

# 艾滋病治理的新实践

New Paradigm of AIDS Governance

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## 序 言

### 注重公民社会参与能力的建设

自 1981 年 6 月美国疾病预防控制中心向全世界报道发现艾滋病病例以来,这种新型传染性疾病已经夺去数以千万计患者的生命,目前仍有数千万艾滋病病毒感染者。全球艾滋病疫情的持续恶化,已经成为当今时代发展的重要威胁,甚至被认为是对人类健康的最严峻的挑战。世界各国政府都高度重视预防和控制这种疾病,投入了大量资源,试图研发药物和新的治疗手段,积极应对这种疾病,然而迄今为止并没有发现能够彻底治愈它的手段。

当人类暂时还不能彻底战胜艾滋病的时候,积极预防它的发生和扩散,倾心关怀这种疾病的感染者和患者,维护他们的尊严,给予必要的生活和医疗服务,减轻带给感染者和病人家庭及其社会的影响,就成为十分重要的事情。能否积极主动地这样做,不仅关乎艾滋病病毒感染者、患者及其家庭的生活福利,更重要的是,它关乎一个社会的质量与品格,关乎社会的自我调适、持续发展的能力。然而,由于艾滋病具有特殊的传染途径,使得艾滋病病毒感染者和患者披上了不道德的色彩,由此而遭受社会歧视并被逐渐边缘化,削弱了其伸张与维护自身权利的意识、能力与机会。一些容易感染艾滋病的高危人群所从事的活动与职业,甚至是为法律所禁止的,这样更加限制了他们获得相关信息与资源的机会与条件。由此,各种感染者和患者自身的组织,以及其他非政府组织,在预防和控制艾滋病方面发挥着特殊的作用。他们更能平等、友善地对待相关人群,所传递的服务也更具有可及性。事实上,代表艾滋病病毒感染者和受影响群体的非政府组织在大多数国际和国家层面的艾滋病政策、项目和资助机构中都发挥着法定的作用。因此,人们对于各种非政府组织在艾滋病防治方面发挥

的作用以及作用机制应该给予更多的关注和研究。

收入本书的两篇文章恰好与此相关。题为民间组织参与艾滋病治理的新实践——对第一届中国全球基金以社区为基础的非政府组织工作委员会（2007~2009年）参与机制的观察与研究的文章是张涛的学位论文。该文通过深度访谈、文献分析等方法，对一个产生于中国艾滋病防治领域的特殊的草根联合体——非政府工作委员会（简称非工委）参与高层决策的实践为典型案例进行了深入的研究和认真的剖析。她认为第一届非工委无论在产生机制、运行状态和工作绩效等方面，都具有重要的研究价值，指出非工委的生成机制和联合特性使其具有显著的合法性、广泛的代表性和一定的独立性，认为非工委在集中民间智慧、优化草根诉求方面作用突出；在发挥联合作用、扩大联合范围方面优势明显；在提高自身能力，促进社区发展方面成效显著。作者同时指出，非工委与多数草根组织一样都存在着资源匮乏、能力不足、效率不高等问题，进而对改进非工委的运行机制提出了一些有价值的建议。另一篇是美国学者高芙曼博士（Joan Kaufman）题为非政府组织在中国艾滋病危机中的作用的论文。该文指出了中国政府在提供医疗服务方面的局限和非政府组织在应对艾滋病风险方面的价值，分析了中国政府与非政府组织之间以及各种类型的非政府组织之间的复杂关系，认为非政府组织在中国预防和控制艾滋病方面发挥更大的作用既面临着机遇，也面临着挑战。与张涛一样，该文同样发现了草根民间组织普遍存在的问题。作者认为既要着眼于协调政府（特别是地方政府）与非政府组织之间的关系，也要注意加强非政府组织自身的建设。

