Mobilizing citizens and communities for better health:

The civil society context in central and eastern Europe

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Democracy is the work of human beings who comprehend their inalienable rights, who respect human rights and who believe in responsibility for their fellow human beings.

—Vaclav Havel, Prague 1990

This draft paper is part of a series commissioned by USAID to provide a conceptual framework and overview of the main thematic topics of the USAID conference "Ten Years of Health Systems Transition in Central and Eastern Europe and Eurasia." Following the conference, each team of authors will revise the papers, compiling the final versions in a book by the European Observatory on Health Care Systems, which will be made available to conference participants in early 2003.

Health as citizenship

Hannah Arendt developed three dimensions of being fully human: family life, work life and public life, the vita activa. Within these arenas, what connects us as human beings is trust, reciprocity and mutuality, dimensions of what increasingly is being called the social capital of societies. Discussing these issues in terms of health presents several difficulties in former closed socialist societies that are now open to the free market and to increasing individualization. It highlights crucial policy conflicts between what is considered a public and collective good and what is considered a private responsibility. Of course, it is quite inappropriate to try to over-generalize trends in countries that are so inherently different in their historical backgrounds and their present social and economic situations (such as the economic differences between Slovenia and Ukraine). Yet all countries discussed at this conference bear a similar legacy of a highly formalized, state-centred system, with forced participation in certain areas of social and public life. Discussing participation in health as an expression of citizenship needs to take into account this legacy and the new environment of rapid change, social insecurity and extreme inequalities. As many authors have stated, high social capital may well be a prerequisite for economic growth — yet high levels of inequality contribute to reductions in social capital and civic cohesion. This paper therefore tries to look more widely in discussing the interface between civil society and health.

As a principle, the mobilization of citizens and communities for better health embodies both the dimensions of democratization (including joint decision-making and accountability) and of individualization. In the countries of central and eastern Europe, it was (and is being) experienced in all its ambivalence and ambiguity as many countries moved from a collective to an individualistic understanding of health This is reinforced by moves (and strong pressures from major donors) to reshape the health system and shift responsibilities from the state to other levels of governance, to the private sector and to individuals and families. Any analysis of this process must take into account the political and social contexts within which participatory and collaborative strategies for health are proposed.

For citizens, it includes the ambiguity of gaining a concept of individual human rights or patients' rights yet perhaps losing the collective right to health as a public good and, in the context of the transition, losing access to services. For health professionals, the changes could be seen as a major loss of authority, both towards the general population and towards other sectors with whom they were now called on to cooperate. Nothing had prepared them to work in this new manner. For politicians, it meant accepting voices outside the formal political system, a more open democratic process than that represented by political parties.

The public health premise: health is everybody's business

Mobilizing citizens and communities for better health is a central component of what we now call the "new public health," and health promotion, intersectoral action and community participation have been defined as key public health functions. In the work of the World Health Organization (WHO), health promotion has been promulgated since the mid-1980s as a democratic and social participatory health strategy, building on the principles first developed in the Declaration of Alma-Ata in 1978. The Ottawa Charter for Health Promotion identifies "healthy public policy" and "community action" as two of the five key action strategies of health promotion, and a recent publication by WHO on evaluating health promotion (Rootman et al. 2001) states: "… we suggest that the primary criterion for determining whether a particular initiative should be considered to be health promoting, ought to be the extent to which it involves the process of enabling or empowering individuals and communities."

To date, any modern health and development strategy pays at least lip service to a broad participatory approach, and donor agencies and international organizations have included community participation and stakeholder analysis throughout their programmes in the developing world and in central and eastern Europe. Indeed, what started with a focus on community participation has been widened to include a wide range of partnerships in order to solve problems related in particular to prevention, which reach far beyond the health sector and now also include public — private partnerships. With this approach, community participation and intersectoral action moved closer together, as did prevention and treatment such as in the case of HIV/AIDS.

