Non-State Actors and Public Health Policies

The role of civil society in the coproduction of health services in the formation of public health policies

Experiences in China, the United States and in France

March, 21st-23rd 2010

Institut de recherche et débat sur la gouvernance

Institute for Research and Debate on Governance

Instituto de investigaciòn y debate sobre la gobernanza

Center for International Studies, University of Virginia

Centre d'études internationales de l'Université de Virginie

With the support of the Embassy of France in Washington
Office of Non Governmental Affairs

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I. Context and Objectives

The role of non-state actors in public action is in full evolution. Whether they are associations, cooperatives, mutual companies, NGOs, unions or businesses, they participate in many countries in the providing of general interest services (health, education, water, environment, land...). They are becoming increasingly active in agendas for negotiation and consultation, from the local level to the international level, in order to promote changes in public policies.

In 2007, the Institute for Research and Discussion on Governance (IRG) and the Foundation for the Development of Chinese Youth (FDJC) organized in Beijing a Franco-Chinese meeting on the role of non-governmental organizations in the coproduction of services and the direction of health and education policies[1]. The success of this meeting made participants want to pursue and expand the dialogue to include other national settings. In 2010, the IRG enlarged this meeting to include the United States, deciding to focus strictly on the health sector. This new step in the discussion process was organized in Charlottesville (USA) in close collaboration with the Center for International Studies at the University of Virginia (UVA).

The meeting was held at the precise moment of the vote on profound reform in the health insurance system, one of the priorities of the Obama administration that sparked a particularly lively social debate in the United States, marked by adamant viewpoints from various personalities and interest groups. This debate, essentially on the evolution of the American healthcare system, did not fail to affect the French government, which is examining the governance of its own healthcare system during the course of the past few decades and the respective role that the State should play, as well as that of professionals and users of healthcare services. This is also a current issue in China, where the search for a new model of social coverage and the eruption of sanitary problems like that posed by AIDS, has seen the introduction of new actors and new causes to the scene.

This international meeting thus allowed for an examination, in each of the three countries, of the role of non-state actors in the coproduction of services and in the formation of public health policies. The objectives were to organize an exchange of experiences in order to undertake a comparative analysis of the actors, the logistics, and the innovative experiences in terms of dialogue and cooperation between civil society and public powers in this sector, especially to enrich strategies of action amongst non-state actors.

In many countries, the question of public health policy creation is being posed more and more, which enables us, thanks to adapted spaces of consultation, to value expertise, the dynamism and deep-rootedness of non-state actors in

1. A summary available at <http://www.institut-gouvernance.org/IMG/pdf/beijing-9-11-2007.pdf>.

the domaine of health services, and to benefit from their experience and their knowledge of health needs.

This evolution that is taking place in all three countries mentioned here brings up questions of an operational order: in terms of non-state actors, how can we prove their legitimacy and have them be recognized as voices of public power? How do we transform acquired knowledge from experience into political recommendations? How can we comprehend the inequality of power relations?

Questions of a political nature are also brought to the forefront. For these non-state actors, is it possible to be involved in partnerships of this type without losing their freedom of speech and their critical capacity? Do their growing involvement in the delivery of health services not risk clearing public powers of their responsibilities and thus undermine their legitimacy? In short, how do we construct a collective cohesion through a diversity of actors working with health policies?

This meeting, the second step of an analysis on the part of the IRG of the activity of non-state actors in the health sector, will be followed today by more specific studies in certain national contexts and by meetings in other geographical zones in the future.

Two challenges plaguing the health sector grabbed the attention of participants as soon as the meeting was prepared, and consequently framed the group discussions: access to health care for the neediest, on one hand, and policies of prevention and action against AIDS on the other. We propose to return to participants' reports in order to more fully examine the contexts of each of the three countries affected by these challenges, before presenting some aspects of transversal questioning that was present throughout the seminar's discussions.

II. Chine

II.1. The Chinese health system and reform perspectives

With the political reforms of the 80's and 90's, the Chinese health system, based on the system of cooperatives and other collective forms of work, slowly crumbled. The indicators of health in China are congruent to the average level of income per habitant, but they hide deep disparities. In the countryside, where almost 80% of rural inhabitants are not covered by insurance, the materials of clinics and health centers are overstretched, and almost half of the population declares never having visited a doctor[2]. In cities, health services were for a while better assured but proved weakened by the abundance of new mar-

2. According to the third national study of health services, completed by the Minister of Health in 2003, 79.1% of the rural population is not medically covered and pays all medical costs. (cited by Mr. Li Gang)

ginalized urban populations. The appearance of new epidemics, such as SARS[3], equally contributed to revealing the fragility of the Chinese healthcare system in general and incited reflection on possible paths for reform in the sector.

Faced with the different possible models of health governance, the government attempted several types of projects, at times being strongly criticized by the media, which was gaining at the same time in influence and more freedom of speech. Furthermore, in order to enrich its strategic analysis, the government turned to foreign experts (international institutions or private organizations) and opened the door to researchers, generally tied to Chinese universities, and to think-tanks linked to pharmaceutical companies. With this apparent strategic openness, the State, however, fully kept control of the directions of the analyses, which were organized around an inter-ministerial committee in charge of formulating propositions and scheduling the calendar of reforms.

At the heart of the debates: the role of the State in the financing of health. Two major approaches that differ: on the one hand, those who tend to consider health as a public good that requires by nature a significant involvement of the State; on the other, those who propose mobilizing mechanisms of the free market and reducing public intervention. Questions concerning which health issues are taken care of, the role of public powers in the prevention and evolution of mindsets, or the obligatory nature of individual insurance, all come to the forefront of a large part of the debates and return to the fundamental problem of the more or less public nature of the health sector.

