

Washington and Lee Journal of Civil Rights and Social **Justice**

Volume 15 | Issue 1

Article 4

Fall 9-1-2008

HIV Discrimination in Health Care Services in Los Angeles County: The Results of Three Testing Studies

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HIV Discrimination in Health Care Services in Los Angeles County: The Results of Three Testing Studies

Brad Sears*

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I. Introduction

This Article presents the results of three studies conducted from 2003 to 2006 measuring HIV-discrimination in health care services in Los Angeles County. Leach of the studies used trained testers posing as either patients who were either HIV-positive or organizations working with such patients. Testers called the offices of health care providers and asked if they would accept HIV-positive patients. The studies focused on skilled nursing facilities, cosmetic and plastic surgeons, and obstetricians, in order to determine the percentage of providers in each area who had a blanket policy of refusing services to people living with HIV-disease. The testers also gathered some qualitative information about the reasons why health care providers denied services to HIV-positive patients. The three types of health care providers were chosen based on current medical needs of persons living with HIV/AIDS, including nursing care as the HIV-population ages, cosmetic surgery to address the impact of facial wasting, and prenatal care for women living with HIV.

The three testing studies discovered that HIV-discrimination remains quite common in the health care sector despite legal prohibitions. The studies found that 56% of skilled nursing facilities, 26% of plastic and cosmetic surgeons, and 47% of obstetricians in Los Angeles County would not take any patient who was HIV-positive for any type of service, even when patients were asymptomatic.

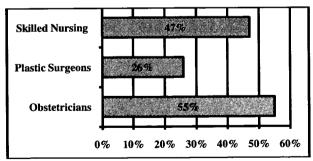


Figure 1: Percentage of Health Care Providers in LA County not accepting HIV-positive patients, 2003-2006.

Brad Sears, HIV Discrimination in Health Care Services in Los Angeles County (2003–2006) (unpublished study, on file with The Williams Institute, UCLA School of Law).

The most common reasons for denying services to HIV-positive patients included lack of expertise or equipment by the health care provider, never having treated an HIV-positive patient before, staff that were inadequately trained or who would refuse to treat HIV-positive patients, and the blanket referral of all HIV-positive patients to "specialists." The studies demonstrate that laws protecting persons living with HIV-disease from discrimination in health care need to be strengthened, and that further education and training of healthcare workers about such laws is necessary.

II. Legal Background

In general, California state law² and federal disability discrimination law³ prohibit health care providers from refusing services to persons with HIV-disease. Exceptions to these general prohibitions are: (1) the providers would not perform the requested service for a person who was

^{2.} See, e.g., Unruh Civil Rights Act, CAL. CIV. CODE § 51(b) (2006) (stating that all persons are entitled to equal treatment). This section specifically states:

[[]a]ll persons within the jurisdiction of this state are free and equal, and no matter what their sex, race, color, religion, ancestry, national origin, disability, medical condition, marital status, or sexual orientation are entitled to the full and equal accommodations, advantages, facilities, privileges, or services in all business establishments of every kind whatsoever.

Id.; CAL. CIV. CODE § 54 (2001) ("Individuals with disabilities or medical conditions have the same right as the general public to the full and free use of the streets, highways, sidewalks, walkways, public buildings, medical facilities, including hospitals, clinics, and physicians' offices, public facilities, and other public places." (emphasis added)).

See, e.g., Americans With Disabilities Act (ADA), 42 U.S.C. § 12181(7)(F) (2000) (listing "professional office[s] of a health care provider, hospital, or other service establishment" as public accommodation); 42 U.S.C. § 12182(a) (2000) ("No individual shall be discriminated against on the basis of disability in the full and equal enjoyment of the goods, services, facilities, privileges, advantages, or accommodations of any place of public accommodation by any person who owns, leases (or leases to), or operates a place of public accommodation."); 28 C.F.R. § 36.104(6) (2003) (implementing the Act's definition of a "professional office of a health care provider, hospital, or other service establishment" as a public accommodation under § 12181(7)(F)); Rehabilitation Act of 1973, 29 U.S.C. § 794(a) (2000) (prohibiting health care providers who receive "federal financial assistance," including payments under Medicaid and Medicare, from denying services to HIV-positive patients); see also Bragdon v. Abbott, 524 U.S. 624, 641-42 (1998) (granting disability protections under Title III of the ADA to protect persons living with HIV-disease). But see Lisa T. Hudson, The Duty to Treat Asymptomatic HIV-Positive Patients or Face Disability Discrimination Under Abbott v. Bragdon: The Scylla and Charybdis Facing Today's Dental and Health Care Providers, 33 U. RICH. L. REV. 665, 666 (1999) (discussing complications created by the way in which Bragdon extended coverage to persons with HIV/AIDS).

HIV-negative, (2) the requested services would pose a "direct threat" to the safety of the health care provider or the patient, or (3) a legitimate referral to another provider is warranted.⁴ To determine if a patient poses a direct threat or to make a lawful referral, the health care provider must make an individualized inquiry about the health condition of the patient and the specific services being requested.⁵ Accordingly, a blanket policy of refusing services to all patients who are HIV-positive is unlawful under state and federal laws.