Even before the changes that started in 1989, the WHO Regional Office for Europe — particularly through its health promotion programmes and initiatives such as Healthy Cities — had provided the opportunity for health professionals and local partners and politicians to learn about such approaches. The Healthy Cities project in particular became a conduit for exchange of experiences between local communities in central and eastern Europe and western European democracies, which reached far beyond the health arena. A similar stakeholder approach was initiated by the Safe Communities initiative, which initially focused on injury control. WHO's health promoting schools programme was deliberately launched first in the countries of central and eastern Europe. It was welcomed by a number of governments, particularly because of its potential to teach democracy at a very local level, for example through the involvement of parents in decision-making — a quite novel concept in many of the countries involved. Other health promotion initiatives in the field of heart health, prevention initiatives such as CINDI, tobacco and alcohol control strategies, family planning, women's health and later activities in relation to HIV/AIDS also stressed the importance of cooperation, advocacy, participation and community involvement. WHO's European regional health policy framework, HEALTH21, repeatedly makes the point that health cannot be resolved through the health sector alone but needs to be approached as a joint societal effort: "health is everybody's business."

Combining the civil society puzzle with the "health puzzle"

An analysis by the Carnegie Endowment for International Peace (Ottaway & Carothers 2000) makes a forceful point about context and attributes many of the failures of civil society assistance around the world to a lack of understanding of what has been termed the "civil society puzzle." Too frequently, well-meaning efforts neglect to take into account:

— the existing civic traditions within a country;

— the variety of organizations that have emerged to tackle key issues; and

— the understanding of the role of citizens and organizations, particularly in relation to the state.

Kevin Quigley (2000), in his analysis of the modest results of assisting civil society in central and eastern Europe, points to the existence of two very different mind sets: that of the eastern Europeans, who believed that the mass movements that had spearheaded the change during the 1980s would turn rapidly into a "new society rich in associational life characterized by a more humane politics" and that of the American donors, who attempted to recreate eastern European civil society in the American image. He states bluntly, "Eastern Europeans and their donors did not share a definition of democracy."

An analysis of the role of the citizen and communities in health and health care in central and eastern Europe needs to be particularly aware of context. In paraphrasing Quigley's point about democracy, it can be stated just as bluntly that eastern Europeans and their donors (in particular the American donors and the US-based consultants used by many of the international organizations) did not share a basic definition of health and health care. The right to health and health care was part of the constitutional right of citizens in many of the countries of central and eastern Europe and a key defining feature of governments' "social contract" with their citizens, reaching back to the first constitution of the Soviet Union written by V.I. Lenin. For a significant period of time (roughly into the early 1980s) universal access to health services and a strong commitment to public health were a source of pride in many of the socialist countries, and constituted a central argument frequently put forward in the debate about the respective superiority of the capitalist and socialist systems of governance. Many a debate about more equity in access in western countries was wiped from the table with the argument that its proponents were intending to create a "socialist system of care," a pattern of response that persists to this day in the United States. It is important to keep in mind that the debate about health care was from the very start a central component of the ideology of the cold war, precisely because the approaches in the United States and the Soviet Union were so diametrically opposed. Consequently, the health sector became a key focus (and in some cases a battleground), in both ideological and economic terms, after the fall of the Berlin Wall.

From the late 1970s, most of the countries of central and eastern Europe were not only losing the arms race but were also less and less able to supply high-quality health care, one of the key "public goods" that was providing legitimacy to the regimes in power. (This point is analysed in more detail in other background papers to this conference.) In addition, the declining health status (as first presented by the WHO Regional Office for Europe in the 1980s) indicated that a broader range of factors needed to be addressed than had traditionally been considered within the highly hierarchical and medicalized health care systems of these countries. Increasingly, experiences from other countries showed that these "lifestyle" problems could only be resolved through cooperation with partners outside the health sector, including the media, and through a cultural acceptance by the public at large. But many central and eastern European governments did not want to draw attention to these developments (for example the very high level of alcohol use), which they saw would be interpreted not only as a "health systems" failure but also as a failure of the "socialist way of life."

