



Phoenix  
苦草工作室

苦草工作室感染者医疗歧视报告

**Phoenix Report:**

**Medical Discrimination Against People Living With HIV/AIDS**

November 9, 2010

2010年11月9日



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### Medical Discrimination Against People Living With HIV/AIDS

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## 概况 Summary

苦草工作室是一个来自性工作者的草根组织，在日常的工作中我们接触到了很多艾滋病感染者，其中部分的感染者时常提到他们遭遇医疗歧视的问题。因此在四个月的时间里，苦草工作室对 X 市感染者遭遇医疗歧视的问题进行了调查研究。我们发现，感染者面临的医疗歧视主要来自常规医院，同时也来自感染者定点治疗医院。造成这写问题的因素是多方面的，有来自院方的，有来自医务工作者的，还有是来自感染者必须定点就医的制度本身。

Phoenix (Chinese name: Kucao Gongzuoshi 苦草工作室) is a grassroots organization run by sex workers. In the course of our daily work we have encountered many people living with HIV (PLHA), some of whom have frequently raised the issue of medical discrimination with us. Therefore, Phoenix conducted research for four months into medical discrimination against PLHA in X City.<sup>1</sup>

We found that PLHA face discrimination by general hospitals as well as mistreatment by hospitals that are designated for the treatment of infectious diseases. Several factors contribute to these issues. Some originate from hospitals, some from medical staff, and some arise from the very system that requires PLHA to seek treatment in designated facilities.

## 简介 Introduction

苦草工作室是一个专为性工作者中的感染者服务的区域性草根组织。成立于 2005 年 10 月，并于 2006 年 2 月在工商部门注册。现有全职工作人员 2 名，兼职员工 4 名。苦草工作室的宗旨是：团结起来，自我管理，自我教育，自我拯救。苦草工作室的工作范围是：知识技能培训、紧急救助、阳性预防、家访、医院护理、治疗教育，临终关怀、生产自救、受艾滋病影响儿童的关怀、以及被贩卖性工作者的关怀和救助。

Phoenix is a local, grassroots organization that provides services to sex workers living with HIV/AIDS. Phoenix was founded in October 2005 and registered with the Bureau of Commerce in February 2006. Phoenix has two full-time and four part-time staff. Phoenix's mission is to organize sex workers for solidarity, self-governance, self-improvement, and self-help. Phoenix's services include skills training, emergency medical financial aid, HIV prevention training, home visits, hospital case work, treatment education, funeral services, small-scale crafts manufacturing, care of children affected by HIV/AIDS, and a project to monitor trafficked sex workers.

苦草目前由妈妈现金基金会支持。亚洲促进会为苦草提供为期两年的能力建设培训，包括财务管理，员工管理，以及调查研究和倡导。

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<sup>1</sup> 根据被访者的要求，为了保护隐私，苦草在此隐去该城市的名称。Phoenix decided to withhold the name of the city at the request of PLHA we interviewed, in order to protect their confidentiality.

Phoenix is currently receiving financial support from Mama Cash Foundation. Asia Catalyst is providing two years of training in financial and staff management and in rights documentation and advocacy.

中国西南部 X 市自 1996 年发现首例艾滋病感染，至今当地疾病预防控制中心 (CDC) 已检测出 3800 多人感染艾滋病。毋庸置疑，X 市已成为艾滋病高度流行的地区。

X City in southwest China is a region with high prevalence of HIV. The first case of HIV in X City was identified in 1996, and the local Center for Disease Control (CDC) has identified over 3,800 PLHA.

如今当地多数感染者已进入机会性感染阶段，这些感染者多为社会底层人员（如成瘾者、性工作者），他们在因机会性感染住院治疗时，时常遭遇来自医疗机构的歧视。这种歧视严重影响了感染者的治疗，彰显了社会的不平等，对于当地的艾滋病防治极为不利。为了推动社会公平和改善当地感染者的就医环境，苦草工作室从 2010 年 6 月起就开始关注当地感染者的就医问题。

Many local PLHA have become prone to opportunistic infections, and many of them are from the lowest levels of society (drug users, sex workers). When they seek treatment for opportunistic infections, many of them encounter discrimination by medical facilities. This discrimination seriously affects the medical treatment of PLHA. It exemplifies social inequalities, and is detrimental to local HIV/AIDS prevention and treatment efforts. In order to promote social equality and improve the environment for medical treatment, Phoenix began to investigate the issue in June 2010.

在我们对案例进行讨论之前，有必要对一个重要的概念进行简单介绍：即所谓的感染者“定点治疗机构”。感染者定点治疗机构是指，由云南省各市县卫生部门指定一些医院，由这些定点医院对当地的感染者提供抗病毒治疗，机会性感染治疗和其它医疗的服务。事实上对感染者的治疗问题全国很多地方都是这样运作的。

Before we discuss these cases, we need to briefly explain one key issue: that of so-called “designated medical facilities” for PLHA. These designated medical treatment facilities are hospitals that have been appointed by each county or city governments in Yunnan Province to provide ARV treatment to local PLHA and to treat their opportunistic infections. In fact, many areas in China handle medical services to PLHA in this way.

规定感染者到定点医院就医是国内艾滋病发现的早期产物，这种一刀切的制度是一定范围内既保护社会公众避免感染艾滋病的风险，又保障艾滋病感染者就医权的折中之举。<sup>2</sup>这种规定运作了这么多年，暴露出来的问题已经不少，却很少引起社会和有

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<sup>2</sup> 2005 年 9 月 19 日起实施的《云南省艾滋病临床治疗管理办法》第三条规定：艾滋病的临床治疗工作由州（市）级以上卫生行政部门指定的定点医疗机构承担。云南省这一规定是依据《国务院关于切实加强艾滋病防治工作的通知》这一规范性文件作出的其中规定：“艾滋病患者的治疗主要在当地定点医疗机构进行，鼓励流动人口中的艾滋病患者回乡接受治疗”。Article 3 of the *Yunnan Regulations on Management of Clinical Treatment of HIV/AIDS*, promulgated on September 19, 2005, stipulates that AIDS is clinically treated by

关部门的关注。我们希望本次研究所收集的案例能够帮助大家重新认识这一规定。

The Yunnan Provincial regulation that PLHA need to visit “designated facilities” is an early product of the time when China first detected HIV/AIDS. This system aims to curb the risk to society of HIV infection while protecting the right of PLHA to medical treatment. This regulation has been in operation for many years and many problems have appeared with it. However, neither the public nor the relevant government agencies have attended to these issues. We hope the cases we have collected here can help us to rethink this regulation.