Under the Americans With Disabilities Act of 1990 (ADA),⁶ a health care provider may refer a person living with HIV/AIDS to another provider if that individual is seeking treatment outside of the provider's specialization or if the provider would make a similar referral for an HIV-negative person seeking similar services.⁷ The American Medical Association,⁸ the American

^{4.} See infra note 7 and accompanying text (providing applicable case law and statutory authority referring to the first exception); infra notes 12, 16 and accompanying text (providing applicable case law referring to the second and third exceptions).

^{5.} See Lesley v. Chie, 250 F.3d 47, 56 (1st Cir. 2001) (holding that transferring a patient is legitimate if a fact-specific and individualized inquiry is made prior to such transfer).

^{6.} Americans With Disabilities Act (ADA) of 1990, 42 U.S.C. §§ 12101-12300 (2000).

^{7.} See 8 C.F.R. \S 36.302(b), (b)(2), & App. B \S 36.302(b)(2) (implementing the ADA). The regulation specifically states that:

⁽b) Specialties—(1) General. A public accommodation may refer an individual with a disability to another public accommodation, if that individual is seeking, or requires, treatment or services outside of the referring public accommodation area of specialization, and if, in the normal course of its operations, the referring public accommodation would make a similar referral for an individual without a disability who seeks or requires the same treatment or services. (2) Illustration—medical specialties. A health care provider may refer an individual with a disability to another provider, if that individual is seeking, or requires, treatment or services outside of the referring provider's area of specialization, and if the referring provider would make a similar referral for an individual without a disability who seeks or requires the same treatment or services. A physician who specializes in treating only a particular condition cannot refuse to treat an individual with a disability for that condition, but is not required to treat the individual for a different condition.

Id.; see also U.S. v. Morvant, 898 F. Supp. 1157, 1168 (E.D. La. 1995) (finding that a dentist could not refuse "to provide treatment to persons with HIV or AIDS, on the basis of their HIV positive status"). The Morvant Court also reasoned: (1) that the dentist could not have a blanket policy of referring all patients with HIV or AIDS to other dentists; (2) the dentist is required to adopt and post an office policy pertaining to non-discrimination on the basis of HIV, AIDS, and other disabilities; and finally (3) that the dentist's office staff are required to undergo special training for dentistry practice on HIV-positive patients. Id. at 1168.

^{8.} The American Medical Association states within their Code of Ethics that:

Nurses Association, and the specific professional organizations for cosmetic and plastic surgeons and obstetricians have determined that practitioners

[A] physician may not ethically refuse to treat a patient whose condition is within the physician's current realm of competence solely because the patient is HIV seropositive. Persons who are seropositive should not be subjected to discrimination based on fear or prejudice. Physicians who are unable to provide the services required by HIV-infected patients should make referrals to those physicians or facilities equipped to provide such services. It is in the best interest of the patient for the physician to focus on treatment of the disease, rather than on making value judgments about how the disease was contracted.

AM. MED. ASS'N (AMA), HEALTH AND ETHICS POLICIES OF THE AMA § H-20.908(1) (2008), http://www.ama-assn.org/ad-com/polfind/Hlth-Ethics.pdf.

9. The American Nurses Association states that:

[Nurses are] obligated to care for clients in a non-discriminatory manner, with respect for all human persons, yet recognizes that there may be limits to the personal risk of harm the nurse can be expected to accept as an ethical duty. Nurses are challenged to thoughtfully analyze the balance of responsibility and risk, including moral obligation and options, in particular situations in order to preserve the ethical mandates of the profession. Nursing creates a relationship of trust between nurse and patient, with special duties for the nurse, including the responsibility to care for patients. The nurse has a moral obligation or duty to patients and is not at liberty to abandon patients in need of nursing care. Moral objections by the nurse do not include personal preference, prejudice, convenience, or arbitrariness.

AM. NURSES ASS'N (ANA), ANA CENTER FOR ETHICS AND HUMAN RIGHTS, Position Statement of the Advisory Board, Risk and Responsibility in Providing Nursing Care (2006).

- 10. See Am. College of Surgeons (ACS), Surgeon & HIV Infection, 89 BULL. AM. C. SURGEONS § 5 (May 2004), available at http://www.facs.org/fellows_ info/statements/st-13.html (urging members to "learn and to follow existing federal and state laws regarding the provision of services to individuals who have tested positive for the HIV virus" and stating that "[s]urgeons have the same ethical obligations to render care to HIV-infected patients as they have to care for other patients").
- 11. See Am. College of Obstetricians & Gynecologists (ACOG), ACOG Committee Opinion No. 389, Human Immunodeficiency Virus, at 4 (2007), http://www.acog.org/from_home/publications/ethics/co389.pdf (describing the ethical standards applicable to treating patients with HIV). The committee opinion states:

[I]t is unethical for an obstetrician-gynecologist to refuse to accept a patient or to continue care for a patient solely because she is or is thought to be, seropositive for HIV. Refusing to provide care to women who are infected with HIV for fear of contracting HIV infection or simply as a practice preference is unreasonable, unscientific, and unethical... Health care professionals who fail to provide care to women who are infected with HIV because of personal practice preferences violate professional ethical standards. The public appropriately expects that health care practitioners will not discriminate based on diagnosis, provided that the patient's care falls within their scope of practice. Physicians should demonstrate integrity, compassion, honesty and empathy. Failure to provide health care to a woman solely because she is infected with HIV violates these fundamental characteristics. As with any other patient, it is acceptable, however, to refer women who are infected with HIV for care that the

in these fields should not deny care to patients merely because they are HIV-positive. In order to make a lawful referral under the ADA, these providers must make "an individualized inquiry into the patient's condition" and the specific services requested.¹²

A health care provider may refuse services to an HIV-positive patient if providing those services would pose a "direct threat" to the patient or to others. The provider has the burden of proving that the patient's disability presents a significant threat that cannot be eliminated by reasonable accommodation—changes in the provider's practices or procedures that would substantially reduce or eliminate the threat. The health care provider must base his or her determination that an HIV-positive patient poses a direct threat upon an individualized assessment of the threat. A health care provider's failure to make an individualized assessment before denying services will likely result in a finding of discrimination. Moreover, the health care provider's assessment of the "direct threat" must

physician is not competent to provide or if care elsewhere would be more convenient or associated with decreased financial burden to the patient.

