Abstract

The links between freedom of expression and the health and well-being of the individual and of society seem readily apparent even if their full ramifications are not immediately clear. Health and health care are dependent on information, and the free exchange of this information is at the base of effective health protection and promotion. Equally, it is clear that such a widely-based concept as health intersects with, and is dependent on, a range of basic human needs. This article examines the links between provision of health care and the right of freedom of expression as set out in Article 19 of the Universal Declaration of Human Rights. It argues that both freedom of expression and commitment to health care are vital objectives but insufficient in and of themselves to realise a wider goal of human well-being. This article draws on examples from inner urban deprivation, women's health and HIV/AIDS to illustrate some of the factors and issues involved.

Les liens entre la liberté d’expression et la santé et le bien-être de la personne et de la société semblent transparaitre aisément même si leurs ramifications complètes ne sont pas immédiatement évidentes. La santé et les soins de santé sont dépendants de l’information, et le libre échange de cette information est à la base d’une protection et d’une promotion efficaces de la santé. De même, il est clair qu’un concept aussi large que la santé recoupe un ensemble de besoins humains fondamentaux, dont il est également tributaire. Cet article examine les liens entre la mise à disposition d’un système de soins de santé et le droit à la liberté d’expression tel que stipulé dans l’article 19 de la Déclaration Universelle des Droits de l’Homme. Il exprime le fait que la liberté d’expression et une volonté de promouvoir la santé sont des objectifs vitaux, mais qui sont insuffisants en eux-mêmes et par eux-mêmes pour atteindre un objectif plus vaste de bien-être humain. L’article illustre certains des facteurs et problèmes impliqués au travers d’exemples provenant de milieux urbains défavorisés, de la santé des femmes et du SIDA.

Las relaciones entre la libertad de expresión y la salud y el bienestar de la persona y de la sociedad, resultan evidentes a primera vista aunque no necesariamente en todas sus manifestaciones. La salud y la atención de la salud dependen de la información, y el intercambio libre de esta información es indispensable para la protección y un promoción eficaces de la salud. Del mismo modo, es evidente que un concepto tan amplio como la salud se relaciona con y depende de un conjunto de necesidades humanas fundamentales. Este artículo examina las relaciones entre la provisión de atención de la salud y el derecho a la libertad de expresión tal como estipula el artículo 19 de la Declaración Universal de Derechos Humanos. Explica que tanto la libertad de expresión como la responsabilidad de los estados para con la atención de la salud son objetivos centrales, pero insuficientes por ellos mismos para alcanzar el bienestar humano. El artículo presenta a partir de ejemplos que provienen de medios urbanos desfavorecidos, de la salud de la mujer, y del SIDA, algunos de los factores y problemas en la relación entre la salud y los derechos humanos.
FREEDOM OF EXPRESSION AND THE HEALTHY SOCIETY

James Welsh

UDHR Article 19
Everyone has the right to freedom of opinion and expression; this right includes freedom to hold opinions without interference and to seek, receive and impart information and ideas through any media and regardless of frontiers.

The links between freedom of expression (and the freedom of association) and the health and well-being of the individual and of society seem readily apparent — although perhaps not immediately in their full ramifications. Health and health care are dependent on information, and its free exchange is basic to their protection and promotion. Equally, it is clear on the briefest reflection that such a broad-based concept as health intersects with, and is dependent on, a range of basic human needs. Therefore although this discussion is limited to the particular area touched by Article 19 of the Universal Declaration of Human Rights (UDHR), this focus artificially narrows the discussion. A wider contextualization of health is necessary for a complete picture of the interconnectedness of health and human rights.