Addressing health concerns in relation to "lifestyles" would also require a change in the culture of socialist health systems and in the mind-set and behaviour of health professionals, who were slow to accept that authoritarian, top-down approaches were doomed to failure. In addition, any policy or campaign calling on the population to adopt a "healthy lifestyle" lacked credibility in the context of deteriorating living conditions and the crumbling "social contract" between the people and the state. Health targets and the means to implement them were worlds apart. The various recurring attempts in Hungary — starting in 1987 following Hungarian participation in the WHO Ottawa Conference in 1986 — to develop a national health promotion programme document these points very clearly. As an extreme example, lack of access to alcohol and tobacco could prove dangerous in already highly volatile political situations. This was the case in the Gorbatchev era in the Soviet Union, when social unrest due to a shortage of cigarettes was averted through a special deal with, and emergency supply by, western tobacco companies.

From 1989 onwards, the rapid social change and "double transition" towards a democratic system of government and a market economy left a deep impact on health and its determinants and on the organization of heath care systems. The recent series of interviews with central and eastern European health ministers published in Eurohealth highlights the ongoing conflicts they face in finding a balance between collective and privatized systems of health care and in giving appropriate attention to disease prevention and health promotion. Suffice it to say at this point that the interest of donors lay more with the privatization of health care than with its democratization — possibly because the population had little interest in giving up the collective rights to health care, while governments were pressured by professionals from within and donors from outside to embark on "reforms" that basically implied cut-backs in public services and increased privatization. Indeed, it would be worth a detailed analysis to understand what role this lack of involvement, information and consideration of people's concerns about health and health care has played in bringing political parties that support universal health care back into power throughout central and eastern Europe.

It must also be said that donors (and in the early days even some international organizations, including WHO) were not ready to prioritize health promotion issues, which were considered less essential than health care reform or were in conflict with the promotion of free markets. This resulted, for example, in a lack of resources to help countries develop strong tobacco legislation or to develop and strengthen HIV/AIDS prevention and advocacy. The price for this failure is being paid now. A well known example is the opposition of the great civil rights advocate, President Vaclav Havel, to strong tobacco legislation, which he sees as running counter to the democratic freedoms gained after 1989.

Not much information is available on how citizen participation and intersectoral action have been systematically fostered in the health sector reforms in central and eastern Europe, or how the existing mind-sets in relation to health and civil society (the respective puzzles of tradition, organizational structure and the relationship between citizens and the state) have structured the response. Also, we know little about the extent to which participatory strategies in the health sector have contributed to the development of civil society. This conference provides an excellent opportunity to attempt a first review and analysis, and perhaps provide an impetus for more detailed research to follow.

Positioning of health in the context of civil society development

As stated above, the mobilization of citizens and communities for better health is part of the broader understanding and organization of civil society within a country or group of countries and cannot be analysed in a vacuum — it is about how policies are made, how priorities are set and how accountability is ensured. This must be underlined, because there is a significant difference in perspective if we speak of individuals as clients or consumers of health care, or as citizens with a voice and a right, or as citizens seeking their rights, such as people living with AIDS. This is particularly important in the field of health promotion, which defines its remit as the process of enabling people (individuals and communities) to increase control over their health and its determinants. Much of this process takes place outside of the health care system in (as the Ottawa Charter states) the "context of everyday life" where health is created.

As a consequence, the organization of civil society, the realms of decision-making and the opportunities for social learning are critical for the new public health. It is for this reason that health promotion has, on the one hand, developed organizational approaches that increase the commitment to health through healthy public policies and participation in health in the settings of everyday life: schools, workplaces and neighbourhoods; and on the other hand has developed and supported grassroots advocacy movements around major health concerns, including equity and human rights. In central and eastern Europe (as elsewhere) it has been difficult for all concerned — politicians, professionals and citizens — to come to terms with a non-medical model of health.

