

Department of Health and Human Services

**OFFICE OF
INSPECTOR GENERAL**

**HIV/AIDS: NURSING HOME
DISCRIMINATION COMPLAINTS**



AUGUST 1993

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AUGUST 1993 OEI-03-91-00960

EXECUTIVE SUMMARY

PURPOSE

This report (1) identifies government agencies that investigate discrimination complaints filed against nursing homes that do not admit persons with the human immunodeficiency virus (HIV) or acquired immune deficiency syndrome (AIDS), and (2) describes the number and outcomes of complaint investigations.

BACKGROUND

As AIDS takes on characteristics of chronic illnesses, the need for skilled nursing and long-term care becomes more urgent. Studies indicate it is difficult to find nursing homes for persons with AIDS or HIV, and patients may remain in hospitals longer than necessary because nursing home care cannot be found.

Until now, evidence of nursing home admission discrimination against persons with AIDS or HIV has been largely anecdotal, and the number of complaints filed nationwide was unknown. This is the first national study to document the volume of filed complaints and describe their outcomes. It is also the first national study to determine the complaint system, if any, at each level of government.

We conducted this inspection at the Federal, State, and local levels of government. At each level, we identified which public agencies would investigate nursing home admission discrimination complaints, and we interviewed the agency representative. We collected data on complaints and used it to determine who filed complaints, length of investigation periods, and case outcomes. We also analyzed anti-discrimination laws and published materials informing the public about the agency and how to file a complaint with them. At the local level we went a step further, conducting interviews and analyzing data from private entities that provide health care or social services.

FINDINGS

Complaints can be investigated at the Federal, State, and local levels.

- Within the Department of Health and Human Services (HHS), the Office for Civil Rights (OCR) investigates complaints.
- Under certain conditions, the Department of Justice and the Department of Housing and Urban Development may investigate.
- Most States have at least one investigating agency. However, it is not always clear which type of agency has this responsibility.
- We found few investigating agencies at the local level.

We found 615 complaints filed against nursing homes from 1986 through 1991.

- More than half the complaints were handled at the Federal level.
- There were far fewer complainants than complaint numbers suggest.
- Federal, State, and local respondents believe complaint numbers are low compared to actual discrimination.

Over half the case outcomes involved corrective actions.

- Sixty-two percent of Federal and State outcomes included corrective actions.
- However, few patients gained admission.
- Fines or monetary penalties were rare.
- The majority of complaints took over 6 months to resolve.

The overall complaint system is difficult to use.

- Investigating agencies cannot be identified easily.
- Public information does not specifically address nursing home discrimination against persons with AIDS or HIV infection.
- Those in a position to file complaints are reluctant to do so.

RECOMMENDATIONS

The OCR has national expertise in the area of nursing home admissions discrimination against persons with HIV or AIDS. Its national database can identify and track these complaints, and its printed materials specifically address this type of discrimination and how to file complaints. Therefore, we recommend that OCR

- lead a departmental initiative with the Public Health Service (PHS), the Health Care Financing Administration (HCFA), and the Administration on Aging (AoA) to improve public information about the occurrence of this type of discrimination and where to file complaints; and
- offer technical assistance to State and local governments.

We also recommend that OCR

- meet its 3-month timeframe for resolving AIDS-related complaints.

COMMENTS

Four HHS agencies commented on the draft of this report: the OCR, the PHS, the HCFA, and the AoA. All commented favorably on working together on a Department initiative to provide the public with information. None disagreed with the desirability of sharing expertise and resolving cases faster. But an overriding concern was how to comply with our recommendations with limited resources.

We believe the agencies involved in the initiative could assist each other in developing creative ways to address this concern since the need for nursing home care for persons with AIDS is likely to increase.

The OCR advised us they are considering a new policy which will require that complaints involving health-endangering situations be given priority over other complaints. The proposed policy would replace the 1987 requirement to resolve AIDS-related cases within 3 months. We continue to recommend that OCR meet the 3-month timeframe on AIDS cases until such time as the policy is officially replaced.

Regarding the agencies' general and technical suggestions, we adopted several which made the narrative clearer but did not alter our meaning or require additional data collection.