## 研究方法 Research Methods

本报告在获得受访者的知情同意下，从 2010 年 6 月到 10 月，通过小组访谈、个案收集、图片采集、问卷调查等方式对当地感染者就医歧视进行调查研究，调查中有针对性地访谈了 10 个典型的案例（访谈对象皆为感染者），收集调查问卷 10 份，其中，8 位访谈者为女性感染者，2 位为男性感染者。此外，这份报告也是基于我们在社区中为艾滋病感染者服务的经验。尽管案例的数量有限，但却准确地说明了我们所服务群体面临的问题。

This report is based on research conducted from June through October 2010. We obtained consent from all interviewees and conducted small group interviews, collected individual cases, photographs, and used questionnaires to interview local people living with HIV/AIDS. Using this approach, we have collected a total of ten cases. Out of the ten cases we studied, eight were women, and two were men. In addition, we drew on our experience providing direct services to people living with HIV/AIDS in our community. While the number of cases in this report is relatively small, we feel that they accurately represent the experiences of the people we serve.

本报告的调查和访谈皆采用口头和书面告知访谈者研究内容，并获得访谈者的书面知情同意。访谈采用开放性自由性交谈，10 个访谈案例中 9 位报告说都遭遇过院方不同程度的婉拒，或是以各种借口进行推诿；2 位曾经被院方强制要求购买医疗器械，7 位曾经被院方以各种名目多收或乱收费用。我们认为，这些做法是任意的。尽管我们收集的案例数量相对较少，但根据我们在社区工作的经验，这些案例非常具有代表性。

In researching this report, we used verbal and written methods to inform participants of the content of the research, and received written consent by participants to participate. Interviews were set up as a free and informal exchange. Out of the ten interviewees, nine had in varying degrees previously been declined services by hospitals, or reported to us that

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the designated medical institutions assigned by the health administrative agencies at the prefecture (city) level and above. This Yunnan Provincial regulation is in accordance with the *State Council Notification on Strengthening AIDS Prevention Work*. This regulatory document states: “The treatment of people with AIDS [sic] should mainly be treated by local designated medical institutions, and should encourage migrants who have AIDS [sic] to return home to receive treatment.”

hospitals had offered excuses as a way to refuse them treatment. Two had been forced by hospitals to buy medical equipment for their treatment, and seven had been overcharged or were subject to what we believe are arbitrary charges. While the number of cases we collected is relatively small, based on our experience working in this community they are representative.

在本报告中，我们将会向大家介绍所收集的案例，并对这些问题进行法律分析，提出政策建议。我们在研究中发现的问题包括：

- 常规医院拒绝就医；
- 定点医院的服务质量较差；
- 定点医院多收、乱收费用。

In this report, we begin by describing some of the cases we gathered, and then provide legal analysis of the issues and our recommendations for policy or legal reforms. The issues we identified in our research include:

- Refusal of treatment by mainstream hospitals
- Poor quality of care at designated facilities
- Overcharging of fees at designated facilities

## 个案 Cases

### 常规医院拒绝就医 Refusal of treatment by general hospitals

案例 1、某女现年 42 岁，2009 年 9 月到 X 市某医院做阴道延长术。她说，院方在未获知其实艾滋病感染者之前对她十分热情，极力推荐院方的手术能力和医院硬件设施。被院方的热情所感染，该女坦诚地向接诊医生说明了自己是艾滋病感染者。该女说，在这一刻医生的脸立马阴沉起来，告诉她第二天再来办理具体的住院手术。

In the first case, a 42-year-old woman went to a hospital in X City to undergo a cosmetic gynecological procedure. According to the interviewee, before the hospital knew she was living with HIV, they were very courteous and enthusiastically recommended the hospital's surgical abilities and equipment. The interviewee, impressed by the hospital's courtesy, told the admissions doctor that she was HIV-positive. The interviewee said that at that moment the doctor's face became unfriendly, and the doctor told her to return for the actual in-patient surgery the next day.

第二天该女如约来到了该医院，接诊医生的态度明显比头天第一次听说她是感染者时有所好转，该女暗里庆幸碰到了一位不错的好医生。该女说，接诊的医生告诉她，她的病情已经上报院方主管领导，经过院方研究，院方决定对其进行阴道延长术。但是，所有手术器械，必须由该女个人购买，仅手术器械大至在 8500 元—10000

元左右，其它费用另计。该女说，面对如此不合理的强制的“附加条件”，她思之再三，同意了购买手术器械后在该女进行手术。也许，接诊医生原本是想用高额的手术器械费用来吓跑该女，谁知该女为了手术竟然接受了这种苛刻的条件。

The interviewee returned to the hospital the second day and found that the doctor's attitude had improved, and the patient was pleased to have found such a good doctor. The patient told us that the doctor informed her that her condition had been reported to the hospital directors. After studying the question, the hospital had decided to proceed with the surgery. However, she would have to purchase all surgery equipment for an estimated price of RMB 8,500-10,000 (approximately \$1,250-1,470), in addition to other fees. The patient said that facing such unreasonable and compulsory "additional conditions", she thought about it, and agreed to purchase the equipment.

也许这是接诊医生始料未及的。她说，面对这样的爽快，接诊医生眉头一皱，接着给住院部打了一个电话，然后很客套地告诉该女主刀医生到上海学习了，大概要半年才结束在上海的学习，暂时没有医生了，让她到别家医院去看看能否给她做手术。

Perhaps this reply was not expected by the doctor. According to the interviewee, the doctor frowned at the woman's decision, and then apparently had a new idea and made a call to the inpatient department. The doctor then told her politely that the gynecological surgeon was in Shanghai for studies and would not return for six months. In the meantime, they had no surgeon. The doctor suggested she check whether another hospital would be able to do the surgery instead.