两篇论文虽然关注的都是艾滋病防治领域非政府组织的参与情况，但是这样的研究对于透视中国公民社会的成长以及更为广泛的公民参与也有着重要意义。自20世纪90年代以来，中国公民社会成为广为关注的议题，社会组织（包括草根组织）在数量上增长迅速，但无论从其结构、环境、价值和影响等维度衡量，都还难以满足社会发展的需求，其中，公民社会参与能力不足、参与水平不高无疑是最明显同时也是最重要的问题。这里既有制度环境的原因，也有公民社会主体自身的原因。在一些情况下，两种原因的相互作用更加严重地制约了公民社会的参与能力。因此，为了推动中国公民社会由成长走向成熟，

更好地发挥其在中国社会经济发展中的作用，更好地促进善治的实现，注重公民社会参与能力的建设已经是当务之急。收入本书的两篇文章也都在不同程度上关联到了这个问题。

按照笔者的浅见，当前制约中国公民社会参与能力的突出因素是公民社会分化不够、联合不足，缺乏凝聚共识的有效平台和参与决策的有效机制。比如说，我们可以看到社会组织数量迅速成长，但是缺乏有效的功能分化。每个组织都要独立地成长、运作，缺乏相应的组织化的资金、孵化、管理、信息、评估、培训、咨询等方面的支持，不利于组织整体力量的成长壮大。我们还注意到，虽然一些社会组织正在采取某种形式走向联合，但是更多的社会组织还是各自为战，或者依附在各自的“婆婆”（主管部门）的怀抱里，嵌入到行政体系中。整体上，中国社会组织之间的关系是行政主管部门之间关系的映射，社会组织之间缺乏有效的横向协作与联合。在很大程度上，这种状况正是目前的制度环境所造成的。政府对于社会组织的管理采取非竞争性、非地域性原则，也就是说在同一个行业、同一个地域之内，类似的社会组织只能成立一家，同时，一个社会组织不能设立地域性的分支组织。这样一种制度上的限制使得社会组织分散地存在，难以形成社会组织联盟，严重制约了社会组织的行动力。由此我们也必然看到，中国社会组织之间缺乏直接的有效的交换意见、演习民主、凝聚共识的平台。而由于缺乏经常化、制度化的机制建设，中国社会组织进入决策领域的机会是非常有限的，对于公共决策的影响力还非常弱小。

中国公民社会的参与能力不足构成了对中国民主化进程的制约，因为能够有效参与的公民社会是现代民主政治的重要基础。随着经济社会的快速发展，深入推进社会主义民主政治已经是不可阻挡的历史趋势。中共十七大报告强调了要扩大人民民主，推进决策科学化、民主化，保障人民的知情权、参与权、表达权、监督权，发挥社会组织在扩大群众参与、反映群众诉求方面的积极作用，从各个层次、各个领域扩大公民有序政治参与，保障社会公平正义。为了实现这些目标，我们必须施行系统的制度变革，高度关注公民社会参与能力的提升，尽快推动中国公民社会走向成熟。

回过头来看，本书重点分析了中国社会中最为边缘的、最为弱势、最为特殊的社会组织参与国家层面决策的案例，揭示了社会组织之间



有效互动、联合并参与决策的条件、机制与问题，无疑可以为其他类型的社会组织加强参与能力建设、有效参与决策提供有价值的启示。希望广大读者能够从本书的研究中有更多的获益。

中国人民大学社会学系教授

2010年12月18日



## Preface

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### Public Participation Capacity Strengthening

Since the first AIDS case reported by the United States Centers for Disease Control and Prevention in June 1981, millions of lives died from this new infectious disease and there estimated hundreds of millions of people living with HIV (PLHIV) now globally. AIDS pandemic has become one of the biggest development barriers, and is even regarded as the most severe challenge to people's health. All states have attached great attention to AIDS prevention and control. Numerous resources have been allocated to develop medications and new treatment measures to respond proactively to the disease. However, no cure approach has been found till now.