Article 19 of the UDHR clearly sets out the right to freedom of expression. It is necessary, however, to concede some limitations which are, in practice, accepted as legitimate areas of restriction by government. For example, racist or hate speech is increasingly viewed as being outside the bounds of what should be permitted, even though in some countries this limitation may not be applied. Similarly states reserve the right to control the importation and exchange of child...
pornography; and in many countries further limits are imposed which prohibit dissemination of state secrets, slander or libel, incitement to carry out criminal acts or acts of espionage. All of these restrictions may in themselves have democratic legitimacy, though all of them provide governments with opportunities to limit freedom of expression through the inappropriate application, misapplication or bypassing of existing laws. Governments are not the only actors who restrict freedom of speech. Political opposition organizations and religious, ethnic or cultural bodies also restrict freedom of speech — however, the actions of nongovernmental entities will not be considered here.

In discussing health in its widest sense and in its relation to human rights and freedom of expression, an important distinction is to be made between the right to speak and the encouragement to speak. A right can be passive, implying that one may undertake a certain action without penalty. In the health care sector, however, there is a positive need to encourage discussion. A whole range of areas relating to women’s well-being have suffered because those holding power, including (predominantly) male health professionals, have not adequately encouraged active discussion of, and participation in, decision-making by those with particular health care needs — for example, needs related to reproductive health, domestic violence, and sexuality.

The Starting Point

Global social indicators point to massive inequalities in income, employment, housing, security and health. Just to examine death rates: 40 percent of all deaths in the world occur in people under the age of 50, against an average life expectancy of 68 years. Recent figures indicate that 10 million children under the age of five end 7.4 million adults between the ages of 20 and 49 die each year. The majority of early deaths are in the developing world and among the underclasses of the industrialized world. Almost 600,000 women die each year of pregnancy-related causes. In Europe the risk of dying from a pregnancy-related illness is one in 1400, yet in Asia it is one in 65, and in Africa, one in 16. Similar global disparities can be seen with respect to indicators of health and morbidity. Provision of health care is tak-
ing place in the context of “global casino economics” — with all that this implies for control of national budgets.7

The same divisions that are evident between nations are also seen within nations, with those groups and individuals at the top of the socioeconomic structure having a massively greater share of resources than those at the bottom. The burden of ill-health is correspondingly uneven in its distribution, with the health status of minorities, the unemployed and the marginalized frequently markedly inferior.8 While the paths to change defective patterns of public health differ in different countries, the common factor necessary for reform will be change in the allocation of material resources and more effective sharing of information. This is particularly relevant for those whose health is kept at less than optimal levels because they lack relevant information. And there, as Shakespeare said, is the rub. Change in all but the most modest form is unlikely to happen without resistance from those who perceive themselves to be disadvantaged by that change — whether through loss of material wealth, control, power or prestige. In particular those who control resources and financial capital are unlikely to applaud efforts at redistribution which they perceive to be at their expense.9 Nor are those who control the value systems and access to knowledge in nondemocratic states likely to readily concede more democratic access to what exists, or to allow alternatives to be explored. In all states, access to information, self-empowerment and control are real political issues. And in all states, vested interests — governments, political parties, religious bodies — need to be challenged on these issues. This may be the reason one public health advocate said that she “view[ed] health and human rights advocacy as an essentially subversive activity.”10

**Commitment to Health Is Not Enough**

I would certainly argue that freedom of expression is an important contributor to an environment in which better health at an individual and public level can be promoted. The question is, however, whether restricting that freedom deals health care delivery and promotion a fatal blow. This is a far from simple question. Some countries start from a very low economic baseline, and health policy develops in unfavor-
able circumstances. Where countries have undergone radical social and political change based on a socialist model, an accessible public health system is likely to have high priority. Thus the postrevolution Cuban government established in 1959 introduced a universal health care policy. However, many people with medical skills soon fled the country, and the new health system had to develop without adequate material and human resources. The changes in Cuba provoked internal opposition and increasingly hostile criticism from conservative critics abroad (notably in the USA) who accused Cuba of controlling, limiting or suppressing freedom of expression (not to mention expropriating foreign assets). After the invasion of Cuba in April 1961 by U.S.-supported Cuban exiles, Cuba faced economic sanctions and intense diplomatic pressure. Human rights in Cuba suffered, as did other components of the social weave. Cuba remains socialist, visible, under sanction and in considerable economic difficulty.11