If these debates of the last two decades have seen the emergence of a series of non-state actors' voices in analyses of the health system (the researchers, the industry, the media, etc.), the organizations for citizens, the workers' associations, the NGOs and the foundations have remained, according to them, relatively distant. In focusing mostly on the action on the ground that is less covered by the media, these groups are however assured progressive recognition for their operational role in several sectors, notably in access to healthcare for those in rural areas and in the fight against AIDS.

Mr. Ding Ningning, of the Council of State Affairs[4], differentiates amongst several categories of non-state actors in the health domaine. For him, it is necessary for individuals to bring to light problems, for the media to spark a public debate, for the NGOs and the businesses to contribute to research and social experimentation, and for the GONGOs[5] to gather the non-state actors' opinions and relay them to the government. Each one must participate in the monitoring of public policies.

3. Or like atypical pneumonia, appearing in China in 2002.

4. The Council for State Affairs for the People's Republic of China is the main civil administrative organization in China. It is led by the Prime Minister and includes members of governmental agencies and departments.

5. Government operated non governmental organizations : associations under public sponsorship, although they can benefit from funding that is essentially private, for example, donation collections.

According to him, non-state actors play an irreplaceable role in the identification of problems needing to be resolved and in the follow-up of public policies. He remembers, for example, that in terms of AIDS in the province of Henan, it is they who denounced the malfunctioning of the hospital system and of the cooperatives. However, their lack of professional competence and desire for their own promotion can, in some cases, drive them to deceive the public, politicians and the government. M. Ding calls for a greater professionalisation of non-state actors.

II.2. Access to care, the fight against AIDS: the reports from Chinese actors

II.2.1. Access to health services: the inequalities of healthcare in the rural world

The rural world, in the aftermath of the disappearance of agricultural cooperatives, has seen the collapse of the health system that relied on these cooperatives. Faced with this space left open, a series of local and national solidarity initiatives more or less achieved success. Two interviews provide clarifications in this area:

o Mrs. Yang Tuan, researcher at the Academy of Social Sciences, describes her participation in local projects aiming to put primary healthcare systems in place on the basis of voluntary membership of users, notably in Luochuan, Yongji and Shijian, from 2000 to 2010. The purpose of one of the projects was to make farmers the main actors in a local cause in favor of healthcare by organizing financed cooperatives funded by contributions, by creating new clinics or even by educating young people in providing basic care. If at first, most of the farmers played the game of contributions, the fact that several quit (notably those who were not recipients of care) progressively caused an end to the project. For Mrs. Yang, one of the conditions for success for these local projects resides in their financing and control by the State, who has to be brought in as a driving role, all the while eliciting active participation of users. They, the users, generally remain too far removed from the formation of public policies. This is why such great transformations on the local level can only be born by a profound transformation of the citizens' relationship with public action within Chinese society.

- For Mr. Li Gang, who directs the program "Hospital of Hope" within the Foundation for the Development of Chinese Youth, the shortcomings of social coverage, particularly significant in rural areas, justifies a significant implication of the private sector in this domain, in close relation with the public powers. Her foundation (a GONGO under the close sponsorship of the Chinese State) mainly functions thanks to private donations. The program

Hospital of Hope aims to rehabilitate health centers and small hospitals in rural areas for a population of mostly farmers. Several small towns and villages, in fact, have outdated equipment, broken down buildings and insufficiently trained personnel. In terms of partnerships with local groups, the program puts into place educational courses, provides equipment, and renovates buildings. These actions are undertaken in a joint effort with other programs driven by the same foundation, notably in the domaine of education, thus allowing to better its effects, especially by joining together prevention and care. In 2009, the program supported the reconstruction of 25 hospitals in the countryside for a population of around one million people. Once reconstruction is complete, the hospital's management, including payment of personnel and medications supplies, must be continued by public powers. Local cooperatives were often set up to deal with, for example, chronic sicknesses, but their action with the hospitals and clinics were not met with success. For Mr. Li, this failure was primarily due to the fact that these cooperatives did not hold enough power, notably on a financial level, in order for their voice to be heard.

II.2.2. The fight against AIDS, fields of action of associations

In the area of AIDS, whose seriousness was denied for a long time by the Chinese authorities, numerous associations, more or less known, have been created in China and are organized today in networks. Several reports allow us to better understand their fights and the evolution of their relationship with the public powers:

- A new type of mobilization was created following the contaminated blood scandal: blood collections performed without sufficient precaution by the public authorities contaminated around 300,000 people according to certain associations. Doctors who looked into the gravity of the situation were chased away and the situation was concealed until international medias relayed the information and forced public powers to assess the situation. The association "Dongjen Center for Human Rights, Education and Action," created in 2003 in the province of Henan where this affair took place, was involved for several years in this struggle. Now forbidden in Henan, the group doubled its efforts in Beijing but did, however, have a very conflicted relationship with the State until 2006. Its director, Mr. Li Dan, personally feels protected by his connections and his social status. The action of his association now seems better tolerated by public authorities, although it is still insufficiently understood. These public authorities are those who continue to easily drown out rebellious voices, creating thus an obstacle for the work of certain NGOs involved in politically sensitive areas, financed in large part by foreign money.