- 12. See Lesley v. Chie, 250 F.3d 47, 56 (1st Cir. 2001) (noting that a gynecologist lawfully referred a HIV-positive patient when he made a fact-specific and individualized inquiry before making his decision to transfer her to a program specializing in prenatal care for HIV-positive patients and where his decision was confirmed by independent and knowledgeable persons at the time).
- 13. See Chevron v. Echazabal, 536 U.S. 73, 74–75 (2002) (referring to the threat to others exception and deferring to the EEOC's interpretation of the ADA extending the direct threat defense to "threat-to-self").
- 14. See 42 U.S.C. § 12182(b)(3) (2005) ("Nothing in this subchapter shall require an entity to permit an individual to participate in or benefit from the goods, services, facilities, privileges, advantages and accommodations of such entity where such individual poses a direct threat to the health or safety of others.").
- 15. See 28 C.F.R. § 36.208(c) (2007) (setting forth the requirements for the "direct threat" exception to the obligation of public accommodations and commercial facilities not to discriminate on the basis of disability).
- 16. See Shultz v. Hemet Youth Pony League, Inc., 943 F. Supp. 1222 (C.D. Cal. 1996) (finding discrimination when a youth baseball league failed to conduct an individualized assessment of a disabled player's risk of harm to himself and others); U.S. v. Morvant, 898 F. Supp. 1157, 1163–64 (E.D. La. 1995) (establishing that a dentist's referral of HIV-positive patients to another practitioner who supposedly specializes in treating HIV-positive dental patients may be a pretext for unlawful discrimination if neither the dentist nor the dentist's staff even examines the patients' mouths); Anderson v. Little League Baseball, Inc., 794 F. Supp. 342 (D. Ariz. 1992) (finding discrimination when a youth baseball league failed to conduct an individualized assessment of a disabled coach's risk of harm to himself and others).

Id. California state law also provides that if a pregnant woman tests HIV positive "she shall, whenever possible, be referred to a provider or provider group specializing in prenatal care for HIV-positive women." CAL. HEALTH & SAFETY CODE § 125090 (2006).

be "based on reasonable medical judgments given the state of medical knowledge." The assessment cannot be based on stereotypic notions about people with HIV-disease, even if such notions are maintained in good faith or made in ignorance because of the provider's own failure to keep up with the current medical literature. 18

Thus, when a health care provider would provide similar services to an HIV-negative patient, he or she cannot lawfully deny services to an HIV-positive patient or refer the patient to another provider based on a blanket policy of denying services to all patients who are HIV-positive. The provider must first make an individualized inquiry of the patient's condition and the services requested.¹⁹

III. Methodology

All three studies used trained testers to measure the level of HIV-discrimination among specific types of health care providers in Los Angeles County: skilled nursing facilities, cosmetic and plastic surgeons, and obstetricians. Testers in each study were trained UCLA School of Law students who used scripts to call health care providers to ask if they accepted patients who were HIV-positive. The testers were trained to be consistent in following the script for each study, recording responses verbatim as the calls were made, and in coding the responses.

The primary focus of the studies was to identify the provider policies that would most clearly violate state and federal law, i.e., those policies that prohibit all services to any person living with HIV-disease without any

^{17.} See 28 C.F.R. § 36.208(c) (setting forth the four factors for health care providers to consider when determining whether the patient poses a direct threat). The health care provider must consider current medical and scientific knowledge about (a) the nature of the risk (how the disease is transmitted); (b) the duration of the risk (how long is the carrier infectious); (c) the severity of the risk (what is the potential harm to third parties); and (d) the probabilities the disease will be transmitted and will cause varying degrees of harm). Id.; see also Sch. Bd. of Nassau County. v. Arline, 480 U.S. 273, 288 (1987) (establishing the four-part test for a "direct threat").

^{18.} See Bragdon v. Abbott, 524 U.S. 624, 649 (1998) ("The existence, or nonexistence, of a significant risk must be determined from the standpoint of the person who refuses the treatment or accommodation, and the risk assessment must be based on medical or other objective evidence."). In Bragdon, the Court found that a health care professional has a duty to assess the risk of HIV infection, "based on the objective, scientific information available to him and others in his profession." Id. Even a good faith belief that a significant risk existed will not relieve a health care professional from liability. Id.

^{19.} See Lesley v. Chie, 250 F.3d 47, 56 (2000) (recognizing that an individualized inquiry is necessary before transferring an HIV-positive patient to another medical provider).

individualized inquiry. The testers were further trained to code ambiguous responses; in other words, unless the provider clearly indicated a blanket policy of denying services to all HIV-positive patients (i.e. "no"), the response was coded as "unclear." All of the original responses and the coding by testers were reviewed by both authors of this study to check for consistency and accuracy in the coding procedure. Further details about the study design for each type of health care provider are outlined below.

