially debilitating for individuals and families, due to a combination of medical costs, costs of transportation to and from health services, time associated with informal care giving, and lost productivity.

The major impact of adult female mortality on household welfare is well established. The burden of NCDs in the family is also borne by girls and women indirectly, as the principal caregivers in many households. Their educational and income earning opportunities are interrupted when having to stay at home to care for a sick family member.

The realization of the right to education is essential to women's ability to enjoy the full range of human rights. Education can be a key determinant of quality of care, with less-educated women facing greater discrimination within health-care facilities. Access to information is a necessary part of women's ability to make informed choices.

Breast cancer is the most common cancer among women worldwide. About one half of these cases occurred in economically developing countries. Despite being largely treatable through early detection, it is the leading cause of cancer death in women worldwide. Lung cancer is the second leading cause of cancer death for women, despite being one of the most preventable types of cancer. Cigarette smoking accounts for 50% of lung cancer cases in women worldwide.

Cardiovascular disease (CVD) is the largest killer of women worldwide and increasingly impacts on women in developing countries. Very few women perceive it as the greatest threat to their health.



Tobacco use is one of the most serious avoidable risk factors for premature death and disease in adult women. Smoking rates are increasing among youth and young women in several regions of the world. Deaths due to tobacco use among women are projected to increase, from 1.5 million in 2004 to 2.5 million by 2030. Women's health is also jeopardized by exposure to second-hand smoke, especially in countries and cultures where many women do not have the power to negotiate smoke-free spaces, including in their own homes. Girls and women are among the new targets of tobacco companies, particularly in emerging economies.

A staggering 43 million children under five years are currently overweight, and at this age girls are more likely to be overweight than boys. Throughout much of Sub-Saharan Africa, high levels of under-nutrition co-exist with rapid changes in nutrition in young adulthood. Urban living is often associated with lower levels of physical activity. Physical mobility for many girls and women in developing countries is curtailed by the social and cultural context they live in. Access to and participation in physical exercise is not only a right in itself, it is also a catalyst for a number of development goals and the empowerment of women and girls.

Global alcohol consumption has increased in recent decades, with most or all of this increase occurring in developing countries. Early detection and treatment of alcohol-related complications in women is limited and alcohol treatment programmes tend to be based on the needs of men, leaving them at risk of developing NCDs.

Women's lack of access to and control over resources limits their ability to pay for healthcare for NCDs. Higher rates of illiteracy among women also mean they have less access to written information about NCD risk factors, prevention and treatment. In many places cultural taboos make it impossible for women to seek medical care from male health providers but there is, at the same time, a shortage of female health professionals.

Healthcare systems in low- and middle-income countries are still geared towards infectious diseases and delivering acute care, and need to be reformulated to integrate NCDs. Innovative partnerships are required to improve access to affordable, quality-assured, gender-sensitive essential medicines to treat NCDs in developing countries. Women's rights are still in need of being realized, and this lack impacts on the control and treatment of NCDs.

## **Human Rights - Children and NCDs**

Children are not only affected by NCDs, but are the key audience in primary prevention and risk factor management. It is imperative that all interest groups work together to protect and fulfill the rights of the world's children with respect to NCDs.

Children are vulnerable and, as such, require and are entitled to a specific set of human rights guaranteeing special care, assistance and protection. The United Nations Convention on the Rights of the Child (1989), provides children with a wide range of civil, political, economic, social and cultural rights. It is the most widely ratified United Nations Convention and the near universal ratification is a clear commitment by the international community to the importance of children.

At the heart of the Convention on the Rights of the Child is the universally accepted principle that "In all actions concerning children ... best interests of the child shall be a primary consideration." The concept of children as a vulnerable group is reflected in many and various international legal instruments. However, too often when it comes to addressing NCDs, children are left off the policy agenda. The lack of reference to children in the recent Moscow Declaration (April 29, 2011) and the most recent World Health Assembly Resolution on NCDs (May 21, 2011) is cause for concern that children will once again fall off the international health agenda. The rights of children cannot be forgotten during discussions related to NCDs.