The situation of these more independent NGOs in regards to public powers, who denounce the malfunctioning of the system and work to protect users, remains tenuous. They benefit from more and more support from foreign NGOs, scientific groups and international organizations who offer them a forum, seek to include them in the management of funds meant for the fight against AIDS and other diseases, and facilitate their access to information or to education, notably in terms of advocacy. Such international support has notably permitted these Chinese associations to gain in legitimacy, to better understand other groups and to get organized on a national level.

- Other independent associations, active in the fight against AIDS, are mobilized around more specific populations, like in the case of the associations who fight for the protection of homosexuals' rights. The "China Male Tongzhi Health Forum (CMTHF)", based in Chengdu, contains several hundreds of associations of this type, originating in various provinces, in order to create a unified political voice for this issue. The group's secretary general, Mr. Wang Jun, discusses the evolution of this movement: up until the beginning of the years after 2000, these associations were able to develop programs for homosexuals thanks to the support of foreign organizations. Since 2004, the government of the Sichuan province is aware of the importance of AIDS but ignores how to help the afflicted populations, by what means information can be collected, and where efforts should be directed. Certain organizations like the CMTHF hold information and are so experienced in this area that they have public powers at their disposition, resulting in a reinforcement of their credibility and a developing collaboration with the State.

The CMTHF, which is concerned above all else with human rights, remains critical of public action in this area and in the way in which a large part of international funds destined to fight AIDS is used. The government seeks to provide free services to seropositive people (in terms of information and dealing with the sickness), without sufficiently taking into consideration the discrimination that they face in regards to the general public and the withdrawal of the community that results, pushing these people to prefer services proposed by certain associations that they trust. They are also often the only ones who take into account the psychological effects of people who are HIV positive.

The CMTHF is a young but greatly growing network that does not see itself as a partner of the government, but rather as an interlocutor capable of criticizing and offering answers, and having a capability to negotiate that they hope to better. If dialogue with the health authorities allows it to better relay its disputes to political members, a lot of difficulties still subsist in the relationship between the associations and the government: in terms of recognition of the quality of their work, in terms of official registration, in terms of public financing, etc. Even if there is no open conflict, which would render their work impossible, these difficulties seem, according to Mr. Wang, persistent if not growing. The CMTHF often plays the role of mediator amongst certain of its members

and the State. For Mr. Wang, the bringing together of associations is an imperative: if only one association negotiates with the government, it will not be able to claim sufficient legitimacy needed to put forth its ideas.

II.3. Some challenges for non-state actors within the health sector mobilized in China

The Chinese reports and their responses to French and American questions allow us to put forth the following points:

· Most of the 800,000 associations existing in China are registered as private groups because of the very restrictive nature of the legislation, with which we find the impossibility for an association to be registered in an area in which another organization is already carrying out the same type of activity, the legal difficulty of accessing international aid, the restriction of the number of associations benefitting from fiscal deduction systems, etc...

· There is no national registry of Chinese associations, except in the environment and AIDS fields. This lack creates substantial difficulties for foreign NGOs in their attempts at identifying possible Chinese partnerships

· The associations represented at this meeting subscribe to a school of thought based on critical dialogue with public authorities, and claim to be inspired by the "Australian model" by cooperating at several different levels with the State: national, regional and local. We must also note the central role of platforms such as the CMTHF in mediation between public powers and certain associations that are rather unknown or marginalized because of their position of protest.

· Decentralization allows associations more room, and in diversifying their political interlocutors, often proved beneficial to them. This is the case, for example, in the province of Sichuan, where local power is deemed by homosexual associations as more tolerant than the central powers. The process of decentralization put in place in the 1980's in China was however interrupted, if not subverted, in the 1990's.

· The legitimacy of associations is based on their knowledge of the land, the confidence of the population, the autonomous financial means to which they have recourse and their ties to researchers and professionals. External support (coming from NGOs, international organizations, the foreign press) thus played an important role in reinforcing recognition of Chinese associations in their own country. However, these external ties are too rare: only a small fraction of the Chinese personnel from these associations speak English and thus have difficulty maintaining international contacts.

· Universities have played an important role in the debates on reform of the health system and are considered in China central participants in this area. Certain public universities have access to analysis groups and research laboratories closely linked to governmental milieus, all while maintaining regular contact with foreign counterparts.

III. The United States

III.1. The American health system and perspectives on reform

There is no actual "health system" in the United States, in the sense of an organized system of financing intended to provide healthcare services to the majority of Americans for most of their needs. There exists a complex and not quite organized system of mechanisms dealing with healthcare, varying according to the area, leaving a rather sizable part of the population (around 15%) uninsured, and remaining strongly marked by unequal access coinciding with social categories and the place of residence of users. This observation made by Thomas A. Massaro[6] is tied to a fundamental characteristic of American culture: the importance attributed to individual autonomy, which leads individuals to still feel hesitation towards action from the State, as it is seen as a matter of personal choice.

The current debates on reform in the health system[7] are centered around several issues, including: bettering health coverage for those who are not insured, founding of the healthcare system on better principles, and more effectively controlling costs. These debates are marked by a large movement of non-state actors, in particular private enterprises, unions, religious groups, but also certain non-profit associations like organizations for the sick and the retired, universities, advocacy groups, etc. The interests, the positions, and strategies of the different actors are extremely varied and find themselves today relayed largely by the media, in a debate that strongly mobilizes public opinion.