As in any sphere of intellectual and political endeavour, definitions abound. The following definition of civil society can serve as a guide for discussions.

Civil society is the critical space between the individual and the state that creates a geographical landscape for social organization and action. It is also a theoretical cornerstone in local community development, a mechanism through which to reassert local priorities through local democracy.

This definition allows an understanding of a dynamic social and political space, which allows citizens to collaborate for shared interests. Ideally, such a space is inhabited not only by a very broad range of actors and stakeholders (a plurality of organizations) but also by a highly pluralistic set of values, views and approaches (political pluralism). Their organizational format can include formally established, private, non-profit, self-administrative, voluntary types of organization (Salamon 1993) as well as social movements.

Central and eastern Europe has a long and rich tradition of civil society organization reaching back into the nineteenth century, which was destroyed first by the Nazi takeover and then by the communist state monopolies. For example, in the 1930s more than 5000 societies were active in Czechoslovakia just in the field of charitable and humanitarian care (Fric et al. 1997). Under communist rule, quasi civil society organizations (usually called "social organizations" or "mass organizations") were established in fields such as sport, education and culture and controlled by the state. In health, the Red Cross was allowed to continue to work but only in close cooperation with the government-run health services. In the 1980s in many of the countries of central and eastern Europe, civil and opposition movements, grass root circles, ecological movements and human rights groups started to emerge. As the health sector began to erode, self-help groups and voluntary associations, for example for disabled children, were established. The Polish sociologist Ewa Les (1993) states that prior to 1989 the voluntary sector was one of the principal mechanisms for breaking citizens' apathy and promoting solidarity and community. Yet we must remember that in countries such as Albania and Romania even these openings did not exist.

Civil society organizations take on a number of roles, all of which can be of relevance to health development, particularly if we look beyond health services to include the determinants of health:

— strengthening democracy

— promoting social8 and economic development

— replacing waning social services

— strengthening social cohesion

— promoting equitable development

— promoting the efficient and socially sustainable functioning of market economies.

It is important to highlight this wide variety because the critical analysis developed in the Carnegie publication underscores the danger of a too-narrow, anti-historical and preconceived definition of citizens' action, focusing on supporting only a certain type of non-governmental organization while neglecting the many other forms of social action and organization. Whereas in the promotion of democracy there was a tendency to focus on policy groups, in the health field there is a tendency to support service-oriented organizations rather than controversial "movement-type" advocacy groups. But particularly with deteriorating living conditions and quality of life and increasing inequity, supporting the mobilization of citizens and communities for better health would imply addressing determinants of health, as many of the environmental groups in central and eastern Europe have done. Or, in view of the spread of HIV/AIDS, the support of controversial groups such as sex workers, drug users and gay or bisexual men gains increasing importance, as has been realized by the Soros Foundation. Also frequently undervalued has been the buffer role of civil society in relation to the stresses of everyday life, which points to the need to support groups and associations that neither provide direct services nor are involved in policy, but that help generate day-to-day social support.

The expansion of civil society organizations was extraordinary in some countries. In Poland in 1989, for example, there were about 5000 nationally registered independent organizations. This grew to about 30 000 by 1997, many of which were tiny organizations involved in service delivery and funded by small individual contributions. A similar trend is true for Hungary, which has about 50 000 civil society organizations, many of them local non-profit bodies created in response to the lack health care, education and social services. One of the strongest areas for activism was the environment, an area of policy that had been severely neglected under communist rule. In her analysis of the civil society sector in the countries of central and eastern Europe, the Hungarian sociologist Elizabeth Vari (1998) shows that while health is still strongly underrepresented it is rapidly increasing. This might be due more to the need to respond at community level to a deterioration of services than to an increase in civic engagement for health per se. Her summary indicates the following (very divergent) percentages for the health field: 7% in Bulgaria, 3-4 % in the Czech Republic, 11% in Hungary and 20% in Poland.