While Cuba has shown a commitment to developing an accessible, cheap and high quality health care service, it has not placed the same emphasis on freedom of expression, and Cuban prisons still contain more than a hundred prisoners of conscience.12 Limits on free speech in Cuba have impinged visibly on the health sector. For example, in 1997, Dr. Desi Mendoza was imprisoned for eight years because he criticized official responses to a dengue fever outbreak in eastern Cuba.13 Reports suggest that there are limits to discussion on other health issues as well, including AIDS, which until recently was the object of a draconian containment policy.14 Other countries have followed similar policies, all of which demonstrate the complex interplay of ideology, foreign pressure, commitment to strong public health, lack of resources and relative intolerance of dissent. If they have succeeded according to some public health criteria (mortality and morbidity rates, for example), they have arguably done less well according to other indicators of a “complete well-being.”

Commitment to “Freedom” Is Not Enough

In contrast to the situation in socialwelfare-oriented systems, in some of the wealthiest liberal democracies there are areas where health indicators fall to the levels common in impoverished developing countries.15 Though the victims
of this level of poor health and health care are formally free to express their opinions, wishes and political beliefs, they often have no access to basic health care because that access is based on having insurance or the capacity to pay — elements they may well lack. Moreover, the conditions in which marginalized persons live are likely to promote continuing ill-health and further unmet need.

The contrast between politically illiberal but welfare-oriented countries and democratic but nonwelfare-oriented countries throws interesting light on the meaning and relevance of freedom of speech as a value in the absence of both personal empowerment and the implementation of complementary rights. Underlining the indispensability of wider social and community rights, some commentators have gone so far as to say (in an African context) that “[f]reedom of expression is meaningless if one is too weak and hungry to speak about the right to food.” Those who live in inner urban ghettos experience a powerlessness and demoralization (arguably, at least in inner urban USA, an effect of the “internalization of their abandonment”) that may well lead them to feel that the right to free speech has not served them well. It would be false logic, however, to jettison the concept of free speech until such time as material circumstances give meaning to the right to free speech. Rather, the challenge is to create conditions in which the “abandoned” can reclaim their right to self-expression and contribute to the development of more effective health policy.

Women’s Health as a Marker of Free Expression

Women’s health reflects their status in society. In many parts of the world, females suffer discrimination as soon as their gender is determined (leading in some cases to abortion or infanticide), and this discrimination remains with them throughout life. Females suffer disproportionately from poverty, low social status, male violence and the risks associated with reproduction. In many countries government control of access to health-related information — particularly to reproductive health information — limits their capacity to manage their own health. As a result, women bear an unfair burden of disadvantage, suffering and compromised health and well-being.
Practices such as female genital mutilation (FGM) are deeply embedded in the cultures in which they occur, and human rights advocates and health reformers face the resistance to change which characterizes traditional practices. In recent decades, efforts to bring about control and restriction of FGM have taken a health-oriented approach. Only recently has a rights-oriented critique emerged as a viable supplement to health-oriented campaigning. The subject is delicate and open to allegations of cultural imperialism on the one hand and cultural relativism on the other. The practice will end only when communities see more value in stopping or modifying it than in continuing. This change in perspective at the community level will reflect the exercise of power by those with the capacity to end FGM.

What constitutes power in this context? Gupta has suggested that there are five essential components of power: information/education; economic resources; mobility/access; perceived social support; and supportive norms, policies and laws (which need to be enforceable). Examining these five components through the prism of women’s health helps to illuminate the role of free expression in promoting and protecting health.