Gene Matthews, professor and former counselor for the Center for Disease Control and Prevention (CDC) of Atlanta identifies four major questions to resolve in order to advance in the intricacies of this debate:

· Who should finance the health system? The federal government intervenes for the most part through Medicare (medical insurance for the elderly) and on the state level through Medicaid (medical insurance for disadvantaged people). Businesses and insurances of the private sector and individuals themselves also significantly contribute.

6. Head of the Medical Center at the University of Virginia

7. The meeting was held at the same time that Congress was voting on reform legislation of the Obama administration.

- How can we better the functioning of the public health agencies? It is currently a complex system of organizations, on the local and federal levels, whose autonomy varies greatly and whose functioning is not very satisfactory.
- What are the objectives of a "public health" system? Is it necessary to treat the sick, work in prevention, do screenings? Must health services be provided to the general population or only to the most in need?
- Who is responsible, who defines the agenda, who has the last word? The government, the private sector, and the non-profit organizations affirm their central place in the creation of public policies, although the dialogue amongst these actors is not always clearly defined and recognized.

It is difficult to understand the system and its reform has always been a politically sensitive subject. For Gene Matthews, the influence of non-state actors is enormous, especially due to the central role of the media, capable of boosting their voice. This influence even seems to largely deform the landscape of the American population's needs and interests to the benefit of certain groups, capable of transmitting their viewpoints more extensively. It nevertheless must be said that in certain sectors, like the fight against AIDS, associations have made considerable progress in debates, contributing to the framing in political terms of certain questions that were limited to scientific and moral aspects in the past.

III.2. Access to services, the fight against AIDS: reports from American actors

III.2.1. Access to healthcare for the most disadvantaged

Even if with Medicaid, the health system for the most disadvantaged, the United States disposes of a tool for taking responsibility of health services, a large part of this population does not benefit from sufficient health services and the levels of coverage noticeably vary from one place to another.

Susie Devins and Bernie Kenny work with the association ATD Quart Monde, helping disadvantaged populations in several regions of the United States, notably in New Orleans or in Appalachia. They deem the lack of access to healthcare to be substantial for these types of populations and acknowledge that those concerned have much to say about the failures of the system. It is often people native to the area who make the first steps towards creating solidarity amongst them, even if they need external support. For them, healthcare, education, employment and the environment form a whole. It is about bettering their living conditions and helping them to regain control over their lives. The goal of the associations that help out is to make it so that people take an active part in

these changes rather than wait for everything to come from the State. Solidarity and dignity constitute the keywords of the program "All together for dignity."

Should this sort of action aiming to be a substitute for public services be supported by asking for help from political authorities, so as to integrate this sort of concern into political action? At the time, ATD Quart Monde believes that they are not capable of political engagement. At the local level, other associations participate, however, in more extensive networks.

III.2.2. The fight against AIDS

The US Positive Women Network represents an example of an American network, created in 2008, that is actively engaged in advocacy causes, for both health issues and general living conditions for seropositive women (questions of housing, work, equality, etc.). Catherine Griffith reports the way in which this young organization knew how to be a part of the political agenda (by mobilizing the media and by increasing direct contact with those politically responsible) and gain ground in the national debate. On the local level, the strategy of the PWN network notably consists in reinforcing the network's local members' capacities to be direct actors in advocacy and to be speakers of the local public powers, and play a central role in local media's awareness. On the national level, the network has participated in the production of specific political propositions from the beginning of the 2008 presidential campaign and continues today to give frequent recommendations to the Obama administration. In order to dispose of a real legitimacy at the national level, the PWN takes part today in more transnational advocacy dynamics through its action within the network WORLD (Women Organized to Respond to Life-threatening Disease) founded in 1991.

The organization Futures Group (represented by Tito Coleman) works in several countries on the reinforcement of non-state actors' participation regarding public policies in the area of AIDS. Non-state actors perceived in all of their diversity: including those who are defenders of marginalized sectors, those who take the role of public services, those who give advice to politicians, those who create networks, those who serve as transmitters to the public sector, etc. Looking at the Dominican Republic as an example, we see how sustainable changes in public healthcare policies require the implication of a large diversity of involved parties, in order to decrease the risk of marginalizing certain categories of people and needs. The issue with this extensive participation is thus to seek out concerned actors where they are based (their participation rarely being spontaneous) so as to relay their needs to analysis experts.

III.3. Some challenges for non-state actors in the health sector mobilized in the United States

The American reports allowed us to clarify the following points:

· In a context greatly influenced by a culture of lobbying and the abundance of specific interest groups, the voice of certain sectors in society (notably the poorest populations) seem very infrequently relayed. The action of certain national NGOs permits, however, albeit in often a precarious manner, the voice of these populations to be heard in political debates.

· The pharmaceutical industry and, more largely, the ensemble of businesses in the health sector including insurance companies, took an active role in the negotiations on health system reform. This participation creates in the United States a lively debate centered on the difficult articulation between the consideration of interests (profits) of these businesses and the preservation of idealism that-- for some-- must necessarily inspire reform of the healthcare system.

· According to American participants, freedom of speech in the United States includes the freedom to transmit alarming information, even to play on confusion and fears as was done in the campaign of opposition to President Obama's health system reform project. The very central media coverage of this debate on the health system and the profusion of contradictory messages that it generated gave to the public often very confusing ideas about the reality of the issues and contexts they were facing.

· The American debate on health care is marked by the important legitimacy of the private sector's actions and by lively polemics on the distinction to be created between public responsibilities (notably those of the State) and private responsibilities (notably those of the individual) in this area.