A. Skilled Nursing Facilities

The study testing for HIV-discrimination by skilled nursing facilities (SNFs) in Los Angeles County used as a sampling frame those facilities surveyed in a study by the California Advocates for Nursing Home Reform (CANHR). CANHR conducts a periodic survey querying California SNFs on their admissions policies, including whether the facilities accept individuals with AIDS/HIV. In July 2000, CANHR published survey responses from 442 skilled nursing facilities in Los Angeles County. The survey grouped Los Angeles County SNFs into five districts: Central, East, North, San Gabriel, and West.

Of the 442 SNFs included in the survey, only 65% (N=289) responded to the AIDS/HIV question. Of those, 76% (N=220) reported that they did not accept individuals with AIDS or HIV. Using the July 2000 CANHR survey as a starting point, we randomly selected 30% of the facilities from each of the five CANHR districts in Los Angeles County for inclusion in this study, resulting in a total of 131 facilities in our sample.

Two testers, both third-year UCLA Law students, one of whom had been a registered nurse, posed as discharge planners from acute care hospitals. The testers called all facilities included in the sample to gather general information about the types of patients the facilities would accept. The testers posed as discharge planners because SNFs generally rely heavily on referrals from acute care hospitals to maintain critical bed census

^{20.} The California Advocates for Nursing Home Reform (CANHR) is a non-profit organization dedicated to defending the rights of long-term care residents in California. Through community education, legislation and litigation, CANHR's goal is to remind decision makers of what needs to be done about long-term care in California. CANHR periodically conducts a written survey of skilled nursing facilities in California as a service to families, consumers, and healthcare providers interested in skilled nursing placement. CANHR Homepage, http://www.canhr.org (last visited Dec. 18, 2008).

^{21.} CALIFORNIA ADVOCATES FOR NURSING HOME REFORM, ANNUAL REPORT, CA NURSING HOMES BY COUNTY: LOS ANGELES COUNTY (2000).

levels, and thus SNFs would have an economic incentive to speak with acute care discharge planners and express a willingness to consider a broad spectrum of patients.²²

After gathering contact information for all of the facilities, the two testers proceeded to contact each facility by telephone in March of 2003, asking to speak to a representative in the admissions department. If the tester was able to reach an admissions representative, he/she would proceed by asking ten questions from the prepared script²³ and record the responses into a spreadsheet.²⁴ The testers asked a number of questions, including whether the SNF would take difficult-to-place patients. Among these questions was the "test" question regarding whether the facility accepted patients who are "HIV-positive." If an admissions representative could not be reached after several attempts, the caller randomly selected another SNF from the CANHR list for the district being surveyed. In May of 2004, SNFs whose initial responses were ambiguous received a follow-up phone call.

^{22.} The surveyors took a number of steps to minimize suspicions among SNFs' admissions representatives. First, callers to all but the North District represented that they were discharge planners from "Ventura Regional Medical Center," a fictitious full-service acute care hospital. Due to the likelihood that North County service providers would be familiar with hospitals located in Ventura County and would not recognize the facility, surveyors calling SNFs in North County stated that they were calling from "South Coast Regional Medical Center."

Two financial payor source questions were first asked to legitimize the inquiry, as ability to pay for care is one of the most significant factors with respect to a referral's eligibility for placement. The surveyors selected three specific clinical questions based on inquiries included in the July 2000 CANHR survey. These questions tend to characterize patients who are more difficult to place: (1) individuals with co-morbid psychiatric diagnosis; (2) patients who wander; and (3) patients who have tracheotomies. An acute care facility would reasonably call various SNFs to inquire about their admissions practices regarding such patients since SNFs can have legitimate licensing or other reasons for policies against admitting these patients. The surveyors asked the "HIV-positive" test question after the "wanderers" question and before the "tracheotomy" question. The "HIVpositive" test question was embedded in this group of questions to avoid raising suspicion. To reaffirm the legitimacy of the call, the surveyors' seventh question involved a common concern of referring hospitals, that is, how long it would take the SNF to determine if it were able to accept the referral, also known as the "turnaround time" of a referral. The final questions involved the tested person's name, if he/she was the proper person to send a referral to, and a confirmation of the correct fax number. These questions were also included to add legitimacy to the call.

^{24.} See Appendix A for the script used during the telephone calls.

B. Cosmetic and Plastic Surgeons

The second study focused on cosmetic and plastic surgeons. Some persons living with HIV-disease need such services in order to treat the side effects of HIV and HIV medications. To create the sampling frame for the study, we obtained a list of surgeons practicing in Los Angeles County²⁵ from searches conducted on the websites of the American Society for Aesthetic Plastic Surgery (ASAPS)²⁶ and the American Board of Medical Specialties (ABMS).²⁷ These two websites provided the names of approximately sixty board-certified plastic and cosmetic surgeons in Los Angeles County. We then increased the survey sample by searching insurance websites and including their listings of covered cosmetic and plastic surgeons.²⁸

After duplicate listings were removed, a total of 213 surgeons remained in the survey sampling frame. The testers attempted to contact all 213 surgeons. The testers were unable to contact approximately 48% of the surgeons (N=96) due to lack of contact information and disconnected or wrong numbers. Another 3% (N=6) did not perform the procedure or were not cosmetic surgeons. Therefore, the study sample includes 49% (N=98) of the surgeons in the original sampling frame.