When AIDS is unable to be cured, others become very important, i. e. preventing its incidence and spreading, caring PLHIV, protecting their dignity, providing them necessary life and health services, and mitigating negative impact to PLHIV, their families and the society. Its accomplishments not only relate to the wellbeing and welfare of PLHIV and their families; but more importantly, reflect a society's quality and character, and its capacity of self-adjustment and sustainable development. However, Due to its special mode of transmission, PLHIV become associated with immorality and discriminated and marginalized, all these undermine their consciousness, capability and opportunity of upholding and promoting their own rights. Some activities and livelihood engaged in by the 'most-at-risk' populations are even forbidden by laws, which further limit their access to relevant information and resources. Against these circumstances, self-support groups and other non-governmental organizations (NGOs) will play special roles in AIDS prevention and control. These organizations could treat their target groups in an equal and friendly way, and their services are more oriented and accessible. In fact, NGOs who represent interests of people infected or af-

ected by HIV/AIDS play an indispensable role in the development of most international and national AIDS policies and projects and in donor agencies. Therefore, more attention and research should be given to NGOs' roles and working mechanism in AIDS response.

The two papers in this book just fit this topic. "New Paradigm of Civil Society Participation in AIDS Governance-*Research on the First China Global Fund NGO Work Committee* (2007 ~ 2009)" is Zhang Tao's postgraduate thesis. Through in-depth interviews and document reviews, her paper conducted intensive research and thorough analyses to a typical case the NGO Work Committee and its participation in the high level decisions as a unique grassroots coalition in China's AIDS filed. She considered the generation, operation and performance of the first NGO Work Committee of great research value. She pointed out the Committee's generation mechanism and alliance characteristics highlighted its legitimacy, representation and independence, she also believed the Committee played an important role in the aspect of centralizing civil thoughts and prioritizing grassroots requirements; the Committee has an obvious advantage in networking and cooperation; and has had remarkable success in self-capacity building and promoting community development. Zhang Tao also indicated lacking resources, inadequate capacity and low efficiency were main constraints to the Committee, as well as to the majority grassroots organizations. Furthermore, she proposed some valuable suggestions to improve performance and efficiency of the NGO Work Committee. The other article is from a American scholar, Dr. Joan Kaufman-'*The role of NGOs in China's AIDS crisis: Challenges and possibilities*'. This paper highlighted Chinese government's limitation in health service provision and value of NGOs' response to AIDS crisis; it analyzed complex relations between Chinese government and NGOs, and those among different NGOs. She perceived NGOs' greater role in China's AIDS response face opportunities as well as challenges. Kaufman's paper also found constraints widely existed in grassroots organizations as Zhang's. She holds that relationship between government (especially local governments) and NGOs need moderating, and NGOs' capacities need strengthening.

Although the two papers focus on the NGO's participation in the AIDS response, such researches are more important in mapping growth of China civil society and broader public participation. Since 1990s, civil society in China has

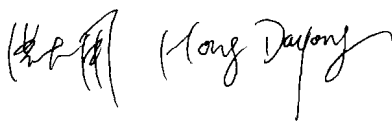
drawn widespread attention. The number of social organizations, including grassroots ones, increased significantly; but from other perspectives as their structure, environment, value and impact, these organizations cannot meet the needs of social development. Inadequate participation capacity and in lower levels are the most obvious and important concerns, which caused by institutional environment, and by civil society itself. Under certain circumstances, interrelation of the two causes further constraint civil society's participation capacity. In order to drive Chinese civil society from growing to maturity, and to play greater roles in China's social and economy development, and to be instrumental to realizing good governance, public participation capacity strengthening should be put in the most priority position. All these topics are addressed by the two papers from different perspectives.