IV. FRANCE

IV.1. The French health system and perspectives on reform

Long time organized around the triptych State-citizens-professionals and based on an individual approach to health and leaving little room for prevention, the health system in France is in constant evolution. Michel Legros (School of Advanced Studies in Public Health) and Roland Cecchi-Tenerini (General Inspection of Social Affairs) remind us of the main dimensions of this evolution.

Beginning in the 1970's, the State has occupied a central role in the managing of health insurance and utilizes a policy of liberal inspiration that aims to handle costs and progressively transfer them to individuals as well as to the different regions (which translated into an increase of mutuals and private insurance plans, payment by the user and the lack of care for certain categories of users).

With the increase of health risks (AIDS, SARS...) between the years of 1995 to 2000, the State stresses again its involvement in the management of the health insurance system. At the same time, by attempting to reduce money spent, it is asking more from the user in the financing of health needs, which has led to a reduction in its own financial participation, decreasing from 74% to 54%. This average on the decline conceals however disparities: around 8 million people suffering from chronic sicknesses see services relating to their sickness reimbursed 100%, while others have to cover an increasingly large part of their healthcare services themselves.

In the beginning of the decade following 2000, the theme of the "health democracy" made its appearance in speech. It was solidified by the law of 2002 that notably ratified a series of rights for users to be individually and collectively informed and heard. Since then, we have seen a great presence of users and associations for users at several healthcare regulation and management proceedings, as well as at the level of evaluation. These associations for the sick and for users of health care structured themselves as a national collective entity[8].

From 1945 to 2010, France has thus evolved in the creation of its health policies, moving from a form of representative democracy, to the beginnings of a participatory democracy that is limited still too often to information and consultation and very rarely permits the collective creation of strategic directions and even less the delegation of power. The creation of the regional Agencies of Health in 2007 is part of the movement towards the decentralization of health policies. What will be the effects? We observe today a certain balancing of the relationship between professionals, patients and public decision-makers, but the influence of the user is limited, and the current balance is fragile. What remains then is to better determine, in France in what way the concept of a "health democracy" only serves as an alibi to static practices, or to the contrary, marks the beginning of a new story.

IV.2. Access to care, the fight against AIDS: the reports of French actors

Access to health care for the most disadvantaged

8. The Interassociative collective on health: (<http://www. leciss.org>).

In France, the CMU and the AME[9], health insurance programs specifically dedicated to low-income people, were put into place during the years following 2000. These reforms owe much to the action of associations that were mobilized in favor of these populations.

François-Paul Debionne, of ATD Quart-Monde, describes how his NGO that helps those who are the most disadvantaged perceives its investment in the health field since the 1970's. ATD considers health not as a simple question of fighting against sicknesses but through the larger issue of the fight for a healthy environment for disadvantaged people. The organization seeks notably to identify the conditions that restrict access to health care and to services, in creating exchanges between concerned people and professionals, especially in order to better understand why people have other priorities than to be treated. In 1985, a partnership between ATD, the health insurance companies, the State, a group of professionals and a series of territorial groups allowed for the creation of "Funds for Health Action" whose goal is to guarantee access to health services that are the least used (dental, vision, hearing). This action particularly enabled them to provide examples of good practices to the Counsel of Europe or at the OMS in terms of pluri-actor construction of unified health programs. It also contributed to forming the law against exclusion (1998) and to creating regional programs for access to care for the most disadvantaged, which still exists today.

In France, the union movement always subscribed to a principle of solidarity in dealing with the health system. Yves Bongiorno, of the worker's union CGT states that since the 1970's, unions have lost power in the health insurance administration, to the benefit of the business leaders. They continue however to fight to break this accounting logic that is currently prevailing, especially in order to reduce inequalities in access to health care and to promote direct spaces of participation of users' associations. The CGT stands by thus the principle of a population that is proactive in its health and brings to light the deep disconnect between those who make decisions and the needs and expectations of the population.

Furthermore, the unions can timely provide health services, while ensuring they do not strip public power of its responsibilities. For example, the Federation CGT of metallurgy created three centers for professional training for those who were injured at work and or elsewhere, and benefits almost 650 people. The excellence of their success served as a spark for other centers in the country.

9. CMU (Universal health insurance) : free health coverage for those who are of low-income households; AME (Medical help from the State): health coverage for foreigners in difficult situations and without resources.

IV.2.1. The fight against AIDS

In the area of AIDS, the NGO Médecins du Monde (Doctors of the World) (France mission) has not ceased filling empty spaces left vacant by public powers: doing anonymous and free AIDS tests, developing needle exchange programs, creating the Observatory of Access to Healthcare, building in 29 French towns Centers of Care and Counseling (CASO) in hopes of bettering access to care for the most disadvantaged, etc. For each of these programs, MDM had to be sure to frame its practices within institutionalized limits so that the State progressively integrated its programs into its programs for the most disadvantaged. For Béatrice Luminet, the presence of the NGO in all of these areas (20,000 patients cared for each year) allows it to have real expertise and an innovative look at health policies that give it an important legitimacy that allows them to contribute to public health policies' development.

In 2000, an inter-associative project came about from the law against exclusion and the setting up of the CMU and the AME. Since then, the group Médecins du Monde (Doctors of the World) has acted on the ground principally by informing patients of their rights in an attempt to guide them towards the appropriate structures and by putting into practice preventative measures, notably in reaching out to populations with the highest risk, like prostitutes and drug users.