The full texts of agency comments are in Appendix D.

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INTRODUCTION

PURPOSE

This report (1) identifies government agencies that investigate discrimination complaints filed against nursing homes that do not admit persons with the human immunodeficiency virus (HIV) or acquired immune deficiency syndrome (AIDS), and (2) describes the number and outcomes of complaint investigations.

BACKGROUND

An estimated 1 million Americans are infected with the HIV.¹ While it may take years for the effects of the HIV to appear, all those infected will eventually develop AIDS. Although often thought of as a single disease, AIDS is a group of specific clinical conditions indicative of a severely damaged immune system. As of January 1, 1993, the Centers for Disease Control (CDC) expanded the official definition of AIDS to include additional conditions. Under the new definition, the number of Americans diagnosed with AIDS could double.²

Until now, evidence of nursing home admission discrimination against persons with AIDS or HIV has been largely anecdotal, and the number of complaints filed nationwide was unknown. This is the first national study to document the volume of filed complaints and describe their outcomes. It is also the first national study to examine complaint systems, if any, at the Federal, State, and local levels of government.

Growing Need for Long-Term Care

Studies indicate that AIDS is beginning to take on the characteristics of chronic illnesses. This change is associated with therapeutic advances capable of lengthening and improving the quality of lives of persons infected with the virus. As the shift toward long-term illness becomes greater, the need for skilled nursing and long-term care becomes more urgent.³

Nursing Home Admission Discrimination Against Persons with HIV or AIDS

Studies also indicate it is difficult to place someone with HIV infection or AIDS in a nursing home.⁴ Some attribute this difficulty to discrimination. As the number of HIV/AIDS cases grows, particularly among the poor, there is increasing concern about discrimination by nursing homes in the Medicaid program. The Health Care Financing Administration's (HCFA) Office of Medicaid Management has advised its regional staff that "discrimination is thought to be a primary reason for the difficulty HIV/AIDS patients have in gaining access to medical services, especially nursing home

admission."⁵ Acting on this concern, the Medicaid Bureau included an element on discrimination by nursing homes in its 1992 program review for its HIV/AIDS initiative.⁶

Patients with AIDS or HIV-related illnesses may remain in hospitals longer than necessary if discharge planners cannot find nursing homes that will admit them. When this occurs, patients and their insurers pay for a higher level of care than is necessary, and AIDS patients in hospitals are at risk of developing more infections.

Laws Protecting the Handicapped Cover Persons with HIV or AIDS

Federally funded nursing homes that discriminate against persons with HIV or AIDS violate Federal law. Under Section 504 of the Rehabilitation Act of 1973, as set forth in 45 CFR Part 84, handicapped individuals are protected from discrimination. This law has been interpreted to cover persons with contagious diseases, including HIV and AIDS.⁷ In addition, nursing home regulations at 42 CFR Part 442.12 (d) (2) state that nursing homes may not receive Medicare and Medicaid funding "even though certified by the State survey agency, if the facility fails to meet the civil rights requirements set forth in 45 CFR Parts 80, 84, and 90." Depending on their location, nursing homes that discriminate against persons with HIV or AIDS also violate State and local laws.⁸

METHODOLOGY

We collected data in three phases, each corresponding to the Federal, State, or local level of government. Data was collected from February to August, 1992. In each phase, we determined which public agencies would investigate nursing home admission discrimination complaints. We interviewed each investigating agency's director, or a representative, by telephone. Some agencies were prepared to investigate complaints but had not received any. We collected complaint data from agencies that had complaint cases. We used the complaint documents to determine who filed complaints, length of investigation periods, and case outcomes. We also analyzed anti-discrimination laws and material informing the public about the agency and how to file a complaint with them.

At the local level we went a step further, conducting interviews and analyzing data from private entities that provide health care or social services to persons with AIDS or HIV infection.