Following a script, the testers, two third-year UCLA Law Students, called the surgeons' offices posing as individuals who had HIV-related lipodystrophy, also known as "fat wasting syndrome." Lipodystrophy is a disorder that involves the loss of fatty tissue in one area of the body, often

^{25.} Surgeons in the following area codes were included in the sample: 213, 310, 323, 562, 626, and 818.

^{26.} See ASAPS Homepage, http://www.surgery.org (last visited Dec. 18, 2008) (describing ASAPS as the leading organization of board-certified plastic surgeons specializing in cosmetic plastic surgery). ASAPS Active-Member plastic surgeons are certified by the American Board of Plastic Surgery or the Royal College of Physicians and Surgeons of Canada. *Id.*

^{27.} See ABMS Homepage, http://www.abms.org (last visited Dec. 18, 2008) (noting that ABMS, a not-for-profit organization, represents twenty-four medical specialty boards that establish and maintain high standards for physician certification and the delivery of safe, quality medical care by certified physician specialists). Certification obtained through one of the ABMS Member Boards denotes that a physician has gone beyond the minimum requirement necessary for licensure and provides assurance that a physician has the appropriate knowledge, skills, and experience needed to deliver optimum care in a specific area of medicine. *Id*.

^{28.} See Blue Cross Blue Shield Homepage, http://www.bcbs.com (last visited Dec. 18, 2008) (providing list of additional providers); Aetna Health Care Homepage, http://www.aetna.com (last visited Dec. 18, 2008) (same).

^{29.} See infra Appendix B (providing the script used during the interviews).

as a result of drug treatments related to HIV.³⁰ There are several types of treatment for lipodystrophy, including facial cheek implants and injections of fat, collagen, or Restolin. If asked, the testers requested an injection in order to minimize possible objections about the procedures posing a "direct threat" to the patient or to the health care providers. The injections are not invasive and involve significantly less risk than a facial cheek implant.³¹

The testers kept records of their conversations on a spreadsheet. Affirmative answers to the request for treatment were noted, and negative answers received follow-up questions as to why the offices did not treat HIV-positive patients.

C. Obstetricians

The third testing study focused on the availability of pre-natal care for HIV-positive women in Los Angeles County. The sampling frame for the study was created through a search for obstetrician offices in the Los Angeles region³² in the Physician Directory³³ of the American College of Obstetricians and Gynecologists' (ACOG).³⁴ This search yielded 494 names of physicians. Because the directory did not provide contact information for most of its members, the testers conducted a search of the Yellow Pages and the American Medical Institute Directory to obtain contact information for these doctors. The contact information for 30%

^{30.} STEDMAN'S MEDICAL DICTIONARY 229710 (27th ed. 2000) (defining lipodystrophy as "defective metabolism of fat").

^{31.} Based upon previous cases, courts sometimes will allow a doctor to assert the direct threat defense to invasive procedures like facial implants.

^{32.} Doctors in the following area codes were included in the sample: 310, 323, 714, 818, 949, 805, 626, and 909.

^{33.} See ACOG Physician Lookup, https://www.acog.org/member-lookup/ (last visited Dec. 18, 2008) (providing a directory that can be searched by physician name, state, or zip code). The directory usually contains the name of the physician and the physician's membership status. If the physician elects, they may include basic information about their specific practices, including addresses, hours of operation, the hospitals with which they are affiliated, and languages spoken. *Id*.

^{34.} See ACOG Fact Sheet, https://www.acog.org/from_home/ACOGFactSheet.pdf (providing historical and factual information of the ACOG). The ACOG is a membership organization founded in Chicago in 1951. *Id.* The ACOG has over 49,000 members and is the nation's leading group of professionals providing health care for women. *Id.* Members are considered Fellows or Diplomats of the ACOG. *Id.* In order to become a member, a person must have graduated from an acceptable medical school, completed an ob-gyn residency program within the geographic confines of the ACOG, and have an active license to practice medicine. *Id.*

(N=150) of these offices was unavailable, and thus 70% (N=344) of the sample remained. A sample from this list was drawn by proceeding down the alphabetized list until the testers received one hundred responses. In total, 45% (N=156) of the sample was contacted. Of these, 21% (N=33) of the sample included disconnected or wrong numbers, 11% (N=17) never returned messages left with the office, and 3% (N=4) were not obstetricians. The testers contacted and received responses from the remaining 65% (N=102) of the offices in the survey sample.

The tester, a third-year UCLA law student who was, in fact, pregnant, then proceeded to contact doctors' offices. She posed as a pregnant woman with HIV-disease looking for an obstetrician that would be willing to provide prenatal care in the Los Angeles area. Following a script, she inquired as to whether a doctor at the office would treat an HIV-positive patient. If asked, the caller would disclose that she had a T-cell count of 700 to 800, that her last period was approximately five weeks prior, and that she was insured under Aetna's PPO plan. (Only two providers asked follow up questions to illicit this information.) Positive responses were noted as such and the calls ended, while negative answers received follow-up questions as to why the offices did not treat asymptomatic HIV-positive patients.