In general, these data indicate that health is still seen as a responsibility of the state and of health professionals, and that explicit health advocacy groups have not yet gained strength and prominence. But what health policy in central and eastern Europe increasingly needs — given the enormity of the problems of morbidity and mortality — is a broad range of civil society coalitions to address major challenges, such as deteriorating living conditions and human costs of the transition, unhealthy products, prevention, control and treatment of HIV/AIDS and premature male mortality, to name but a few. The health crisis is at the very core of eastern European societies, and in some cases is threatening both social cohesion and economic progress. These will not be resolved through a fiscal or medical solution but need broad societal consensus and energy. Donors — as far as they remain active in central and eastern Europe (many of them have been too quick to move out given Ralf Dahrendorf's estimate of time needed for significant change) — should also take note.

The importance of civil society for health

In the light of this enormous challenge, the examples presented at this conference in relation to mobilizing citizens and communities for better health in central and eastern Europe could be structured around the following questions.

— What contribution has civil society made with regard to priority health problems?

— How can the role of civil society in health best be enhanced at different levels of governance (national, regional and local)?

— How can health systems facilitate and enable greater civil society involvement?

— What balance is emerging in different countries in addressing policy, advocacy and accountability and service delivery?

— What role can the international and donor communities most usefully play in this context?

The acceptance of the role of civil society in health is related both to understanding the importance of civil society organizations in general and to the contribution it can make in a highly professionalized arena such as health. In central and eastern Europe, a not infrequent claim by the new political elite is that the establishment of democracy and political parties makes grass-root activism and social movements redundant or even illegitimate. Most visible was the conflict between Premier Vaclav Klaus and President Vaclav Havel on the issue of tax relief for voluntary associations in 1994. Also, civil society organizations and social movements experienced a major brain drain, since many of the activists of the 1980s were now running the new political and social institutions and had become active in the new political parties.

It has taken time to understand that a vibrant civil society is a crucial social space of learning and trust building, which helps to mobilize individuals to participate as citizens in the affairs of their societies, and that this also applies to what has been considered a domain for medical professionals. The health sector is still grappling with accepting the role of the empowered citizen, the involvement of other actors and sectors, and new forms of accountability for health outcomes. Both eastern Europeans (politicians, professionals and activists) and western donors have underestimated the time and effort this takes. Ralf Dahrendorf (1990), for example, has stated that while it takes 6 years to build a market society it takes 60 years — at least a generation — to build civil society. Democracy is as much a political practice as it is a culture of social tolerance, and the region as a whole still needs to cope with the legacy of paternalism, suspicion of the government (even if democratically elected) and mutual suspicion of one another. And it needs to deal with a certain amount of disillusionment, as not all promises of democracy and market economy have been realized.

In relation to health, two additional important dimensions have to be considered:

— the impact of a vibrant civil society as a key determinant of health; and

— the contribution of health activism to a democratic society — many health issues have a strong dimension of quality of life and many social issues (such as violence, drug abuse and prostitution) have become part of the health domain.

Robert Putnam (2000) underlines the contribution of social capital not only to "civic health" but also to personal and community health. A large body of research now shows the very strong positive connections between social integration and health, as well as the feeling of empowerment and health. Studies in the United States show that health is better in "high social capital states" or, as Putnam expresses it, "What these studies tell us is that social engagement actually has an independent influence on how long we live." For the countries of central and eastern Europe, the rapid deterioration in life expectancy has been linked to the (non) functioning of civil society, in particular the low levels of trust, as well as to social isolation and low levels of control over life and control over health. Hertzman & Siddiqi (2000) describe the changes experienced in the societies of central and eastern Europe as "the most comprehensive natural experiment in population-wide stress available, short of war or mass starvation." A detailed analysis is still outstanding as to what social coping mechanisms have been developed. Boris Genov, in his analysis of Bulgaria, indicates that almost every second citizen over 18 relies on a survival strategy, which does not leave room for forward-looking organized civil engagement. Many donors, according to a recent UNDP analysis (2002), have failed to understand the complexity and painfulness of the transition.