Phase One - Federal Level

Phase one focused on the Office for Civil Rights (OCR) within the Department of Health and Human Services (HHS). We interviewed all 10 regional managers and obtained the total number of complaints received through 1991 from OCR's national database. We then reviewed documents for all cases received in 1989 and 1990. We chose this period because it allowed us to examine 2 full years of resolved complaint

cases for which documents would still be available in OCR regional offices. Cases prior to 1989 might not have been available, and cases after 1990 might not have been resolved.

Phase Two - State Level

In phase two, we contacted agencies in all States and the District of Columbia (hereafter referred to as a State) to determine if they would investigate nursing home discrimination complaints. Agencies were initially identified by OCR respondents. If the agency identified by OCR would not investigate the complaints, we asked for the responsible agencies. With each State agency contact, we asked if there were any other agencies in their State which would investigate. We did not interview agency directors if the agency would not investigate complaints of nursing home admission discrimination.

States received far fewer complaints than OCR. Therefore, on the State level we collected data for all years from 1986 through 1991 and from four complaints received in early 1992. (There were no complaints filed prior to 1986 at any level.)

Phase Three - Local Level

In the third phase, we collected data from a total of 10 metropolitan areas.⁹ We drew a sample of cities from CDC's report of AIDS cases in 95 metropolitan areas. The sample consisted of areas with a high incidence of AIDS and areas with a low incidence. After identifying public investigating agencies in the sample cities, we interviewed an agency representative and collected whatever complaint data was available.

As previously mentioned, we also collected data from private entities that serve the HIV/AIDS population. Forty-seven respondents were selected based on their knowledge in at least two of the following areas: (1) appropriateness of nursing homes for persons with HIV or AIDS, (2) prevalence of nursing home admission discrimination, (3) complaint process, and (4) cases of filed complaints. The respondents were either involved in finding nursing home care or were in a position where they might provide information about filing a discrimination complaint. We interviewed the respondents and collected data on (1) the services they provide to persons with HIV or AIDS, (2) the complaint system, and (3) complaints they filed or were aware of. Most interviews were by phone. We conducted on-site interviews in only one of the sample cities.

This study was conducted in accordance with the *Quality Standards for Inspections* issued by the President's Council on Integrity and Efficiency.

SCOPE

This report deals only with discrimination against persons with HIV or AIDS by nursing homes that participate in federally funded programs. Whenever we use the term complaint, we are referring to this specific type of discrimination complaint.

This report further deals only with complaints that were filed with a public investigating agency. Anecdotal cases of discrimination in which a complaint was not filed were not included in our analysis.

We did not attempt to determine the amount of actual discrimination. Although we know how many complaints were filed, there is no comparative data on the number of HIV-infected persons who needed nursing home care or the number who applied for such care.

State agencies sent us complaint data in different formats and levels of detail. As a result, our analysis of some cases was based on several data sources. For example, if case information was incomplete, we may have used data from the interview or other materials the respondent sent us.

In one State, a complainant filed 162 complaints. This high number of complaints by one complainant skews the aggregate data on State complaints. Therefore, in our findings we note if we are including or excluding this mass filing.

FINDINGS

COMPLAINTS CAN BE INVESTIGATED AT THE FEDERAL, STATE, AND LOCAL LEVELS.

Within HHS, the Office for Civil Rights (OCR) investigates complaints.

Regional OCR staff have investigated complaints since 1987 (see Appendix A for a list of OCR regional offices). Section 504 of the Rehabilitation Act of 1973 grants OCR legal authority to handle these cases. In 1992, OCR was given added responsibility under Title II of the Americans with Disabilities Act of 1990. The OCR now also investigates complaints against State and municipal nursing homes that do not receive Federal funds.

The OCR has a national database which collects and tracks complaint information from each of the 10 regional offices. Through the database, one can identify complaints related specifically to HIV/AIDS, nursing homes, admissions, and Section 504 of the Rehabilitation Act. The OCR classifies nursing home complaints under the broader category of public accommodations.

The normal investigation period for OCR cases begins with receipt of the complaint. It ends when the nursing home is found in compliance or when an agreement addressing deficiencies is signed. The time a nursing home is given to submit proof that all deficiencies have been corrected is called the monitoring period.