IV. Results

A. Skilled Nursing Facilities

The responses from SNFs as to whether they would admit a patient who was HIV-positive were broken down into three categories: yes, no, and unclear.³⁶ An affirmative response was categorized as "yes." If the admissions representative indicated that the SNF would not take any HIV-positive patients, the response was categorized as "no." Any responses that

^{35.} See infra Appendix C (providing the script used during the telephone calls).

^{36.} Unclear responses included, but were not limited to, the following: 1) statements that acceptance was discretionary, 2) statements that acceptance was dependent upon the availability of isolation rooms, 3) admissions representatives expressing reluctance to accept, 4) admissions representatives expressing unfamiliarity with the law, and 5) admissions representatives expressing a preference for elderly patients. Such responses may be evidence of a discriminatory practice of excluding individuals with HIV. However, because the surveyors limited the depth of their questioning to avoid suspicion, such responses are not conclusive of discrimination.

did not indicate either acceptance or a blanket exclusion of patients with HIV-disease were coded in the "unclear" category.

Of the 131 facilities contacted, 36% (N=48) responded with an unqualified "yes" to accepting HIV-positive patients. Nearly 18% of the SNFs' responses met the criteria for "unclear." The remaining 46% (N=60) stated that they did not accept individuals who are HIV-positive.

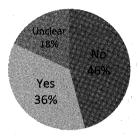


Figure 2: Acceptance of HIV-Positive Patients by Skilled Nursing Facilities in LA County, 2003–2004)

1. Rationales for Blanket Policies of Excluding HIV-Positive Patients

Many of the facilities that indicated that they would not take patients who were HIV-positive gave no justification for their response. For example, one admissions representative said: "We try not to . . . I'm just trying to be honest." Approximately one-third of the admissions representatives that indicated that they did not accept HIV-positive patients, however, provided some justification for their policies. Although the testers did not push every admissions representative to provide a justification, these comments illustrate some of the reasons that SNFs deny admission to HIV-positive patients.

The most common justifications for refusal were that the SNF had never taken an HIV-positive patient before ("In thirteen years we haven't had that"), inadequate training of the staff ("Our nurses are not yet ready"),³⁷ no available isolation room or units ("We don't have isolation"),

^{37.} These responses also included the following: "We haven't had any. The staff is not well trained for that type of patient...."; "We've never had a case before, but staff is currently being trained and we should be able to take HIV-positive patients in about two months...."; and, "We've never had an HIV-positive patient and we have no training. I think we would need experience before we accepted these patients."

and no protocols or procedures were in place to accommodate such patients ("We don't have the protocol yet. We are working on it.").

Several of the admissions representatives responded to the question about whether the facility took HIV-positive patients by stating they had a policy of only taking elderly patients ("We only take people 55 years and older" and, "We focus on elderly patients."). When one admissions representative was pressed by the tester on whether her facility would accept an elderly patient who was HIV-positive, she responded, "It depends on how big the need was—is it worth it to train all the staff for one patient?"

In addition, several admissions representatives defended their refusals because their facility did not specialize in HIV-positive patients, indicating that they would refer positive patients to other SNF's ("We don't really specialize in that here. We generally refer them to other facilities [that] do specialize. You know, there are a lot of factors to consider.").

Finally, one facility justified their refusal of HIV-positive patients based upon the sexual activity of their residents: "We don't want to discriminate, but we are locked.... Our residents are sexually active, and we have to protect them. We have a lot of hepatitis."

2. "Unclear" Responses

To provide a conservative estimate of the level of HIV-discrimination by SNFs, any responses that did not indicate a policy of excluding admission of all HIV-positive patients, or of accepting such patients, were coded as "unclear." However, many of these responses also indicated the potential for unlawful discrimination in admissions criteria and/or treatment of persons living with HIV/AIDS.

Responses classified as "unclear" included statements that acceptance of HIV-positive patients would require closer scrutiny. These statements ranged from explanations that patients would be considered on a case-by-case basis, possibly in compliance with the ADA and state disability laws, 38 to those that indicated HIV-positive patients would be held to stricter, and possibly unlawful, criteria than other patients seeking admission.

^{38.} These responses included: "Maybe if they are ok to stay here. The Director of Nursing would have to decide...."; "We haven't been in that position. Technically you can't say no as a rule. So, it depends on the patient....;" "In reality we're supposed to and that's not a problem. It depends on other diagnoses...."; and, "No. Well, she'll [the Director of Nursing] have to take a look at it, so you can put down yes."

Some of the admissions officers fell short of saving that the SNF did not take any HIV-positive patients, but expressed reluctance to accept such patients (e.g., "Yes, if we have to," and, "Technically you can't say no as a rule. So, it depends on the patient."). In addition, some of the reasons were similar to those accompanying statements that the SNF would not admit HIV-positive patients (coded as "no" above),³⁹ such as that acceptance is dependent upon the availability of isolation rooms ("If we can isolate them. we can take them...."), 40 and that the facility preferred elderly patients ("Depends on the status of other patients. Normally we like older patients. They blend in better," and, "Yes, but it's discretionary. Our residents are elderly, and we don't want to put them in danger.").⁴¹ and that the facility had never admitted an HIV-positive patient before ("We have no knowledge of HIV-positive patients. We've never had one before in the 36 vears of the facility, but I don't want to say no. It hasn't come up."). Often, admissions officers' responses included more than one of these reasons.

B. Cosmetic and Plastic Surgeons

Of the ninety-eight surgeons surveyed, 26% (N=25) stated that they would not treat HIV-positive patients. Sixty-six percent (N=68) of the offices sampled stated that they would accept HIV-positive patients, 42 while 8% (N=5) gave qualified answers to our inquiry.