该女说：“一万元，对于我来说是一笔很大的花费，但为了争一口气，我还是硬着头皮在他们面前硬撑，没想到最后还是被他们给戏弄了。”

The woman said to us, "Ten thousand RMB is a lot of money for me, but I was willing to swallow my objections and face the doctor down. I never thought that in the end they'd still mess with me like that."

案例2、某女现年32岁。于2009年8月份，因宫外孕到X市常规医院妇科就诊。接诊医生得知其是艾滋病携带者后，对她说：“我们医院不对HIV感染者就医，另外一家医院是政府指定的感染者定点医院，你还是去那边看看”。她说，感觉心里很不舒服，医生一点职业道德都没有，并没有把自己当病人来看待。该女想：X市的感染者定点医院，并没有设立妇科，自己怎么可能去一个没有妇科设备，没有妇科医生的医院去看宫外孕。

The second case was reported by a 32-year-old woman. According to the interviewee, in August 2008 she went to the department of gynecology of the general hospital in X City to seek treatment for an ectopic pregnancy. After the admissions doctor learned that she was HIV positive, the doctor said, "Our hospital doesn't treat PLHA. Another hospital has been designated by the government for medical services to PLHA, and you should go there". The woman felt very uncomfortable. As she told us, she felt that the doctor was not exhibiting

professional ethics and was not looking at the situation from the patient's perspective. The woman told us that the designated hospital for PLHA in X City does not have an OB/GYN department. How could she be expected to go to a hospital without gynecological equipment and without an obstetrician capable of treating an ectopic pregnancy?

俗语虽说“病急乱投医”。对于可能会涉及生命安全的宫外孕，她却不敢拿自己的生命作为代价，去感染者定点就医医院乱投医。思之再三，为了自己的生命，她只能拖着沉重的脚步，再次到之前去的那家医院的妇科央求，还是那位接诊过她的女医生在接诊。她说，女医生用冰冷的眼光看着她，吐出了：“你有两个选择，第一个是转院到感染者定点就医医院。第二个是你自己在我们这里购买手术器械。并且得等我们医院现在还没有做的手术做完，才能给你做。”

As the saying goes, “When critically ill, turn to any doctor”. In the case of this possibly life-threatening ectopic pregnancy, she was unwilling to risk her life at the designated hospital for PLHA. On further thought, out of concern for her own safety, she dragged herself back to the hospital that had an OB/GYN department to appeal for the surgery. There she encountered the same female admissions doctor. According to the interviewee, the doctor looked at her with cold eyes and spat at her: “You have two choices. The first is that you go back to the designated hospital for PLHA. The second is that you can buy the surgical equipment for us to use. Also, you'll have to wait until our hospital has finished our other surgeries, and we'll deal with you then.”

半个月以后，该女捧着那堆对自己再也用不上的、新买的旧手术器械，走出了 X 市的这家常规医院，感慨万千。我们做问卷调查的那天，她说：“根本没有人关心我们的就医，医院对我们的歧视，使我们得不到一个公民应有公平和公正的就医环境。”

A half month later, the woman left the general hospital filled with emotion, and carrying the newly-bought, now used equipment that she would never have a use for again. On the day we filled out the questionnaire with her, she said, “No one cares about us [PLHA] needing medical services. The hospital discriminates against us. We have no way to get the equal and fair medical treatment that a citizen ought to have.”

案例 3、某姐妹，现年 43 岁。09 年 9 月份，机会性感染住进了 X 市常规医院。她说，刚入住时，医生的态度十分热情。后来院方检测出她携带艾滋病病毒，医院的态度就骤然变化。那天早上查房的护士面如冰霜，冷冷的对她丢下：“你今天就去结清费用，转院去你们的医院吧。”她说她结清了三天 700 多元的住院费用，没有任何选择余地来到了 X 市感染者定点医院。

The third case is that of a 43-year-old sister.<sup>3</sup> In September 2009, due to an opportunistic infection, she checked into the general hospital in X City. According to the interviewee, when she checked in, the doctor's attitude was friendly. After the hospital had tested her and found she was HIV-positive, the hospital's attitude suddenly changed. That same morning [of

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<sup>3</sup>苦草工作室的成员称对方为姐妹。 Members of Phoenix refer to each other as “sister” (姐妹).



the test] the face of the nurse who did rounds was like frost, and she said, “Settle your bill today, and go move to your hospital.” The interviewee reported that she paid her bill of over 700 RMB for three days and had no other choice than to go to the designated hospital of X City.

入院第一天，医生给她开了一组点滴。点滴过半的时候，她不经意地抬头看了看点滴架上的吊瓶，怎么上面的名字不是自己的？这是怎么回事，来不及多想的她，立即拔出针头，跑到值班室去问护士。护士到病房来看看，一言不发，转身另外提来了一组吊瓶，给她重新挂了起来，又一言不发地转身走了。

On the first day of her stay at the designated hospital, the doctor ordered her an intravenous drip. After about half of the infusion was done, the woman raised her head and looked at the name of the medicine, and realized that the name on the infusion bottle was not her name. She took out the needle and went to the nurses' office to enquire. The nurse came to take a look, and without saying a word, left the patient's room to return with another intravenous drip. She hung it on the stand and left again without saying a single word.

该女说：“我最想不通的是，对于这种很严重的错误，她（护士）竟然没有一句解释、道歉的话。”我们的研究发现，在所谓的定点医院，由于缺少资源，以及医生的专业训练不足，导致出现了一系列的问题。我们将在下面展开讨论。

The woman said: “What I don't understand is that she [the nurse] had not a single sentence of explanation or apology about such a serious mistake.” However, our research has found a number of issues that arise from poor training and resources at the so-called “designated facilities” for treatment of HIV/AIDS, which are discussed in the next section.