In 1987, OCR made complaints related to AIDS its highest priority. The agency instituted an expedited process for these cases that was not to exceed 3 months.¹⁰ As we were drafting this report, OCR advised us they intend to replace this policy. The proposed new policy would not be focused on AIDS-related complaints. Instead, any complaint involving a life-threatening or health-endangering situation would be resolved within 80 days.

Complaint investigations result in a letter of findings to the nursing home and complainant. The letter indicates whether the nursing home is in compliance with Federal laws and regulations. If a nursing home is not in compliance, a plan is drawn up specifying the corrective actions to be taken as well as the time period in which the corrections must be made. If a nursing home refuses to correct violations, OCR can take steps to cut off its Federal funds.

Prior to 1991, some cases could be resolved informally, before issuance of a letter of findings. Nursing homes could take corrective actions and come into compliance or sign a voluntary compliance agreement specifying how and when they would achieve compliance. While both these resolutions required corrective actions, the nursing home was not cited for violations. The OCR discontinued these types of resolutions in June 1991.

Under certain conditions, other Federal agencies investigate.

Two other Federal agencies have authority to investigate complaints. One is the Department of Housing and Urban Development (HUD). Under the Fair Housing Amendments of 1988, HUD may investigate nursing homes which are considered residences. The HUD would not be involved with other types of nursing homes, e.g., facilities providing temporary skilled nursing care. The HUD's national database includes Fair Housing complaints. However, it cannot identify complaints associated with HIV or nursing home admission. Therefore, we confined our Federal level inspection to OCR.

In our State level inspection, we found HUD has work-sharing agreements with at least one agency in three different States. In one of these States, HUD and the State agency jointly investigated four cases.¹¹

The other agency with authority to investigate complaints is the Department of Justice. As noted above, Title II of the Americans with Disabilities Act (ADA) covers State and municipal nursing homes. The Justice Department designated OCR as the lead investigative agency for Title II but will be responsible for any judicial enforcement that may be necessary to enforce a compliance agreement OCR obtains. Title III of the ADA covers privately owned facilities that offer health care or social services, regardless of whether they receive Federal funds. Generally, the Justice Department is responsible for investigating private facilities under Title III. Where there is overlapping jurisdiction, Justice and OCR will coordinate their investigative activities on a case-by-case basis.

Most States have at least one investigating agency. However, it is not always clear which type of agency investigates complaints.

Seventy-two agencies in 46 States investigate complaints (see Appendix B). Twenty-seven States have one agency and 19 States have more than one. Five States do not have an agency to investigate these complaints.¹² Contacts in these five States said they would refer complaints to HCFA or OCR.

While most investigating agencies (58 of 72) are of two types, overall six types were identified. There were 36 civil rights or human rights agencies and 22 agencies that license nursing homes and certify them for participation in the Medicare and Medicaid programs. These types of agencies received most of the complaints we discuss later in this report.

The other types of agencies include eight Long-Term Care Ombudsmen, four Medicaid, one Protection and Advocacy for the Disabled, and one Health Department's Division of Disease Control. Of this group of agencies, two ombudsmen received at least one filed complaint. While ombudsmen ordinarily serve as advocates for elderly nursing home residents, we were referred to eight who said they felt responsible for any type of complaint against a nursing home.

State agencies investigate complaints under the authority of Federal laws, State laws, or a combination. Human rights agencies usually investigate under State anti-discrimination laws and/or Section 504 of the Federal Rehabilitation Act, while licensing agencies investigate under Federal and State nursing home regulations.

Complaint classification systems varied by type of agency and the legal authority to investigate. Civil rights and human rights agencies classified complaints as public accommodations cases. Licensing agencies generally classified them as residents' rights cases. Overall, State databases and tracking systems were not as specific as OCR's. State complaints were generally identified by searching paper logs or case folders.

When State complaint investigations uncover deficiencies, they are resolved through corrective actions and/or settlement agreements. Procedures and names of agreements vary by agency type. Most human rights agency complaints were resolved through pre-determination agreements. These are essentially the same as the voluntary compliance agreements OCR used before 1991. Licensing agencies resolve complaints through a plan of correction. Ombudsmen do not have enforcement powers. They try to reach settlements informally by mediating with involved parties. If a resolution cannot be reached, the case is referred to another agency.