^{39.} Responses were classified as "no" if they indicated that the facility would not take HIV-positive patients for the reason given (we do not take positive patients because they require isolation rooms) and classified as "unclear" if the reason was a limitation, but not an absolute bar, to accepting HIV-positive patients (if we have an isolation room available we take positive patients).

^{40.} These responses also included: "Not sure. If there's a bed available, we might do isolation. It depends on the type of patient ...;" "Not sure. If there is an empty bed I need to ask the Director of Nursing ...;" and, "Yes, if we have a bed available. Isolation is a standard precaution. We need to consider what other patients are in the room. We can't have patients with open wounds."

^{41.} These responses also included: "When we have a bed available. We don't take young ones;" "We prefer more of a geriatric age;" and "Only geriatric patients."

^{42.} Most of the doctors that said they would treat HIV-positive patients ("Yes") were located in the Los Angeles metro area, area codes 310, 213, 323. The doctors in the surrounding areas provided the majority of "No" answers.

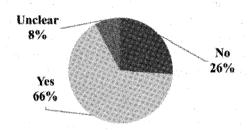


Figure 3: Acceptance of HIV-Positive Patients by Cosmetic and Plastic Surgeons in LA County, 2004.

1. Rationales for Blanket Policies of Excluding HIV-Positive Patients

One in four offices (26%) refused to provide any services to HIV-positive patients, including even an initial consultation. These responses included offices that initially claimed to perform procedures to treat lipodystrophy but then after the tester disclosed his or her HIV status, provided reasons why it would be better for the tester to seek services elsewhere. The reasons given included that another surgeon was better, the surgeon contacted did not have experience treating people who were HIV-positive, the surgeon's staff would "revolt," and the office would lose its medical malpractice insurance if it accepted HIV-positive patients.

For example, one surgeon claimed that she would be happy to perform the treatment until the caller's HIV-status was disclosed. The surgeon then recommended that the caller see Dr. X because "he is the best at treating this condition in the country." After the caller told the surgeon that she actually wanted to see her and not Dr. X, the surgeon replied, "No, because you should have the best." The caller then followed up by calling Dr. X, a renowned plastic surgeon who has appeared in *Vogue* and other internationally distributed magazines. Dr. X's patient care coordinator said he would not treat the tester because he "does not believe in injections to treat lipodystrophy, he only performs facial cheek implants." Even after stating that the doctor did not believe in treating lipodystrophy with injections, the patient care coordinator tried to refer the caller to a doctor in New York who does treat lipodystrophy with fat injections, stating the

doctor's unique methods make injections last years longer than any other doctor's treatment. The caller told the patient care coordinator that she did not have the resources to fly to New York and would like to see Dr. X to pursue the possibility of facial cheek implants. The patient care coordinator then responded that Dr. X would not treat her because, "We are a stand alone facility. The risk is too high. If we treat HIV patients, we will lose our medical malpractice insurance."

In addition, some of the offices responded that they would not accept HIV-positive patients because their offices lacked necessary medications or equipment ("We don't have the new medication for that syndrome;" and "The center is not a sophisticated one. Those people need to go somewhere with modern equipment"). The vast majority of these responses were given without attempting to gauge the specific health status of the caller. Overall, only two offices asked about the caller's current health status before stating that they could not treat the patient.

2. "Unclear" Responses

Responses were coded as "unclear" if they did not clearly indicate a blanket policy of refusing services to all patients who were HIV-positive. Five responses (8%) were coded as unclear. These responses included statements that the office would only provide services to an HIV-positive patient if they were "medically necessary" or as long as there "is no virus in the blood." Three of these responses also included statements that the provision of services was dependent upon what specific services were needed. One response indicated that services would be contingent upon "a doctor's letter approving your health is good enough." Arguably, these responses could comply with state and federal anti-discrimination laws.

C. Obstetricians

Of the 102 obstetricians surveyed, 39% (N=40) stated that they would accept an HIV-positive woman for prenatal care. A handful of offices, 6% (N=6), gave qualified responses. These were coded as "unclear." However, over half of those contacted, 55% (N=56), had a blanket policy of rejecting HIV-positive patients without consultation.

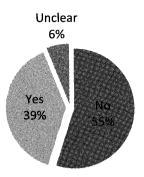


Figure 4: Acceptance of HIV-Positive Patients by Obstetricians in LA County, 2005–2006.

The 39% of obstetricians who stated that they would take an HIV-positive patient did so without hesitation. In most of these responses, the receptionists, office managers, or nurses whom the testers spoke with knew the answer immediately, indicating the existence of a general office policy. Of the positive responses, three offices also indicated that the decision would be made on a case-by-case basis, echoing the doctrinal requirement of the ADA outlined above. Similarly, another three offices indicated that the patients would be accepted and that specialists in treating HIV-disease or pregnant women with HIV-disease would be brought in as needed. These answers demonstrated a familiarity with the legal requirements imposed by state and federal disability discrimination law.

1. Rationales for Blanket Policies of Excluding HIV-Positive Patients

Over half of the providers' offices surveyed (55%) stated unequivocally that they would not treat a patient with HIV. Many did not hesitate in saying no, and some provided no explanation for why they would refuse to treat an HIV-positive patient. Others stated that the obstetrician lacked the requisite experience ("This is not discrimination, the doctor just doesn't have any experience" and "We don't have the facilities or skill to treat you."), or that pregnant women with HIV-disease had to go to a hospital ("No, AIDS has to go to a hospital." Then after the tester explained that she did not have AIDS and was asymptomatic, the representative replied "Same thing.").