### **定点医院存在的问题 Problems at Designated Treatment Facilities**

前面提到，云南省规定了感染者必须到定点医院就医。根据我们对 X 市定点医院过去的了解，该医院在艾滋病在当地流行之前，主要是针对一些常规性的传染病和精神病患者进行收治，而并非一家常规综合医疗机构。换言之，该医院的并不具备常规的医疗能力，从而导致下面一些问题的出现。

As mentioned above, the provincial regulations state that PLHA must seek medical services at “designated facilities”. According to our understanding of the designated hospital in X City, before HIV/AIDS became prevalent in the area, this hospital mainly attended to infectious diseases and mental illnesses, and was not a general medicine facility. Therefore, it is not equipped or skilled in cases of general medicine. This leads to some of the cases described below.

案例 4、2010 年 8 月，某 35 岁女性感染者到 X 市定点治疗医院就医，接诊医生给做拍了胸片，胸片报告出来后，医生诊断为肺结核，然后给她开了抗结核药服用。

In the fourth case, a 35-year-old woman living with HIV went to the designated hospital in X City in August 2010. The attending physician did an X-Ray of her chest, diagnosed her with pulmonary tuberculosis and prescribed anti-TB medication.

一个月后该女感觉肺部服药以后更为不适，就到该市 CDC 做了痰检、PDP/X 光检测，结果为阴性。她就停服了定点治疗医院开出的抗结核药。

After one month, the patient felt even more uncomfortable in her chest area, so she went to the local CDC for a tuberculosis sputum test. The result of the PDP/X-ray test came back negative, so she stopped taking the medicine that had been prescribed by the hospital.

一般确诊为肺结核感染，需要经过下面几个流程，主治医生诊断→PPD→痰检→ELISPOT（血液检测）→X 光。可这家感染者定点就医医院的医生仅仅只是给她拍了胸片就确诊她已经为肺结核，没有任何的血液检测。而且根据其他苦草成员的反映，该定点医院的 X 光机已经陈旧不堪，准确性有待考察。

In our experience, if a patient has tuberculosis, the patient needs to follow this process: first a medical examination, then a PPD skin test, then an ELISPOT (blood test), and then an X-ray. However, the doctor of the designated hospital only took a chest X-ray before diagnosing the patient with tuberculosis, without giving any blood test. According to other members of Phoenix, this hospital's X-ray machine is quite old, and the accuracy of it should be tested.

二个月后这位患者不治而亡，尸检结果显示，其肺部已经糜烂。她的一位朋友接受我们访问的时候提到，解剖医生认为是在没有感染结核的情况下服用抗结核药所引发的。但是，这个朋友告诉我们，该女的母亲曾向医院提出这个问题，但该医院却置之不理。

Two months later the patient did not improve. She passed away, and the autopsy showed that there had been an erosion of her lungs. According to a friend of the family, with whom we spoke, the autopsy doctor stated that this could have been due to the fact that she took medication for a condition she did not have. However, the friend reported to us that when the patient's mother attempted to raise this with the hospital, the hospital ignored her.

案例 6、某男，37 岁，因肾衰竭到 X 市感染者定点治疗医院就医。在住院治疗中，他出现心律失常，其母亲希望院方能一并对其心脏进行必要的治疗。据他的母亲说，该医院坦言他们没有设立心脏专科，所以并没有这方面的医术和药品。其母亲十分纳闷：为何该医生不具备治疗心脏的专科，却依然收治她的儿子？

Case 6 is a 37-year-old man who went to the designated hospital in X City for renal failure. During his stay at the hospital he experienced arrhythmia, and his mother asked the hospital to provide necessary treatment for his heart. According to the mother, the hospital stated that they did not have a cardiologist, so they didn't have either the medical knowledge or the medication. The mother told us that she was very surprised, and wondered why the doctor accepted her son for treatment if the hospital didn't have skills in cardiology.

案例 7、某男到定点医院去看望朋友时，刚好遇到护士在给病人做静脉穿刺，护士做了三次都没有成功。出于好奇，他走到近处仔细观看，原来该护士竟然戴着三双手套在操作静脉穿刺。试想一下，护士戴着这么厚的手套能够准确的触摸到静脉吗？看着朋友痛苦的样子，他主动为朋友做穿刺。事后他和该护士聊起戴着三双手套做穿刺的事情，该护士隐隐约约地说到了担心被感染艾滋病。

In case 7, a man went to see his [HIV-positive] friend who was receiving treatment at the hospital. At the moment [when he arrived], a nurse was trying to insert a needle into the patient's vein. She attempted three times and did not succeed. When the man went closer to observe, he realized that the nurse was wearing three pairs of gloves. With such thick gloves, how could the nurse properly feel the vein? Seeing his friend's pained expression, he took over from the nurse to do it himself.

显然这种担心是多余的，假如一位在感染者定点治疗机构工作的护士对于如何防护职业暴露都不清楚的话就太不切实际了。显然，因为过多的担心，她才会戴着三双手套进行操作。

In our experience, there are many situations like this; it is impractical if a nurse working at a designated hospital for PLHA does not understand what to do for occupational safety. Clearly, she would only use three pairs of gloves if she was anxious.

访谈中一些感染者还提到，定点医院硬件设施落后，软件不足的问题。如该医院不具备骨科、妇科、心胸血管科等接诊能力。但是，感染者如果需要对骨科和妇科等疾病进行治疗，还是必须到该医院。而该医院对于以上病人，最终还是邀请其它常规医院的医生过来会诊，这种高额的会诊费最终的买单者还是感染者本人。

During our interviews, some PLHA observed that even when the right equipment is provided, the knowledge is insufficient. This hospital does not have capacity for orthopedics, gynecology, cardiology etc. However, PLHA are still required to go to this hospital to seek treatment for those conditions. In our experience, eventually the hospital may need to ask doctors from other general hospitals to attend to the patient. The high fee for such a visit will ultimately need to be paid by the patient living with HIV/AIDS.

我们的最后一个案例是关于艾滋病感染者所面临的高额治疗费用。一个姐妹经常到我们苦草工作室来参与活动。据她说，她的丈夫入住 X 市感染者定点治疗医院四天后，出现了严重的口腔溃疡，这位姐妹向院方提出了对病人提供口腔护理。

Our final case also relates to this issue of high fees for treatment borne by patients who are living with HIV. The sister in this case often takes part in Phoenix's program activities. According to her account, four days after her husband was admitted to the designated treatment facility for PLHA in X City, he had serious oral ulcers, so the sister told the hospital that he would need oral care.