Christian Andréo, from the Aides Association, discusses patients' experiences of organizations and their close interaction with the public powers in the area of AIDS. The lack of a medical solution since the emergence of the epidemic precociously encouraged an auto-organization for the sick and justified the demand for their experience to be valued in the creation of policies, as well as in an examination of the evolution of treatment methods. The objectives pursued by these associations were notably the obtention of rights for the individual to be informed and for the collective group to contribute to decision-making. This increased participation has not ceased to be reaffirmed during the last few years. A few steps:

- In 1992, people afflicted with HIV started to participate in research projects directed by the National Agency for AIDS and Hepatitis Research (ANRS), which is composed of public research ministries and organizations.
- In 1994, the Declaration of Paris, concerning the inclusion of people living with HIV in political considerations, was signed by 42 countries and taken up by the ONUSIDA known as the "GPA principle" (Greater Involvement of People living with HIV & AIDS[10]).
- In 2002, the law of the "Health Democracy" was seen as favorable at the meeting of representatives of patients and users, but also set limits: the representatives must be members of organizations approved by the State. The

10. <http://www.unaids.org/fr/PolicyAndPractice/GIPA/default.asp>.

danger of this evolution, signaled by several participants, lies in the attempt to instrumentalize or anesthetize the associations and reduce their capacity to speak to public powers.

Paloma Moreno presents the experience of UNA, a federation of relief associations. This type of organization of professionals finds itself faced with the challenge of attaining the status of veritable partner with the public powers in the co-construction of health policies. Once again, their legitimacy derives first from their own expertise and by the compilation of recommendations coming from experience and practices of member organizations. This ascending method involves articulating the identification and collection of experiences on the ground, with the project of creating collective recommendations resulting from a series of partnerships. For several years, this project of collecting experiences and of constructing a collective voice has permitted the UNA to be recognized by a large number of associations and public powers. However, the spaces of consultation with public powers continue to be insufficient and, with certain subjects, confrontation seems to remain the only possible means.

IV.3. Some challenges for non-state actors in the health sector mobilized in France

During the presentations, exchanges between participants at the meeting bring to light the following points:

- While the United States is leaning towards a health system where the State plays a bigger role, France seems to be going in the opposite direction: the State is withdrawing financially while still intervening in its management, controlling its costs and opening areas of participation to users.

- Furthermore, with the development of internet sites specially dealing with health care, users progressively become (informed) consumers of health care. We can see different movements that mix up the power relations between the State, users and professionals.

- The result of the law of the 4th of March 2002, the notion of a "health democracy" defines the place and the role of the patient within the healthcare system[11]. Since then, laws regarding the handicapped, elderly people and their autonomy, or other issues fit in with the place of users and the sick in terms of the direction taken by the sector. Similarly, as for the psychiatric field, users' associations have taken a significant place, especially in defending the right of those who are mentally ill.

- The National AIDS Commission represents a prime example of a multi-actor institution responsible for the formulation of propositions for public organizations. Representatives for Philosophical and Spiritual Family Prin-

11. The massive mobilization of organizations for people afflicted with AIDS regarding these themes played a central role in the evolution of practices in the health sector.

ciples, a member of the National Assembly and a member from the Senate, experts or representatives from associations and designated personalities by national organizations (like the Social and Economic Counsel, the Ethics Committee, the National Union of Family Associations, the Commission for Human Rights, the Council of Medical Doctors, the Conference of University Presidents...) are all housed within this space. There equally exists, in public institutions, spaces of participation for users of all levels (national, regional, departmental...).

- The health democracy is thus officially declining in all of the structures, with an obligation of respect for users. It is being put in place with all of its contradictions and possible instrumentalizations, but remains nonetheless a considerable advancement in terms of recognizing the voice of the sick in the health system. What are the actual effects of this participation? Do the spaces of cooperation act as places of dialogue, of consultation, of public policy construction? Are they efficient? In short, what is the reality of the French health democracy ? A collective diagnostic still remains to be completed.

V. Elements of synthesis and questionings

Three healthcare systems were presented during the course of this meeting. Despite their differences, which seem reasonable, they present certain common characteristics: they are comprised of multi-actors, and are decentralized, multi-leveled and in constant evolution. What challenges face the concerned actors?

1- A challenge for the State: find its place in the governance of a complex public health system

In China or in France, the State, currently led to reduce its direct contribution to the financing of health services, is questioning by what means it can preserve its role as guide, while opening spaces of participation to new actors. In the United States, the State is equally confronted with the necessity to reduce costs or to better the efficiency of the system, but must also promote a system of more united social coverage. It is seeking to earn a more central role in a sector where its legitimacy of action is still fragile and where the private sector and numerous agencies have existed for a long time.

Whether we consider this evidence as proof of failure or as an opportunity, one remark can be made: in China, in France and in the United States, the State alone cannot carry the cost of health care, nor guarantee the putting to work of its policies by its own means. It must closely connect its action to those of other actors, who can be in a position to relay its ambitions concerning public health. This necessity currently poses two challenges.

The first consists in defining a framework for this notion of "public health" by viewing the results of collective solidarity and those of individual responsibility. The defining of health care as a "public good" is largely put into question today in all three countries. Should health care coverage be obligatory or for the user to choose? To what extent can public powers be involved in prevention without infringing on the rights and freedom of the individual? The responses to these questions vary in accordance with each country and the actors working within each of them.