We found few investigating agencies at the local level.

We identified one public investigating agency in each of four cities (see Appendix C). One agency was a city attorney's office, and the others were human rights agencies.

These four agencies investigated complaints under local anti-discrimination laws. Two had limited jurisdiction that did not include federally funded nursing homes. Respondents from both of these agencies said any complaints against a federally funded nursing home would be referred to OCR.

Complaints against nursing homes would be classified as public accommodations cases in these agencies. This classification was used in human rights and civil rights agencies at all government levels.

WE FOUND 615 COMPLAINTS FILED AGAINST NURSING HOMES FROM 1986 THROUGH 1991.

More than half the complaints were handled at the Federal level.

Of the 615 complaints filed, OCR received 363 complaints in 6 years while States received 251. The number of State complaints includes one State's 162-case mass filing. We found only one complaint filed with a local public agency. Table 1 on the next page shows the number of complaints agencies received each year.

Table 1.

| COMPLAINTS FILED ANNUALLY | | | | |
|---------------------------|------------|------------------|--------------------|------------|
| YEAR | FEDERAL | STATE | LOCAL ¹ | TOTALS |
| 1986 | 0 | 1 | 0 | 1 |
| 1987 | 53 | 17 | 0 | 70 |
| 1988 | 92 | 22 | 1 | 115 |
| 1989 | 64 | 1 | 0 | 65 |
| 1990 | 94 | 10 | 0 | 104 |
| 1991 | 60 | 200 ² | 0 | 260 |
| TOTALS | 363 | 251 | 1 | 615 |

¹ Based on a review of 10 metropolitan areas.
² Number includes four 1992 cases, seven inaccessible cases, and the 162-case mass filing.

According to OCR's national database, complaints regarding nursing home admission discrimination represent 41 percent of all AIDS-related complaints and 94 percent of all AIDS-related nursing home complaints received from 1987 through 1991. We do not know what percentage of AIDS-related complaints involved nursing homes or admission discrimination at the State and local levels.

Table 2 shows the complaint cases we reviewed and the year they were filed. We reviewed 401 cases representing nearly two-thirds (65 percent) of the 615 filed. Of the cases reviewed, 156 were received by OCR in 1989 and 1990. Files for two other Federal complaints received during this period could not be located. At the State level, we reviewed 244 cases filed with 15 agencies from 1986 through 1991. (This includes four complaints filed in early 1992.) At least seven other complaints were filed at the State level, but the cases were either pending or could not be accessed.

Table 2.

| COMPLAINT CASES REVIEWED | | | | |
|--------------------------|----------------------------|-----------------------------|-----------------------------|------------|
| YEAR | FEDERAL CASES Two Years | STATE CASES All Years | LOCAL CASES All Years | TOTALS |
| 1986 | | 1 | | 1 |
| 1987 | | 17 | | 17 |
| 1988 | | 22 | 1 | 23 |
| 1989 | 63 | 1 | | 64 |
| 1990 | 93 | 10 | | 103 |
| 1991 | | 193 ¹ | | 193 |
| TOTALS | 156 | 244 | 1 | 401 |

¹ Number excludes seven inaccessible cases.

As shown below, the 244 State cases were handled by three types of agencies. While we identified a total of 72 State agencies that investigate discrimination complaints against nursing homes, only 15 agencies were associated with the 244 cases.

| <u>TYPE OF INVESTIGATING AGENCY</u> | <u>NUMBER OF AGENCIES WITH CASES</u> | <u>TOTAL NUMBER OF CASES</u> |
|-------------------------------------|--------------------------------------|------------------------------|
| Civil/Human Rights | 9 | 217 |
| License and Certification | 4 | 24 |
| Long-Term Care Ombudsmen | 2 | 3 |
| TOTALS | 15 | 244 |

There were far fewer complainants than complaint numbers suggest.