当时，医生就提供 3 瓶漱口水（生理盐水、碘伏、碌安已定），并没有进行过其它任何方式的特殊护理。住院 8 天后，病情进一步恶化，病人生命体征完全消失。医院提出对病人进行心肺复苏。家人认为对于一个生命体征完全消失的病人而言，任何意义上的抢救都为时已晚，所以拒绝了医生提出的心肺复苏抢救措施。但是，据这位姐妹说，后来她去医院结算其丈夫在住院期间的治疗费用时，发现在结算账单上凭空多出了几项开支，其中最为明显的是医院每天对病人提供 10 元的口腔护理费用，以及心肺复苏。尽管病人并没有进行心肺复苏，但医院依然收取了 380 元的费用。

At that time, the doctor provided three bottles of mouthwash (saline solution, iodine, and lyu'an yiding), but did not undertake any further special treatment for the ulcers. After the patient had been at the hospital for eight days, his condition deteriorated and the patient's vital signs disappeared, whereupon the hospital offered to provide CPR. The patient's family felt that to a patient without vital signs, it was too late for any sort of meaningful rescue, so they declined CPR. However, according to the interviewee, when she went to pay the bills at the hospital, she saw some additional items. Among them was a daily expense of 10 RMB for oral care, and a fee for CPR (which had been declined and never performed), for a total of 380 RMB.

这位姐妹保留了其丈夫住院结算的明细清单，多处讨要说法，但没有一个地方可以为其主持公正。这位姐妹说，她一直不得其解，何以挂着感染者爱心家园的感染者定点医院竟会如此巧取豪夺，胡乱收费。她说：“人已经死了，病毒也死了，医院却不让他（她老公）安静的离开这个痛苦的世界，还要这样折磨他。”上文的案例是 X 市定点医院多收乱收感染者费用中较为典型的一例。

The woman kept the hospital bill listing the expenses and appealed in many places, but no one was willing to help her obtain justice. According to the interviewee, she could never understand how a designated treatment facility could be so predatory and charge arbitrary fees. She said “The patient had already died, the virus died [with him], but the hospital still won't let him [her husband] leave this sad world in peace, they still have to torment him.”

在我们的访谈中，有 7 位访谈者都表示有在住院阶段被该医院多收和乱收过治疗费用的经历。为什么这样的问题会在该医院会长期存在？首先是当下的国内医疗环境不尽如人意，很多地方就医消费不公开不透明，医院对于多收费乱收费有恃无恐。其次是当地政府部门监管不力。再次是就医维权的渠道不畅通。这些主要因素必然滋生了医院多收乱收的感染者就医费用的现象继续上演。

In our interviews, seven interviewees reported that they had been overcharged during hospital stays. Why has such a problem persisted for so long at this hospital? First of all, the domestic medical treatment environment in China is less than ideal. In many places medical fees are not handled transparently, and many hospitals are not afraid to charge arbitrary fees. Supervision by local government is weak. Also, there are obstacles to protecting the right to medical treatment. All these factors contribute to the fact that hospitals continue to charge PLHA arbitrary fees.

乱收医药费在中国是一个极具普遍性的现象。但由于目前行政机关对医疗机构监管不力以及其他多种原因，法律并没有得到有效的实施。对于医院要求感染者支付额外医药费及购买医疗器械的，依据法律的授权，一方面，政府有职责履行监管职能；另一方面，感染者自身也可以依法维权。<sup>4</sup>

In fact, arbitrary medical fees are common all over China. Because administrative agencies currently do not execute strong supervision, and for numerous other reasons, the law which should prevent hospitals from charging additional fees or making PLHA buy medical equipment is not properly enforced.

在最后一部分，我们会从权利和法律的角度对这些问题进行分析，并提出政策建议，希望能够保障感染者的医疗权益。

In the final section, we analyze the issues from a legal and rights-based perspective, and make recommendations for reforms that can better ensure PLHA obtain medical treatment.

## 法律分析与建议 Legal Analysis and Recommendations

尽管调查开展的时间较短，我们所收集的案例却代表了感染者在生活当中所遇到的几类问题。

While the research was for a short period of time, the few cases we gathered highlight larger patterns that we often experience in working with the community of people living with HIV/AIDS.

主要有三方面的问题。第一是目前国内的医疗系统在商品经济的冲击下，由于缺少资金，有的医院和医生散失了机构和医者的最基本的职业道德。第二是社会大环境依然对一些弱势群体的持有严重的社会歧视，特别是多年以来对艾滋病感染者污名化导致社会机构对感染者的歧视更为严重。第三是省级政府部门规定感染者需要定点治疗，给常规医院提供了拒绝感染者就医的借口。

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<sup>4</sup> 《中华人民共和国执业医师法》第二十七条：医师不得利用职务之便，索取、非法收受患者财物或者牟取其他不正当利益。第三十七条 医师在执业活动中，违反本法规定，有下列行为之一的，由县级以上人民政府卫生行政部门给予警告或者责令暂停六个月以上一年以下执业活动；情节严重的，吊销其执业证书；构成犯罪的，依法追究刑事责任：

(十) 利用职务之便，索取、非法收受患者财物或者牟取其他不正当利益的。

According to article 27 of the *Medical Professionals Law of the People's Republic of China*, medical professionals may not use their position to illegally obtain patients' property or obtain other unfair profit from them. Article 30 states, "In the course of their practice, medical professionals who break laws and policies, or engage in any of the following behaviors, may be warned or suspended from practice for six months to one year by health administrative departments of the People's Government above the county level; [if the offense] is serious, their certificates of practice may be revoked; [if the offense is] criminal, they will be punished in accordance to responsibilities under criminal law:

X uses his professional position to obtain or illegally accept patients' money or seeks other illegitimate interests from the patient."