The second challenge is to assure consistency amongst multi-actor and multi-level policies: faced with the growing number of places and actors involved in providing health care or inviting change, the State finds itself faced with the challenge of regulating intricate systems whose efficiency can only be assured by complete cohesion and consistency amongst the numerous, often poorly coordinated interventions. The State must succeed in finding its right place within the system and affirm its role, at times as a financier, at others as a source of inspiration, a regulator, a pilot or as a leader in public health policies, without stifling private actors' freedom of action and thought. It must lead to a more solid cohesion all the while allowing for challenges to examine the system and allow it to evolve. It must find a way to allow different experiences to be shared and for experts from its partnerships to meet so that they may identify health needs and the populations who need it the most,the areas of intervention to prioritize, etc. In order to be considered legitimate and susceptible to being carried out satisfactorily, the definition of public powers' role can only result from a shared reflection amongst various actors, both private and public. Eventually, the issue of this dynamic certainly remains in the governance of health care policies, but also in the both collective and cohesive definition of their objectives.

2 - A challenge to non-state actors: hold a collective and legitimate voice when dealing with public powers.

The reports from this meeting question the role of public powers as well as of non-state actors. Whether they are veritable intermediaries of public action, or if they are more so focused on practical issues by tending to areas neglected to by the State, or if they attempt to guide public action towards the fulfillment of certain users' needs, few amongst them subscribe to a global view of health care and remain focused on one particular issue or group. Moreover, it is this knowledge of a specific subject or population that grants them a certain legitimacy in the eyes of public powers, as they are holders of a particular expertise. The association for seropositives, for example, have benefitted in all three countries(and still do) from their knowledge of sicknesses or of the concerned population, using it as a reason for recognition and a way to earn a place amongst the official organizations. Thus the question is raised of knowing to what point it is possible for these actors to be involved in the creation of global political orientations, by using as its basis the protection of categorical interests, as legitimate as they may be, or by conceiving their own role as one of opposition. Does the construc-

tion of public policies not suppose a capacity to take a step back and consider the population as a whole and not simply the most fragile or most concerned categories? The public authorities, in affirming themselves as advocates for the public good, do not fail to remind them of it and thus justify their monopoly in the final political decisions.

One of the answers provided by the participants is the following: it is the capacity to have one collective voice representing several, capable of surpassing the defense of categorical interests, that appears as a central element to their legitimacy to be partners in the construction of public policies. The question of alliances amongst non-state actors is thus an important question in all of the countries. Networks exist or are in construction, for example in France, where certain associations for diseases are engaged in the creation of alliances in order to increase their influence, and are thus brought to make difficult negotiation amongst themselves in order to pull away from purely categorical positions. In China, associations are sometimes in competition to receive financial support and recognition from abroad; they discuss ways of developing collective strategies that will be mutually profitable. The innovative experience of a platform like CMTHF, and the role of mediation that it has been able to undertake regarding certain organizations that are little known by public powers, shows the power that this type of group can hold.

3 – A common challenge: defining a dynamic of dialogue that veritably allows for the construction of policies.

Returning to the experiences of putting into question healthcare policies in their own countries, the participants equally give two warnings:

- On one hand, the risk of possible straying away from certain public statements to civil society regarding political and technical issues that people find difficult to understand. The Chinese participants also evoke the necessity of safeguards in the ways of representing and defending the sick. From their viewpoint, several American participants remind us how incoherent or untruthful messages from certain influence groups in the media were able to eventually provoke a feeling of incomprehension and confusion in public opinion. In bringing to light the long term, adverse effects of certain interest groups' opportunistic strategies, even if they prove beneficial to them in the short term, the warning raises ethical questions for strategies to influence, notably due to the excessive showcasing of the debates concerning a highly sensitive debate for society.

- On the other hand, the creation in public institutions of spaces of so-called "dialogue", not really functioning but rather mainly destined to create the illusion of a partnership or to second governmental action without overtly stating as such, constitutes another risk. The instrumentalization of dialogue as a simple opening also often opens the way to an even more radical dispute

on the part of non-state actors who feel manipulated. It forces us to question processes of cooperation and their ethics and evaluations.

The French notion of "health democracy," which allows for the creation of new spaces of consultation, elicited the attention and interest of American and Chinese participants: the latter are notably questioning the link between what they qualify as "institutionalized" spaces and the moral global dynamics of dialogue between the State and non-state actors, who are the result of more complex processes, mobilizing informal and often interpersonal spaces. What is then the most valuable of these "formalized" spaces of consultation? What do they bring in terms of transparency in information and in exchange, of the efficiency of methods, or of collective creativity, etc? Or to the contrary, do they have adverse effects? In remembering, for example, that certain categories of marginalized populations never are spontaneously represented and that it is necessary "to go to them wherever they may be," several participants raise the question of the excluded's participation at the heart of these spaces of dialogue and underscore the importance of method options.

Each of these challenges must be enriched by testimonials of other actors who were absent from the meeting and whose influence was evoked by participants: the press (simultaneously an opportunity and a risk, a sound box and an instrument to distort messages), businesses, moral and religious authorities, etc.

Participants

CHINA

Mr. DING Ning Ning: Senior Research Fellow in Development Research Center of the State Council (DRC) of the People's Republic of China, Director of the Department of Social Development Research and Member of the Academic Committee of the DRC. The DRC is a research think tank directly under the Chinese State Council with a portfolio of a broad range of social and economic issues.

Ms. YANG Tuan: Professor. President of Chinese Social policy Special Interest Committee. Deputy Director of Center for Social policy Studies, Chinese Academy of Social Sciences. Her academic achievements include The Study of Social Security Policy in China, The Development of NGO and NPO and its Relations with Community Construction, Rural Social Security System and rural community health system.