In accordance with my view, the most prominent barriers to civil society participation are no systematic compartmentation and alliance, no effective platform for them to reach consensus, and no participation mechanism in decisions. For example, the number of civil society organization increase rapidly, but they have no effective functional differentiation. Each organization need to grow and operate independently, lacking relevant support in funds, nurturing, management, information, assessment, training and counseling. All these have negative impact to civil society as a whole to grow up and become stronger. We also realize that few social organizations approach united in some forms, but most of them exist without allies, or rely on their "mother-in-law" (supervising departments) and embed themselves into the administrative system. So in a whole, the relationships among Chinese social organizations are those among administrative departments, lacking horizontal synergy and integration, to larger extend, which is caused by current institutional environment. The government management to social organization is based on non-competitive and non-territorial principles, which means there can only be one similar organization in the same sector and within the same geographical; at the same time, one social organization cannot set its regional branches. This kind of institutional constraint makes social organizations exist in fragment, and hard to networking so as to restrict their capacity of taking actions. In addition, we need to notice, there is no regular and institutionalized platform for Chinese social organizations to exchange opinions, to practice democracy and to reach consensus directly and effectively. Because of

these inadequacies, Chinese social organizations have few opportunities to participate in decisions and produce little influence on public arenas.

Chinese social organizations' low capacity construct bottlenecks to China's process of democratization, as civil society's meaningful participation is the important foundation of modern democratic politics. The rapid economic and social development make deepening of socialistic democracy become an irresistible trendy. Report of the 17th National Congress of the Communist Party of China addressed to expand people's democracy, to ensure scientific and democratic decision-making, and to guarantee the people's rights to be informed, to participate, to be heard, and to oversee; to encourage social organizations to help expand the participation by the public and report on their petitions so as to expand the citizens' orderly participation in political affairs at each level and in every field, and to safeguard equity and justice. In order to realize these goals, we need to implement institutional changes systematically and to pay high attention to public participation capacity strengthening, so as to facilitate the development of Chinese civil society into a fast track.

Looking back, the two papers analyzed the most marginalized and disadvantaged grassroots organizations' participation in the national decision-making process, highlighted the effective interactions, networking, generation conditions and series issues concerning with a joint participation mechanism in decisions. All these will undoubtedly provide valuable inspirations to other types of social organizations to strengthen capacity building and to participate in decisions effectively. Hope readers could benefit from their researches.



Professor of Sociology, Renmin University of China

December 18<sup>th</sup>, 2010

## 前 言

这是一本有关疾病防治和治理创新的书，由两篇文章构成。内容涉及中外学者对艾滋病问题的理解、对中国艾滋病疫情特点的分析、对公众参与艾滋病防治理念的认识，重点是对中国民间组织在公共卫生治理中的特殊作用及其实践进行了探讨性的研究。基本结论是，在中国特有的社会和文化背景下，没有广泛的参与和真正的治理，艾滋病问题将难以得到有效的解决。

在我的印象当中，艾滋病在传入中国的初期是被称为“爱滋病”的。名称的变化，反映出人们对这种疾病认识的改变。艾滋病在中国已经流行了近30年，目前预测的感染者人数为74万，艾滋病问题对中国社会和谐与发展的负面影响已经显现，但大多数人对于艾滋病的认知依然停留在疾病的层面，很少有人对艾滋病长期流行进而成为一种社会问题的深层原因产生兴趣。因此，人们除对艾滋病普遍抱有一种恐惧心理之外，很难产生主动了解艾滋病病毒感染者及其受影响群体的愿望，也不会主动参与艾滋病的防治工作。这种状况最终将导致公众参与的不足甚至出现社会的漠然，而这正是艾滋病疫情难以遏制的重要因素。

2005年秋，缘于一个偶然的机，我应聘到联合国艾滋病规划署北京办事处工作。第二年，我受命参与了一个在全球抗击艾滋病、结核病和疟疾基金（全球基金）背景下的中国艾滋病社区基层民间组织的选举工作。这一经历使我有幸接触到许多国际、国内艾滋病防治领域的专家和学者，对全球基金、艾滋病问题以及相关的受影响的群体有了比较深入的了解，初步接触了关于艾滋病治理的理念。