It appears that there are three main issues. First, the domestic medical treatment system operates under the impact of a commodity economy. As a result of lack of funding, some hospitals and doctors have lost their basic professional ethics. Secondly, larger society continues to exhibit serious discrimination towards vulnerable communities, and the social stigma related to PLHA has resulted in intensifying discrimination by institutions. Third, regulations by provincial government departments that PLHA should seek medical services at designated facilities gives general hospitals an excuse to refuse services to PLHA.

但是，定点医院也并不具备接诊艾滋病感染者的能力。上文所述的案例说明了感染者必须到定点医院就诊带来的问题。感染者面临的机会性感染，定点医院并没有能力和设备为其提供治疗。医院的任意收费，也让出于社会边缘的感染者群体无法承担。

However, the designated hospitals are not equipped to handle PLHA either. The cases we have introduced demonstrate the problems that arise when PLHA are sent to designated hospitals. Designated hospitals are not trained or equipped to handle the many opportunistic infections to which PLHA are vulnerable, and they also sometimes charge arbitrary fees, which this marginalized community is not equipped to pay.

以下是我们的法律分析和政策建议。

Our legal analysis and recommendations for policy reform follow.

**1. 推动公平和公正的就医制度，取消感染者定点就医的地方性规定。 To promote an equal and fair medical system, abolish local regulations that require PLHA to be treated by “designated facilities”.**

事实上，规定感染者必须要到定点医院就医，而定点医院没有能力提供相应的服务，这与中国在 2001 年批准的《经济、社会和文化权利国际公约》是相违背的。该公约规定每个人都享有最高可获得健康标准。这种情况，有违国际社会对感染者就医的通行做法，更有损于我们政府树立的良好的艾滋病防治国际形象。

The fact that PLHA need to seek out designated facilities, which in some cases are not equipped to handle their treatment, is contrary to the International Covenant on Economic, Social and Cultural Rights, which China ratified in 2001, and which guarantees all persons the right to the highest available standard of health.<sup>5</sup> The current situation is detrimental to the Chinese government’s ability to set a good international example of HIV/AIDS prevention and treatment.

关于感染者的就医权，我国立法早已有相关规定，这些规定明令禁止医疗机构及医务

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<sup>5</sup> International Covenant on Economic, Social and Cultural Rights (ICESCR), United Nations General Assembly, A/HRC/WG.6/4/CHN/2: People’s Republic of China, December 16, 2008.

人员拒绝或推诿治疗艾滋病患者，同时对违法者将处以严厉的惩罚措施。<sup>6</sup>

In regards to the right for medical services for PLHA, China's Law on Treatment and Prevention of Infectious Diseases early on established regulations that forbid medical institutions and medical service personnel to refuse services to PLHA, and that also outline severe penalties for offenders. Article 50 of the law clearly states that the government must "strengthen and improve the service network to treat infectious diseases."<sup>7</sup>

但由于我国目前医疗水平尚不完善，同时专业人员配备有限，再加上艾滋病本身会引发多种机会性感染等问题，专门的传染病医院并不能解决 HIV 感染者面临的全部问题，特别是机会性感染造成的各种疾病。因此，《传染病防治法》中又补充作了这样的规定：

However, our national medical treatment standard is not yet ideal, and professionals also have limitations. Moreover, HIV/AIDS can lead to many different kinds of opportunistic infections, and infectious disease hospitals may not be able to solve all the medical problems that PLHA face through these various opportunistic infections. Therefore, the following regulation was added to the same law.

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<sup>6</sup> 《传染病防治法》第六十九条：医疗机构违反本法规定，有下列情形之一的，由县级以上人民政府卫生行政部门责令改正，通报批评，给予警告；造成传染病传播、流行或者其他严重后果的，对负有责任的主管人员和其他直接责任人员，依法给予降级、撤职、开除的处分，并可以依法吊销有关责任人员的执业证书；构成犯罪的，依法追究刑事责任：

（三）发现传染病疫情时，未按照规定对传染病病人、疑似传染病病人提供医疗救护、现场救援、接诊、转诊的，或者拒绝接受转诊的；

《艾滋病防治法》第五十五条：医疗卫生机构未依照本条例规定履行职责，有下列情形之一的，由县级以上人民政府卫生主管部门责令限期改正，通报批评，给予警告；造成艾滋病传播、流行或者其他严重后果的，对负有责任的主管人员和其他直接责任人员依法给予降级、撤职、开除的处分，并可以依法吊销有关机构或者责任人员的执业许可证件；构成犯罪的，依法追究刑事责任：

（六）推诿、拒绝治疗艾滋病病毒感染者或者艾滋病病人的其他疾病，或者对艾滋病病毒感染者、艾滋病病人未提供咨询、诊断和治疗服务的；

《云南省艾滋病防治条例》第五十二条规定更加细致：医疗机构违反本条例规定，有下列行为之一的，由县级以上卫生行政部门责令改正，通报批评，给予警告，可以并处 5000 元以上 1 万元以下罚款；造成艾滋病传播、流行或者其他严重后果的，对负有责任的主管人员和其他直接责任人员，依法给予行政处分，并可以依法吊销有关责任人员的执业证书；构成犯罪的，依法追究刑事责任：

（四）推诿、拒绝接诊艾滋病病毒感染者和艾滋病病人的。

我国《执业医师法》及《医疗机构管理条例》中对此也均有相关规定：医疗机构如果推诿、拒绝治疗艾滋病患者的，权益受到侵犯的患者完全可以依据任何一部法律规定向县级以上卫生行政部门举报或申诉，主管部门依法有权对相关责任人及机构予以处罚。同时，责令相关机构予以改正。

<sup>7</sup>第五十条 县级以上人民政府应当加强和完善传染病医疗救治服务网络的建设，指定具备传染病救治条件和能力的医疗机构承担传染病救治任务，或者根据传染病救治需要设置传染病医院。 Article 50: Governments on district level or above should strengthen and improve the service network to treat infectious diseases, specify the conditions and abilities for treatment of infectious diseases can be taken on by medical institutions, or set up infectious disease hospitals according to the needs of infectious diseases treatment.