It is important to acknowledge that a lack of resources is not always the sole barrier to the attainment of rights of children. A lack of understanding of the problems and possible solutions also impedes efforts for change. Member states are being encouraged to uphold their international commitment to the rights of the child and affirm that children remain central in the battle against NCDs: "We now have an opportunity to achieve real, lasting progress – because global leaders increasingly recognize that the health of women and children is the key to progress on all development goals." Ban Ki-moon, United Nations Secretary-General, *Foreword: The Global Strategy for Women's and Children's Health, 6 August 2010*).

## **Human Rights - Indigenous Populations and NCDs**

Throughout the world there are marked inequalities between indigenous peoples and their non-indigenous counterparts for almost every socioeconomic and health indicator, with indigenous people faring clearly worse. Indigenous peoples tend to live shorter lives and their health status is worse than other population

groups. Indigenous populations are more likely to suffer from obstacles to the enjoyment of the right to the highest attainable standard of physical and mental health (“the right to health”) and to other related human rights and fundamental freedoms.

The right to life of Indigenous communities is frequently at risk, since this vulnerable group has substantially higher mortality and morbidity rates than the general public. Infant mortality is a special problem among indigenous peoples, which has serious implications with regard to the human rights of children. The right to equal protection of the law and the right to physical, mental and moral integrity are absolutely crucial to indigenous peoples who have been denied equal health care, both officially and unofficially.

Both the United Nations and several Regional human rights systems have a body of legal instruments that can be used to protect the rights and liberties of indigenous peoples and, therefore, their enjoyment of good health and well-being. They can be used to guide the formulation or review of policies, plans or programs; the enactment of pertinent legislation; and the restructure of health services to benefit indigenous peoples. The existence of a UN Special Rapporteur on the situation of human rights and fundamental freedoms of indigenous peoples is of great importance for this population group.

There is now an international *Declaration on the Rights of Indigenous Peoples* (2007). Article 1 states that indigenous peoples have the right to the full enjoyment, as a collective or as individuals, of all human rights and fundamental freedoms as recognized in the Charter of the United Nations and the Universal Declaration of Human Rights and international human rights law. The most relevant rights enshrined in this Declaration include the right to their traditional medicines and to maintain their health practices and to the enjoyment of the highest attainable standard of health (article 24) which are fundamental for exercising other rights and freedoms included in this Declaration such as the right to be free from any kind of discrimination (article 2); the right to life (article 7); the right to physical and mental integrity (article 7).

Given the high incidence of NCDs among indigenous populations (for example, diabetes is two to four times more prevalent in the indigenous communities), there is a compelling need for countries with those populations to accelerate their commitment to search for sustainable solutions to health challenges, and to detect, monitor, and reverse inequities in both the health of indigenous peoples and their access to basic health services. A right to education

includes the promotion of disease-prevention and health-promotion programs for indigenous peoples, with information processing of traditional knowledge, medicine, and healing practices that are consistent with the right to freedom of expression.

Human rights and the social determinants of health are intertwined, requiring the promotion of research and initiatives to increase information about the health of indigenous peoples. Governments and health providers can be more aware of the impact of ethnicity on the exercise of human rights and fundamental freedoms related to health and the right to health *per se*. Many indigenous people cannot access acceptable health care and services (and therefore do not exercise other civil, political, economic, social, and cultural rights) because of cultural barriers.

All governments, policy makers and health organizations working on NCDs and human rights issues should understand how international human rights legal instruments protect the basic rights and freedoms of indigenous peoples and how to use the mechanisms of protection provided by the human rights bodies. Also, national and international mechanisms, working through important international, regional, and national bodies can promote policies and strategies that meet the health needs and human rights of marginalized ethnic populations.