没有广泛的参与就没有真正的治理，这是全球基金运作所秉持的根本理念。为达成善治目标，全球基金要求受援国必须建立一个包括政府部门、民间组织、私营部门和受疾病影响群体等多方代表构成的决策机构，以确保各利益相关方平等地参与治理与决策。在这一制度背景下，中国的社会组织，特别是草根民间组织在艾滋病防治中的特殊作用得到展现，尤其是在决策过程中的作用令人耳目一新。“非工委”就是在这一背景下产

生的一个既有特殊形态又有特殊机制还有特殊贡献的现象。从传统意义上说,“非工委”甚至不能称其为一个组织,它既不是全球基金组织序列中的一个单位,也不能在民政机关登记注册,并且一无办公场所,二无办公经费,三无人员工资。然而,它的运行却体现了草根的智慧,发挥了社区的作用,丰富了治理的内容,提高了参与的效率,从而实现了中国艾滋病防治领域的一个民间创新。这个现象令人感到新奇并且引发我对其进行了长达数年的观察和记录。2007年,我进入中国人民大学学习,期间,在导师洪大用教授的启发和指导下,我对“非工委”参与艾滋病治理的实践进行了梳理和研究并最终成为我的学位论文。这就是本书的第一篇文章。

本书的另一篇文章出自美国著名学者高芙曼女士之手。她是美国哈佛大学和布兰代斯大学研究社会政策的教授,对世界公共卫生领域的问题有深入的研究。20世纪80年代,她曾在联合国人口基金供职,是该机构首位驻中国的国际项目官员,而后还担任过福特基金会驻中国办事处的项目官员。她的文章以中国的SARS危机为切入点,分析了传染性疾病带来的危机及其对中国非政府组织发展空间的拓展作用,记述了中国草根组织在艾滋病领域的出现与发展,面临的挑战与机遇。我感到她与我的研究方向大体一致,而且在研究方法和结论上具有独到之处,比较客观地反映了一个西方学者对中国艾滋病问题的独特视角。因此,经她同意,也将该文收入书中,希望相得益彰。

本书能够出版,得益于邱仁宗教授的举荐和协和出版社同志的辛勤工作。感谢我的导师洪大用教授,他不仅指导我完成了学位论文,还满怀激情地为本书作序。借此机会,我还要感谢我的同事、同仁和亲人,他们在我撰写和翻译论文的时候提供了无私而亲切的支持。虽然我没能将他们在此一一列出,但每当想到他们,我的感激之情便油然而生。没有他们,尤其是那些受访者的合作,也就没有我的研究成果。我希望本书所提供的观察视角、基本观点和研究成果能使更多的人关注中国的艾滋病问题,能够激发更多的社会力量参与艾滋病的治理,更希望能为从事疾病防控、社会组织管理以及相关理论研究的人士提供一些有益的借鉴,从而能够在更广阔的社会领域推进治理的创新与实践。

张 涛

2011 年秋



## Foreword

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*Disease control and governance innovation* are the two key themes that run throughout this book. From the perspective of both Chinese and Western scholars, the two papers that make up this book analyze characteristics of the AIDS epidemic in China, and present the authors' interpretation of public participation and AIDS governance. Exploratory research focused on Chinese civil society organizations' particular role and practice in the public health governance. The basic conclusion is, under China's unique socio-cultural context, without broad participation, no meaningful governance can be achieved, and the AIDS challenges cannot be effectively solved.

In the past three decades, people's attitude towards AIDS has changed with more understanding of the disease. By the end of 2009, the number of people living with HIV/AIDS in China, estimated by the Chinese Center for Disease Control and Prevention, was 740,000. The negative impacts of AIDS to China's harmonious society and sustainable development has begun to show. Most people's awareness for AIDS remains superficial; few people have interest to find out why AIDS has spread so broadly and for such a long time, and evolved into a social problem. Thus, besides the common feeling of fear, few people are willing to know more about people infected and affected by the disease, nor to proactively participate in AIDS-related work. All of these lead to insufficient public participation and social exclusion, which are crucial drivers of the AIDS problems in China.