The other dimension is the importance of activist groups to help redefine the health agenda and defend the human rights of vulnerable and disadvantaged people. As is the case throughout the world, government officials in central and eastern Europe are wary of advocacy groups and more easily accept groups willing to be active in service provision, particularly as services are cut and demands rise. For many donors, turning to nongovernmental organizations was also a cheaper way of getting some things done quickly rather than investing in more long-term organizational and administrative change.

For the health sector, this simple division into policy/advocacy-oriented organizations and those oriented towards service provision does not always hold. This proved to be particularly true in the field of HIV/AIDS, where issues of human rights advocacy and service provision in relation to prevention, testing and care were heavily intertwined. Civil society groups were far in advance of government representatives in recognizing the problem and reacting to it. It is perhaps in the area of HIV/AIDS where the interface of democracy, human rights, civil society and health comes to the fore with the greatest clarity. But it is also in this area — as in the field of family planning — where wide differences in opinion and ideology are frequently played out, and where platforms for dialogue and mediation need to be developed.

Where are we today?

Nikolai Genov in his analysis of the present situation in Central and Eastern Europe states, "To put it bluntly, what is going on in the central and eastern European region might be shortly defined as the triumph of individualization at the cost of the common good." Under a period of rapid transformation and increased social and personal uncertainty "a typical central and eastern European dilemma" emerges that aims for increased private initiative but wants the security of state-provided services (as in health), yet at the same time mistrusts the state institutions and is disillusioned with the private sector.

The civil society sector continues to be weak. In many countries it still lacks a consistent legal framework. Despite many training workshops and an influx of consultant services from donor countries, most nongovernmental organizations are still managerially inexperienced, have weak communication infrastructures, show a lack of technical expertise and suffer from a severe shortage of money. A recent UNDP conference in Vlora, Albania discussed the failure of nongovernmental organizations to develop greater participatory democracy, stressing that one of the reasons has been the focus on service delivery and humanitarian assistance because of the economic, social and humanitarian crisis in the region. But — similar to the Carnegie report — the conference also highlighted structural factors related to the donors. In particular, it pointed to their tendency to support nongovernmental organizations that were willing to work according to procedures and concepts laid down by the donors, rather than systematically support civil society development at the local level and according to the local societal context. The trend has now moved towards community-based coalitions, a concept spearheaded early on by WHO's Healthy Cities project and environmental initiatives such as Agenda 21. This includes new approaches to financing: for example, 70% of Hungary's local governments have established municipal foundations to support social services and health care (Szeman 1997).

In a recent interview, the former Georgian Minister of Labor, Health, and Social Affairs, Mr Avandil Jorbenadze, stated, "Citizens' poor awareness and participation in the reform process, and the realization of their own rights, also pose additional threats for achieving the reform priorities." There is an urgent need to explore the social and political mechanisms that support or hinder citizen and community involvement in health in the countries of central and eastern Europe. Too easily, the mobilization of citizens and communities for health is framed only in their adherence to healthy lifestyles or rational use of the health system. No systematic efforts are made to create transparency and accountability, promote health citizenship and increase health literacy and empowerment.

Paying attention to context remains a crucial challenge, and the rapid transformations in the societies of central and eastern Europe seem to reinforce individualization rather than community — in the health arena as elsewhere. The disarray that ensues as institutions are reformed, and the daily experience of lack of institutional capability, erode trust and social capital. The key conflict facing all modern societies is how to balance personal autonomy and community, and the countries of central and eastern Europe face this choice in the extreme. In the face of weak institutions, more than any other challenge in health this must be faced squarely as a priority political task and a governance challenge of the highest order.

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