Mr. LI Gang: Director of the Programme "Hope Hospital" of the China Youth Development Foundation, Beijing. The CYDF is an important « GONGO » (Government operated non governmental organization), an institution with private resources, created and controlled by the Chinese government. Mr. Li leads the programme "Hope Hospital" which aims to rebuild hospitals and clinics in rural areas.

Mr. LI Dan: Director of Dongjen Center for Human Rights Education and Action, a Beijing based, non-government, non-profit organization which supports human rights education to protect the rights of marginalized groups, especially people affected by HIV/AIDS and ethnic minorities.

Mr. WANG Jun: Secretary General of the China Male Tongzhi Health Forum (CMTHF), Chengdu. The CMTHF is a network made of about 70 independent organizations of gay people, dedicated to supporting its members in China and to implementing educative actions to prevent AIDS. It develops cooperative relations with local health authorities.

FRANCE

Ms. Béatrice LUMINET: Doctor of Public Health, member of the board of the French NGO Médecins du Monde (Doctors of the World), she is Head of the Bureau of HIV and Risk Reduction for France and foreign missions. She is also in charge of the Observatory of the access to health care in France.

Mr. François-Paul DEBIONNE: Doctor of Public Health, Head of the service "Promotion of Health" of the Metropolitan area of Strasbourg, former volunteer of the French NGO ATD Quart Monde (ATD Fourth World), he is the author of the book « La santé passe par la dignité – L'engagement d'un médecin » (Health passes by dignity – The commitment of a doctor).

Mr. Christian ANDREO: Director of national programs in AIDES, the largest HIV/Aids Community Based Organisation in France, he has been working for 13 years on methodological, advocacy and policy issues. His department is in charge of relations with ministries and aims to increase the influence of the organisation on a national level.

Ms. Paloma MORENO: Health and Social Policy Manager of the UNA (Union Nationale de l'Aide, des Soins et des Services aux domiciles), a non profit federation of over 1,200 member organisations which provide social care (which may include nursing services) to people in their own homes, promoting high standards of care and providing representation with national and regional policy-makers and regulators.

Mr. Yves BONGIORNO: Mr. Bongiorno is a confederate adviser for Health at the CGT (General Confederation of Labour, French trade union)

Mr. Roland CECCHI-TENERINI: Doctor of Public Health, Director of Health in the MGEN (largest mutual insurance company in France), he is Professor at the University of Angers (ISSBA, High Institute of Health and Bioproducts of Angers) and member of the IGAS (General Inspectorate of Social Affairs, public administration).

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UNITED STATES OF AMERICA

Mr. Thomas MASSARO: Dr. Thomas A. Massaro is Chief of Staff of the University of Virginia Medical Center and Associate Dean for Clinical Affairs in the University of Virginia School of Medicine. He is a tenured professor in the Department of Pediatrics and also has appointments in the UVA Darden Graduate School of Business Administration and the School of Law.

Ms. Ruth BERNHEIM: Ms. Ruth Gaare Bernheim is director of the Division of Public Health and the School of Medicine's Master of Public Health Program, as well as associate director of the Institute for Practical Ethics and Public Life at the University of Virginia. She works on numerous public health projects, including initiatives with the Virginia Department of Health and the Centers for Disease Control and Prevention.

Ms. Margaret RILEY: Margaret (Mimi) Foster Riley became a member of the faculty in the University of Virginia School of Law in 1992. She also has a secondary appointment in the Department of Public Health Sciences at UVA's School of Medicine. She teaches food and drug law, health law, animal law, bioethics, regulation of clinical research and public health law.

Ms. Carolyn ENGELHARD: In the University of Virginia, Ms Engelhard's expertise deals with health policy analysis including: private and public health coverage; expenditures in the organization and financing of medical services; quality issues in health care; patient safety and medical errors; and changes in health workforce.

Mr. Gene W. MATTHEWS: Senior Fellow at the North Carolina Institute for Public Health, he also holds faculty appointments at the University of North Carolina School of Public

Health and the Georgia State University College of Law. He was chief legal advisor to the Center for Disease Control and Prevention (CDC) in Atlanta from 1979 to 2004.

M. Tito COLEMAN: M. Coleman is Deputy Director of the Health Policy Initiative in Futures Group, a leading international expert on HIV/AIDS and the development of research and programs in developing countries to reduce HIV transmission and the impact of AIDS.

Ms. Kathleen GRIFFITH: Ms Griffith is a member of the U. S. Positive Womens Network, a Division of WORLD (Women Organized to Respond to Life-threatening Diseases). The US Positive Womens Network is a body of HIV+ Women, including Trans Women, who work together to create changes in all levels of Policy and decision making, thereby improving the lives of Women.

Ms. Bernie KENNY: Sister Bernie Kenny is a member of the International Movement ATD Fourth World, an NGO working for poverty eradication. She has a long experience in health care with people in poverty situations in Appalachia.

Ms. Susan DEVINS: Susan M. Devins is a full-time member of the Volunteer Corps of ATD Fourth World. She is the liaison person between this Movement and the Center for Social Policy at the University of Massachusetts, Boston.

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Mr. Pierre BOLLINGER: Mr Pierre Bollinger, Advisor for Non-Governmental Affairs at the French Embassy since October 2007, has been previously an Associate Director at the American Center of Sciences Po in Paris, and a lecturer in political science, as a Visiting Fellow and Teaching Fellow at Harvard University (1998-2000), and a Fulbright student.