The recent political change in Afghanistan has totally stripped women of these components of power. Women have largely been confined to their homes. To appear in public, they must be accompanied by a husband or male relative. Their access to education, information and services — including medical services — has been severely limited in a manner which can be life-threatening. For example, one pregnant woman with serious bleeding was not attended to until a male relative could be found to give consent to treatment on her behalf. Also placing women’s health in jeopardy are restrictions on their rights to seek or receive medical care from male doctors. Education of females has been restricted to teaching the very young to read the Qur’an, and public debate on women’s rights can be undertaken (if at all) only by men.

This type of massive assault on women’s rights should not, however, draw our attention away from the subtle (and not so subtle) ways in which women’s rights are diminished more universally, nor from the role of open debate and free
expression in combating these restrictions and working for improved health.\textsuperscript{23}

Information on women’s health has been shaped substantially by (notably male) health professionals. Cook has illustrated how health professionals have both “mitigate[d] the consequences of women’s gendered disadvantage” while also sharing “prevailing perceptions of women’s natural role” and exhibited “blindness toward women’s gender-specific health risks.”\textsuperscript{24} For example, the medical establishment has for years maintained the status quo by focusing on individual distress and looking for medical causes for maladjustment and unhappiness. However, more recent feminist analysis has suggested that frustration and anger are a “natural healthy reaction to social injustice.” Cook suggests that (even) organizations of health professionals are recognizing the need for change, citing the International Federation of Gynecology and Obstetrics’ recent conclusion that future improvements in women’s health require not only improved science and health care, but also social justice for women — including the removal of barriers to equal opportunity for women.\textsuperscript{25}

It nevertheless remains the case that in all parts of the world women do not have power.\textsuperscript{26} Looking again at Gupta’s five essential components of power, we see that women lack access to information and to education — often as a result of illiteracy, lack of effective concern by state authorities about women’s health, and as a result of male cultural dominance and prejudice; lack economic resources, either because they are dependent on male partners or because their income is inadequate to meet daily needs; lack mobility and access to health care facilities and to sources of help — often because of restrictions imposed for religious, cultural or security reasons; and in many cases have inadequate social support due to lack of social infrastructure, though they can derive support from networks of friends. Women’s status with respect to the final component of power — supportive norms, policies and laws — is perhaps one of the major barriers to their well-being, though the circumstances differ from country to country. Issues such as violence against women carried out with impunity, sexual abuse within marriage, discrimination based on gender, all contribute to an assault on women’s well-being and weaken the delivery of effective health programs.
In order to address all of these issues — to change health policy, implement legal protection, augment education programs and involve women in decisionmaking — a climate must exist in which free discussion can take place.27

While many organizations of health professionals hold constructive views on women’s health rights, it has to be noted that in many ways health professionals can also contribute to negative health outcomes. Poor practice or unethical behavior can range from, for example, unethical experimentation or putting commercial interests above individual health needs to collaboration with police interrogations and involvement in torture or executions. The promotion of artificial infant foods is a well-documented example in which some health professionals played an important role in promoting breastfeeding and associated good health practice but, at the same time, others impeded health promotion through their connections with commercial infant formula companies and promotional programs. Such deleterious actions by health professionals need to be exposed, controlled, disciplined and reformed as appropriate.28 This can only take place where means are established to conduct audits, carry out investigations, implement legal measures where available, and push for the creation of laws which are necessary but absent. All of this presupposes a climate in which debate, review and dissemination of information can take place.

**Attacks on Health Promotion**

The discovery in the early 1980s of the basis for transmission of acquired immunodeficiency syndrome (AIDS) was followed by national HIV/AIDS prevention campaigns of varying levels of candor, visibility and effectiveness. It has become apparent over the past decade that the effectiveness of community response to these campaigns reflects the willingness of governments and communities to speak frankly, openly and inclusively. For the most part, countries unwilling to address the central messages of a prohealth campaign (which of necessity requires frank discussion of sex and sexuality, as well as of behavior) saw infection rates increase. Prejudice against gay men, injecting drug users and others considered (with varying degrees of justification) to be “at high risk” was quick to surface and took varying forms, including so-
cial exclusion and violence. In some places, such prejudice was transferred to those working in health education. For example, in El Salvador in 1994 and 1995 the deputy director of the Oscar Romero AIDS project, and staff (including the medical director) of the AIDS organization FUNDASIDA were threatened with death by unknown armed men. Similar levels of threat and menace have also been experienced in other countries. Equally, however, more subtle forms of pressure have been applied to health workers and community activists which impinge on health, notably as a result of laws controlling the distribution of sexually explicit materials.