根据《传染病防治法》第五十二条，医疗机构不具备相应救治能力的，应当将患者及其病历记录复印件一并转至具备相应救治能力的医疗机构。

According to Article 52, medical institutions that do not possess the relevant treatment capacities should refer PLHA, together with a copy of their patient records to a medical institution that does have the relevant capacities.

《医疗机构管理条例》中也有类似规定：第三十一条，医疗机构对危重病人应当立即抢救。对限于设备或者技术条件不能诊治的病人，应当及时转诊。

In addition, the Medical Institution Management Regulations have a related regulation: Article 31 states that medical institutions should offer immediate rescue to critically ill patients. In the case of a lack in medical equipment, or a patient who needs special treatment that cannot be met by the clinic, the hospital should quickly transfer the patient to another clinic [which does have the necessary capacity].

由此可以看出，立法的原意是将传染病医院作为救治患者的第一道防线，传染病医院在对传染病的医治方面承担更多的责任；在第一道防线不能够挽救患者时，任何其他具备医疗条件的医疗机构作为第二道防线都无权推诿或拒绝治疗。因此，尽管做出了感染者定点就医的相关规定，但这在法律上并不意味着排除其他医疗机构救死扶伤的职责。

As we can see, the law treats infectious disease hospitals as first line of defense or treatment for PLHA; infectious disease hospitals thus must shoulder a greater share of the responsibility. If the first-line treatment facility cannot fully care for a PLHA, then any other medical institution with the relevant treatment capacities becomes the second line of treatment, and this facility does not have the right to refuse treatment or find excuses. In other words, even though a regulation for designated treatment institutions exists, the law does not absolve other medical institutions from their live-saving and treatment responsibilities.

2005年9月19日起实施的《云南省艾滋病临床治疗管理办法》第三条规定：“艾滋病的临床治疗工作由州（市）级以上卫生行政部门指定的定点医疗机构承担。定点医疗机构分为抗病毒治疗定点医院、中医药治疗定点医院、艾滋病母婴传播阻断定点医院（含县级以上设有产科的综合医院、妇幼保健院、中医院）和定点门诊。定点医院必须承担定点门诊工作。”

As mentioned earlier, article 3 of the Yunnan Province HIV/AIDS Clinical Treatment Management Regulations states: “Clinical treatment of PLHA will be carried out by designated treatment institutions as specified by health departments above the prefectural (city) level. Designated treatment institutions are divided into ARV-designated hospitals, Chinese-medicine-designated hospitals, PMTCT-designated-hospitals (including general hospitals with obstetric department, mother-and-child hospitals, and Chinese medicine hospitals above district level), and designated outpatient facilities. Designated hospital must



commit to designated outpatient work.”

同时第二十条补充规定：各定点医疗机构之间和定点医疗机构与非定点医疗机构之间要密切配合、互通信息、共享资源。因此，常规医院以定点医院为借口推托职责是没有法律依据的。

Additionally, Article 20 of these regulations includes a supplementary regulation: “Designated treatment facilities should closely cooperate among each other and between designated treatment facilities and non-designated treatment facilities, should exchange information and share resources.” Therefore, general hospitals that use the existence of designated hospitals as reason to refuse services have no legal basis for this behavior.

现存的法律规定造成了混乱，使得艾滋病感染者不得不面对歧视，以及不尽人意的医疗服务。因此，我们建议取消感染者必须到定点医院就医的相关规定。

However, the existing regulations create confusion and leave PLHA vulnerable to discrimination and to poor medical treatment. For this reason, we recommend abolishing the requirement that PLHA only be treated by designated facilities.

## 2. 政府部门规范医院的制度，抓强政府职能部门对院方及医务人员的监管力度。 **Strengthen supervision of local hospitals.**

其次，行政机关应当充分履行监管职能，对医疗机构的违法行为必须依法处罚。如前所述，禁止歧视艾滋病人的法律见诸于各级法律及规章之中，且大部分法律规定都详细的列出了责任条款，对歧视艾滋病人的医疗机构施以处罚，但现实中存在的问题是：这些法律都未能得到有效的实施。

Secondly, administration should exercise their supervisory responsibilities and punish illegal behavior in accordance with existing laws. As mentioned above, laws against discrimination of PLHA are found in laws and regulations at every level, and most laws outline specific responsibilities and have penalties against discriminatory medical institutions. However, the problem is that these laws are not effectively enforced.

应当履行监管职能的卫生行政部门往往成为违法医疗机构的庇护人。如何确立一种良性的机制，可以使卫生行政部门对医疗机构的管理透明化，应当成为未来的探索方向。

Often, the health departments that should be supervising hospitals instead end up protecting illegal behavior by medical institutions. Establishing an effective system that makes the supervision of medical institutions by health departments more transparent should be the direction of future exploration.

## 3. 推动院方医德医风的建设，提高医务工作者的业务能力。 **Promote medical ethics in**

## **hospitals and improve the professional capacity of medical staff.**

医疗机构及医务工作者本身应当提高认识。主要是对医务工作者加强培训教育，推动院方医德医风的建设，提高医务工作者的业务能力。一方面，通过德育倡导消除医疗歧视；另一方面，加强对医务工作者预防职业暴露的防范能力，并建立相应的保障机制，如为医务人员建立职业保险等。确立相关标准设立传染病工作补贴。同时也应该为医护人员提供关于职业防护的培训。只有确保医务工作者的人身安全，艾滋病预防知识，与意外保障制度，使医务人员没有后顾之忧，他们才能一心一意的工作，患者的治疗才能得到保障。

Medical institutions and medical personnel should improve their knowledge. In particular, there should be stronger training of medical staff to improve all hospitals' medical ethics and improve the professional capacity of the medical staff. On the one hand, medical discrimination can be eliminated through education and advocacy; on the other hand, the staff's capacity to prevent occupational exposure can be improved by establishing security systems: establishing occupational insurance for medical staff; standards for occupational subsidies for infectious diseases. Staff should also be trained in the use of universal precautions. Only if the personal safety, HIV prevention knowledge and security system are guaranteed so that medical staff don't have to worry, will they be able to do their work with the proper attitude, ensuring treatment for PLHA.