## **Section V. NCDs and Human Rights: Conclusion and Recommendations**

### **Conclusion**

The Special Rapporteur on the right to health has emphasized that: “The right to health gives rise to a responsibility of international assistance and cooperation on developed States to assist developing States to realize the right to health ... This responsibility is reflected in Millennium Development Goal 8, which is a commitment to develop a global partnership for development.”

Non-communicable disease, by its very definition, can be prevented and controlled. Much could be eliminated through earlier diagnosis, treatment and supportive care. Disease control and alleviation through the protection and promotion of human rights and dignity is a natural outcome of collaborative work and vision in the world community.

A human rights-based approach to NCDs is concerned with the population groups most exposed to human rights violations. The identity of the rights-

holder(s) becomes an important and central feature in analyzing why the right to health is not being enjoyed.

A human rights analysis reveals why rights are not realized, paying particular attention to why duty-bearers are not living up to their human rights obligations or responsibilities. The involvement of rights-holders in all stages of a rights-based analysis is not only a question of safeguarding the right to participation in greater well-ness, but also has instrumental value, ensuring that interventions are culturally appropriate and sustainable. A priority focus for a human rights-based response to NCDs is how to enhance accountability of the duty-bearers so that they live up to, and deliver on, their recognized obligations and responsibilities.

## **Recommendations**

Realize that the role of human rights law and international human rights standards is essential in order to reduce the impact of NCDs at the global level.

Resolve to integrate the promotion and protection of human rights into national NCD policies, ensuring particular attention is paid to women and girls, young people, orphans and children, older people, migrants and people affected by humanitarian emergencies, indigenous people, people with mental and physical disabilities, and other vulnerable populations.

Recognize that the respect for and promotion and protection of human rights for all is an integral part of addressing NCDs; and that the realization of human rights is essential to reduce vulnerability to NCDs; respect for the rights of people affected by NCDs creates an effective response; and that appropriate legislation, regulations and other measures need to be adopted to ensure the full enjoyment of all human rights by people affected by NCDs.

Recognise that access to safe, effective, affordable, quality-assured medicines and technologies in the context of the NCDs epidemic are fundamental to the full realisation of the right of everyone to enjoy the highest attainable standard of physical and mental health throughout the life-cycle.

Recognize that all initiatives to address NCDs should protect and promote human rights. While this seem obvious it should be remembered that experience in other health matters such as the compulsory testing and quarantining of people with HIV

demonstrates that sometimes initiatives in the name of health can undermine, not promote, human rights and cannot be justified on public health grounds.

Resolve that human rights standards should guide our response to NCDs. Human Rights standards relevant to NCDs need to be further developed, perhaps by the Committee on Economic, Social and Cultural Rights issues a General Comment on NCDs. An immediate practical measure would be for the Office of the High Commissioner for Human Rights to organize briefings on NCDs and human rights for the relevant treaty body committees and special Rapporteurs.

Recognize that initiatives to address NCDs should contribute to the capacities of ‘duty-bearers’ to meet their obligations and/or of ‘rights-holders’ to claim their rights, which involves education and the engagement of civil society in the political process.

Realize that the social determinants of health are intricately related to human rights issues; that they do not exist in isolation to one another; and that human rights principles will aid and abet the improvements of social determinants in many cases.

Realize that the interest of other partners in the NDCs group will and should have a human rights based approach, which will need to be harmonized in order to gain further strength.

Recognize that governments have the obligation to respect rights in the context of NCDs which includes the issue of policy coherence across government.

Recognize the right for treatment of NCDs, noting the importance of international cooperation, including the sharing of scientific knowledge.

Suggest that it would be useful to develop a package to educate and inform international and national human rights commissions about the health and human rights impacts of NCDs and identify how they could respond within their mandates (e.g. an investigation into the illegal sales of tobacco and alcohol to children, or at least receiving complaints on these grounds).

Commit to establishing and strengthening effective monitoring systems, where appropriate, for the promotion and protection of human rights of people living with NCDs and those who are caring for people with NCDs.