Health professionals have also been targeted simply for practicing their profession in areas where such practice was seen as “inherently subversive.” During civil conflicts in Central America and in southern Africa, for example, health clinics and staff were targeted in order to disrupt their important work in health care provision and education, but also to fracture the social network in which that work was carried out. Attempts to promote health by addressing issues that have direct and measurable impact on well-being, for example, environmental policies and practice, public and private transport systems and safety and security at work, also meet resistance in many places. Although the resistance more usually consists of attempts to control information and stifle discussion, it sometimes takes the form of violence. In some countries, the issue of abortion has sparked contentious and difficult debate. In the USA, abortion clinics have been bombed and the lives of clinic personnel threatened by activists committed to the “right to life” (sic).

Finally, the role of health professionals and their own rights to freedom of expression should not be overlooked. In numerous countries where professional associations have been effectively shut down, attacks have been made on the freedom of health professionals to discuss such matters as human rights, professional ethics and their own working conditions — all of which affect how these professionals are able to function in the health care system.

Is Promoting Free Speech a Mechanism for Improving Public Health?

There is no guarantee that those who contribute to pub-
lic discussion of health issues are motivated by a desire to promote either wider access to health care or better health for every member of the community. Neither is there any guarantee that a free debate will result in the optimum outcome in terms of policy development and change. Nevertheless, there is abundant evidence to suggest that free exchange of views and availability of relevant data, among policy makers and the public alike, is vital for promoting good public health in its widest sense. Minorities, children, women, the marginalized all need to have current prejudices challenged and overcome. This will happen only through open discussion, debate, and action. The action part of this formula is the component most dependent on other rights enunciated in the UDHR and other human rights instruments. Information is essential, but it is not the sole determinant of changing or improving behavior. Those seeking fulfillment of their rights need both empowerment and mechanisms to pressure those who do not want to honor the rights of others.

The Electronic Future: Battle for the Internet

The battle between those who seek to maintain a free flow of communication and those who seek to control information and limit free expression is moving beyond the written and spoken word (though that battle will endure) into the new arena of electronic communications. Telephone, fax, video and satellite television have all subverted governmental monopolies on information. Admittedly, these technologies are not universally available and remain vulnerable to governmental attempts to control or block them. Moreover, having viewing access to video or television does not guarantee access to pluralistic and accurate information. Nevertheless, the actions which some governments have taken to control access to satellite dishes suggest they are fully aware that the new media have weakened their control over information.

The rapid development of Internet technologies has opened new possibilities for disseminating information quickly — rich and useful information as well as misleading propaganda, racist text and pornography. Governments are aware that such technologies can bypass conventional controls, and are seeking to impose their will on this new form...
of communication. Repressive military governments are not alone in their desire to control the Internet’s capacity to transmit information free from prying eyes. The United States government has vigorously combatted attempts by U.S. software developers to develop and sell encryption software that would allow transmission of encoded (and therefore unreadable) electronic communications. This battle has longer to run.

In addition to crude government measures to control the Internet (for example, by taking steps to block access), increasing interest in that medium from corporations and other businesses may also affect the ways information is shared. For example, businesses could increase their levels of advertising on web sites, or control or attempt to monopolize access to Internet technology. Finally, the development of software which monitors and tracks Internet usage has the potential to inhibit free use of the Web. These means of implicit control suggest that the flow of opinion, organizational communications and debate may be vulnerable to the illegitimate desires of governments to limit freedom of expression and the development of a virtual community.