In August 2005, I accepted a position in the UNAIDS Beijing Office and soon after became involved in the coordination and facilitation of the China Global Fund Country Coordinating Mechanism (CCM) membership election for the sector of community-based organizations (CBOs) and other NGOs. With the refor-

ming background of the China Programs of the Global Fund to Fight AIDS, Tuberculosis and Malaria (the Global Fund), the election was processed to promote Chinese CBOs' meaningful participation in AIDS governance. This experience enabled me to develop relationships with many global and domestic experts and scholars in the AIDS field, learn more about the Global Fund and people infected and affected by HIV, and accepted the concept of AIDS governance.

No governance can be reached without broad public participation, which is also the guiding principle of the Global Fund. In order to maximize the grants value, the Global Fund requires the recipient country to establish a governing body at country level, namely the Country Coordinating Mechanism (CCM). In accordance with the Global Fund, membership of the CCM should include representatives from governments, multilateral or bilateral agencies, non-governmental organizations, private sectors and people living with the diseases, thus ensuring multi-stakeholders' equal participation in the decision-making process. This institutionalized requirement provided China's AIDS NGOs, especially community-based organizations, a rare opportunity to not only play their indispensable roles in AIDS control, but also explore a new path for effective participation in public decisions, which gave birth to the "NGO Work Committee" (the shortened name of the China Global Fund NGO Work Committee).

The NGO Work Committee, composing of 11 sectoral representatives, was the outcome of a new, meaningful & standardized civil society election. It has a special organizational structure, special working mechanism and unique participating contributions. In the traditional sense, the NGO Work Committee cannot be called an organization – it is neither an affiliate to the China Global Fund hierarchy, nor a registered entity; in addition, it has no office space, no administrative budget, and no personnel salary. Despite these factors, its creation and operation represented grassroots wisdom, played community's role, enriched governance options and improved participation efficiency. NGO Work Committee was an innovation of China AIDS NGOs, and inspired me to spend years to observe its development. In 2007, I started my postgraduate study at the Renmin University of China. With my supervisor, Professor Hong Dayong's constant encouragement and support, I completed this thesis – case study of the NGO Work



Committee in AIDS governance. This is the first paper of this book.

The other article was written by a well-known American scholar, Professor Joan Kaufman. She is a lecturer in Global Health and Social Medicine at Harvard Medical School, and a distinguished scientist and senior lecturer at the Heller School for Social Policy and Management at Brandeis University. Dr. Kaufman also works as the China Team Leader for the International AIDS Vaccine Initiative. Through solid studies, Dr. Kaufman has a deep and expert understanding in the arena of ‘global public health’. She was the first UNFPA international program officer in China during the 1980’s and from 1996 ~ 2001 she was Ford Foundation’s Reproductive Health Program Officer for China based in Beijing. During correspondence with Professor Kaufman, she shared with me her paper on the NGO development in China’s AIDS sector. Taking China’s SARS crisis in 2003 as the entry point, her paper analyzed the crisis and identified the threat of emerging infectious diseases which have pushed the boundaries of NGO political space in China. She had also documented China’s grassroots NGOs development, opportunity and challenges. I think her research had similarities with mine, and preserved a unique approach and a conclusion reflected by a western scholar’s perspective to China’s AIDS issue. With her consent, Professor Kaufman’s article is also enclosed in this book. I believe both articles complement and supplement each other.

Various individuals and organizations have contributed in different ways towards the completion of this thesis. This book could not be published without my mentor, Professor Qiu Renzong’s recommendation, this book’s publisher, Mr. Xie Yang’s approval and responsible editor, Ms. Fang Lin’s hard work. I am thankful to my supervisor, Professor Hong Dayong not only for his professional guidance, but for his generosity in writing the preface. Taking this opportunity, I would also like to thank my colleagues, friends and my family, who extended warm and selfless support throughout this thesis writing and its translation. Although I am not able to list them here, they are in my thoughts and my gratitude goes to all of them. Without them, there is no my paper. The thesis would have been rather sterile if I had not received the insights from members of the first NGO Work Committee and other key informants. My special thanks go to them