The most troubling of these rejections were the ones where receptionists expressed surprise or dismay when the caller confirmed that she was HIV-positive and pregnant and that she intended to continue the pregnancy. For example, one receptionist responded this way: "I don't know, let me ask. Do you want to keep the baby?" After coming back to the phone, she reported, "He will see you for gyn exams but will not handle pre-natal care."

Over half of the responses, 55% (N=56), that were classified as "no" included a referral to another provider. These responses ranged from general statements that the tester should seek pre-natal care from a specialist or hospital (12), to referrals to specific providers by name (9), and referrals to specific hospitals or clinics (12), including UCLA, Cedars, USC, King-Drew Memorial, and Saint Francis.

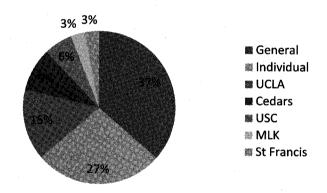


Figure 5: Referrals to Other Providers by Obstetricians in Los Angeles County not accepting HIV-positive pregnant women for pre-natal care, 2005–2006.

2. "Unclear" Responses

Six responses were classified as "unclear" mainly because the person answering the tester's call did not know the answer. Two offices responded that they were not taking patients at that time. At least one of these responses strongly indicated the reason might be a pretext for unlawful discrimination: "Are you going to continue with the pregnancy? Really?

Let me call you back after I talk with the doctor." When the receptionist called back, she reported, "Dr. [X] is not accepting patients at this time."

IV. Conclusion

Despite advances in disability law and medical treatments for persons living with HIV/AIDS, these three testing studies indicate that HIV-positive individuals continue to experience high levels of discrimination when seeking health care services. Of the several hundred health care providers surveyed by these three testing studies, 26% of plastic and cosmetic surgeons, 47% of obstetricians, and 56% of skilled nursing facilities refused to provide services to any HIV-positive patients.

The most common reasons given by providers for denying services to HIV-positive patients include lack of expertise or equipment, having no prior experience in treating an HIV-positive patient, inadequately trained or uncooperative staff, and the referral of all HIV-positive patients to "specialists." These reasons suggest that, in addition to strengthening anti-discrimination protections for people living with HIV/AIDS in the health care setting, health care workers need more education and training about current legal protections, the risk of transmission of the HIV-virus, and the use of standard precautions for preventing infections in health care settings.

Appendix A

Skilled Nursing Facility Script

The testers used the following script with the staffperson who answered their calls:

"Hello. May I please speak to someone in your admissions department?"

[Proceed to next section with individual the facility identifies as representing their admissions department:]

"Hi, my name is _____, and I'm calling from _____ Regional Medical Center. We are trying to increase our list of referrals in your area because many of the facilities in our area are over-crowded, so I'm calling to get some information about your facility for possible referrals in the future. Do you have a couple of minutes? I'd love to ask you a couple questions about the type of patients you accept, so that we can hopefully refer some folks to you, and also so we can avoid unnecessarily referring people to you who you are unable to take."

[If admissions representative is willing to answer questions:]

"Great,

- (1) Can you take patients with MediCal only?
- (2) What about Medicare/Medicaid?
- (3) Can you take patients who have a co-morbid primary Psych diagnosis?
- (4) Are you secure enough to take people who wander?
- (5) Can you take patients who are HIV-positive?
- (6) What about Trachs?
- (7) What is your turn around time for referrals?

 Great. Thanks for answering my questions. One last thing...
- (8) If I have a referral, should I fax it to you?
- (9) What is your name?
- (10) And your fax number?

Thank you so much. You've been very helpful."

Appendix B

Surgeons Script

Hello, my name is (Kate Johnston) or (Claire Kim). I am calling because I have fat wasting syndrome. I have sunken cheeks, and I'd like them to get filled in. I was wondering, though, if you treat people with HIV at your office.

If answer is yes

Fantastic, thank you. I need to double check with my insurance and/or primary care doctor to see what is covered and will get back to you.

If answer is no

Oh, may I ask why? Is there another place you can refer me to for this procedure?

If answer is with follow up questions

Re: Symptoms

I have asymptomatic HIV.

Re: Blood cell count

I have a T-cell count of 900.

Re Viral Load Under 100,000.

Re: Current medications

Sustiva Emtriva

Retrovir (AZT)

Appendix C

Obstetrician Script

Hello, my name is ______. I just found out I am pregnant and am doing some preliminary research to find an obstetrician. I was wondering if Dr. ____ will treat a patient who is HIV positive.

If answer is yes

Fantastic, thank you. I need to double check with my insurance to see what is covered and will get back to you.

If answer is no

Oh, may I ask why? Is there another place you can refer me to for this procedure?

If answer is with follow up questions

Re: Insurance I have Aetna PPO.

Re: Date of last menstrual period

Five weeks from time of phone call (varied given when obstetrician was interviewed).

Re: Symptoms

I have asymptomatic HIV.

Re: Blood cell count

I have a T-cell count of 700-800.

Re: Viral Load Undetectable.

Re: Current Medications

Sustiva Emtriva

Retrovir (AZT)