**Conclusion**

The link between health and free expression is complex but undeniable. Strengthening individual and public health requires health data collection, research, policy development and the dissemination of information to both health care providers and consumers. Open and free discussion of topics with a narrow, health-oriented focus is not the only issue. Discussion is also needed on wider social issues that bear on individual and community well being — issues such as the environment, employment, women’s and children’s rights, asylum and refugee policy, and many others. Finally, the rights of health care workers to discuss ethics, human rights and conditions relating to their own functions are important and can affect health care delivery. The development of new means of communication, such as the Internet, opens new possibilities to enhance these discussions and to improve the flow of information, while at the same time providing those who want to control free discussion with a new battleground.
References

1. The definition of health of the World Health Organization moves beyond the absence of disease to speak of a sense of complete well-being.


3. In 1995 Amnesty International adopted a policy which excluded as possible prisoners of conscience, prisoners who “advocated national, racial or religious hatred that constitute[d] incitement to discrimination, hostility or violence.”


5. Ibid.

6. Ibid.


9. In any event, recent history within many societies has shown redistribution to be taking place in the reverse direction.


11. Cuba’s visibility can be contrasted with that of Nicaragua, a country which also attempted to implement universal health coverage based on grass-roots mobilization of health workers and a commitment to education and preventive health care. Nicaragua has virtually disappeared from the world’s media after the electoral defeat of the Sandinista government in 1990. For a report on the effect of United States embargoes on the Cuban heath system, see American Association for World Health, Denial of Food and Medicine: The Impact of the United States Embargo on Health and Nutrition in Cuba (Washington D.C.: The American Association for World Health, March 1997).


14. The containment policy has been the subject of strong criticism on human rights and public health grounds though it had some qualified support. See N. Scheper-Hughes, “AIDS, Public Health and Human Rights in Cuba,” *Lancet* 342(1993):965–67. There are signs that in recent times, Cuban policy on AIDS is moving in the direction of internationally recommended approaches.

15. “Survival analysis showed that Black men in Harlem were less likely to reach the age of 65 than men in Bangladesh.” See McCord and Freeman, note 8.

16. “Welfare-oriented” is used to indicate a government concern with maintaining minimum levels of health and other needs such as housing. It does not imply any profound meaning to the word which normally would include spiritual, or at least psychological, well-being. Likewise, “nonwelfare-oriented” does not imply an absence of measures to support the indigent or less well off; merely that the society is not oriented to guarantee minimum standards for all citizens.


20. Kenya Broadcasting Corporation, August 20, 1996, reported on a rite of passage ceremony in central Kenya, in which 30 young girls went through an extended ceremony to mark their transition to new status rather than undergoing genital cutting.


23. The impact of religious, ethnic or racial discrimination on health care is not discussed in this paper, though it clearly is relevant and deserves further detailed consideration.


25. Ibid. The Commonwealth Medical Association has been one of the more proactive of the establishment professional bodies on women’s health issues. See M. Haslegrave and J. Havard, “Women’s Right to Health and the Beijing Platform for Action: Retreat from Cairo?” *Health and Human Rights* 1(4)[1995]:461–471.

27. This is well illustrated in a study of free expression and health care in Burma which stressed the importance of “access to essential health information to allow people to make informed choices.” Article 19, Fatal Science! Freedom of Expression and the Right to Health in Burma (London: Article 19, 1996).

28. In the past, unethical or harmful actions by doctors have been rather impervious to external review — except in cases where disaster ensued (e.g. death due to gross negligence) or where grossly abusive behavior, such as sexual exploitation took place — with the disciplinary function taking place within the profession.


31. The debate on health care reform in the USA in 1993 and 1994 was marked by disinformation, transparent self-interest and poor quality information.

32. In Iran, for example, the government ordered that possession of a satellite dish would be illegal. (“Iran Bans Satellite Dishes,” Wall Street Journal, April 6, 1994, p. A16.) The control over satellites in Iran has not be wholly successful however and foreign television is still accessible.