#### **4. 建立透明公平的就医消费制度，规定院方必须对各项收费项目明码标价，对感染者的就医出具各项明细清单。Establish a transparent and fair system of medical fees, regulate that the hospital needs to clearly list services and respective prices, and that they issue a clear list of medical services for PLHA.**

建立透明公平的就医消费环境。院方必须严格按照医疗机构收费标准对各项收费项目明码标价，对感染者的就医出具各项明细清单。<sup>8</sup> 对收取不合理费用的，患方有权提起民事诉讼，要求予以返还或赔偿损失。对于院方强制感染者购买医疗器械的，这明显属于歧视行为，政府也应当加强监管。在这方面可以依据的法律法规有云南省发改委、云南省卫生厅发布的《云南省非营利性医疗服务价格》及《云南省非营利性医疗服务价格管理暂行办法》。

Establish a transparent and fair system of medical fees. Hospitals must strictly standardize all medical fees, including those for PLHA, and make the costs of services openly available to the public. If they encounter arbitrary fees, the patient should have the right to legal redress, to ask for compensation.

Regarding the requirement by some hospitals to buy medical equipment for use of PLHA, this is clearly discriminatory behavior, and the government should strengthen supervision. In

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<sup>8</sup> 我国《医疗机构管理条例》第三十七条规定：医疗机构必须按照人民政府或者物价部门的有关规定收取医疗费用，详列细项，并出具收据。遗憾的是该部法规中并未列出相应的责任条款，即使医疗机构违反规定，也没有相关规定对其进行处罚。

Yunnan, this should be handled according to two documents: the Yunnan Province Non-profit Medical Services Pricing and Yunnan Province Non-profit Medical Service Pricing Interim Measures, which were promulgated by the Yunnan Province Development and Reform Commission and Yunnan Province Health Department.

#### 5. 支持感染者保护自己的法律权益。 **Support PLHA to protect their legal rights.**

在这种情况下，感染者可以依法向卫生行政主管部门提出申诉，要求对违法行医行为依法予以处罚，同时向医疗机构主张返还或赔偿。

When they experience discrimination, PLHA can use the law to file complaints to the health administrative department and demand that doctors who violate the law be punished according to the laws. At the same time, they can demand a response or compensation from the health administrative chief.

患者在受到就医歧视的情况下，也可以依法向司法机关提起诉讼，这些都是公民享有的基本权利。但遗憾的是，在这个庞大的受歧视的 HIV 感染者及艾滋病患者群体中，主张自身权利的声音却太过微弱。很多感染者担心，站出来会把医生推得更远，毕竟病人要仰仗医生的服务而存活。当然，选择沉默有其背后不可言说的痛，揭开痛苦需要另一种勇气，在这方面，我国法律也规定了医疗机构的保密义务，对于泄露患者秘密的，相关部门有权对其进行处罚。司法机关也允许患者通过化名或者不公开的方式进行诉讼，以保护患者的隐私权。

If PLHA experience medical discrimination, they can also use the law in litigation; these are all basic rights of any citizen. Unfortunately, for those people living with HIV/AIDS who experience discrimination, their collective voice is too weak to claim their rights. Many also fear that they will alienate the doctors they rely on to survive when they are ill. Of course, in choosing silence one has no way to voice their pain, and to reveal this pain requires courage. Thus, China's regulations demand that medical facilities protect confidentiality, and if confidentiality is not protected, respective departments can penalize those who violate it. Legislative bodies also allow PLHA to use fake names in legal proceedings or use other non-public measures to protect their privacy.

我们建议，仿照其它国家，成立一些官方或半官方的委员会。委员可以由政府工作人员、感染者代表、NGO 代表、医疗机构代表等多方组成。该机构可以承担接受感染者歧视方面的投诉，进行调查，提出相关建议，还可以定期或不定期的组织一些讨论会或交流会，将提出的问题或有成效的建议提交相关部门。

In the model of some other countries, we recommend the establishment of an official or semi-official committee, comprised among others of government officials, PLHA representatives, NGO representatives, and representatives of medical institutions. This institution could be responsible for accepting, investigating, and issuing recommendations on discrimination-related complaints from PLHA, and could also organize some regular or irregular discussion groups or exchange groups to generate questions to or feedback for

relevant government departments.

此外，我们建议为感染者提供法律权益方面的培训，作为对医生和医护人员培训的补充。我们还建议成立法律援助中心，为那些无力承担费用的感染者提供免费的法律服务。

In addition, we recommend establishing training workshops for PLHA in their legal rights, to complement the above-recommended training for doctors and medical staff. We also recommend establishing free legal aid centers to provide legal services to PLHA who cannot afford to pay legal fees.

通过这样的方式，我们相信医生、感染者、官员和专家能够通力合作，改善和提高患者和医生之间的关系，从而防止艾滋病的进一步传播

By working together in these ways, we believe that doctors, PLHA, officials and experts can help to improve the partnership between patients and doctors, and prevent the further spread of the HIV/AIDS epidemic.

## **致谢 Acknowledgements**

本报告由苦草的成员和志愿者撰写。惟谦法律中心为本报告提供了法律分析和建议，由亚洲促进会进行英文翻译。本报告由这三家机构进行编辑和修改。

This report was written by staff and volunteers of Phoenix. Legal analysis and recommendations were provided by Korekata AIDS Law Center, and translation into English and layout were provided by Asia Catalyst. All three organizations worked together to edit the report.

苦草工作室十分感谢接受本报告访谈的感染者朋友，如果没有他们提供的案例和接受我们的访谈，我们是完成不了这个报告的。特别感谢在本报告撰写过程中给予法律方面建议的惟谦艾滋法律中心，特别感谢给予我们经费支持和技术支持的亚洲促进会。

Phoenix would like to express our sincere gratitude towards our friends living with HIV/AIDS that participated in the research for this report. Had they not shared their experiences and agreed to be interviewed, we would not have been able to produce this report. Special thanks to the Korekata AIDS Law Center for providing legal recommendations throughout the writing process. Special thanks also to Asia Catalyst for their financial and technical support.