Complaints often represent one individual who alleges discrimination by a number of nursing homes. The 401 cases we reviewed were filed by 65 complainants. Table 3 below shows the types of complainants and how many of each type filed cases at the Federal and State levels. Some complainant types were individuals such as the patients themselves, relatives, social workers, and physicians. Others were groups such as hospitals, advocacy groups, public agencies, and nursing homes. A patient filed the one local complaint. Local information is not included in Table 3.

While few patients were complainants, most complainants filed cases on behalf of patients who were denied nursing home admission. Only six complainants filed cases which did not involve an individual patient. These complaints were test cases. They were investigated to determine nursing home access for persons with HIV/AIDS as a group rather than for a specific patient. The test cases were filed by advocacy groups and State agencies.

Table 3.

| FEDERAL AND STATE COMPLAINANTS BY TYPE | | | |
|---|----------------|--------------|---------------|
| TYPE | FEDERAL | STATE | TOTALS |
| Hospital | 8 | 7 | 15 |
| Relative/Friend | 6 | 4 | 10 |
| State Agency | 3 | 6 | 9 |
| Advocacy Group | 6 | 2 | 8 |
| Patient | 1 | 5 | 6 |
| Anonymous | 0 | 6 | 6 |
| Legal Advocate | 3 | 0 | 3 |
| Federal Agency | 1 | 1 | 2 |
| Social Worker | 0 | 2 | 2 |
| Physician | 0 | 1 | 1 |
| Local Agency | 0 | 1 | 1 |
| Nursing Home | 1 | 0 | 1 |
| TOTALS | 29 | 35 | 64 |

Respondents believe complaint numbers are low compared to actual discrimination.

Respondents at each government level and in local private agencies generally shared the belief that the number of filed complaints does not reflect the prevalence of nursing home discrimination against persons with HIV or AIDS. The number of complaints is much lower than actual cases of discrimination, they said. The main reason few complaints are filed is that people do not complain; they just stop trying to place patients in nursing homes which have denied admission to persons with HIV or AIDS in the past.

All 10 OCR regional managers believe the number of complaints filed is lower than actual instances of discrimination. A common explanation for low numbers was that filing complaints is not a priority for persons in poor health or for hospital discharge planners. Other reasons noted were that persons with HIV/AIDS handle their own situation or seek help from advocacy groups, lack of OCR staff limits outreach activity, and public agencies at every level are not willing to deal with the issue.

Over half of State agency respondents (37 of 69) also thought there was more discrimination than complaint numbers indicated. They said people tend not to complain for the following reasons: they do not know their rights, they do not know whom to call, they are too sick to think about it, they are afraid, the process takes too long, and discrimination is hard to prove.

In contrast, over a quarter of State respondents (20 of 69) said the number of complaints did reflect the level of discrimination. Eight of these respondents said this kind of discrimination was not a problem. Five said nursing homes admit persons with AIDS. The remaining seven said other care was available or the State had a low incidence of AIDS.

Local government respondents offered two reasons why complaint numbers are low compared to actual discrimination. One is that hospital social workers, who are in the best position to file complaints, do not want to jeopardize their working relationship with nursing homes. Another reason is that advocacy groups step in and resolve problems with nursing homes informally. The threat of a law suit by an advocacy group can make a nursing home change its policy.

Most local private agency respondents (40 of 47) said the number of complaints did not reflect the level of actual discrimination. These respondents provide health care or social services to persons with AIDS or HIV. Reasons complaints are few include: people choose not to complain, people do not know how or where to file, people do not know they have the right to complain, the process is too cumbersome, and patients do not have the energy or resources. Only two of these respondents filed complaints.

OVER HALF THE CASES REVIEWED INVOLVED CORRECTIVE ACTIONS.

Sixty-two percent of Federal and State outcomes included corrective actions.

Nursing homes were required to take different corrective actions. Table 5 shows that corrective actions were required in the majority of Federal and State outcomes. Typical corrective actions include: adopting and publicizing a non-discriminatory admission policy, notifying referral sources of non-discriminatory policy, instituting universal precautions, training staff, maintaining a record of all persons who apply for admission along with reasons why any are not admitted, discontinuing contractual relationships with referral sources that discriminate, and modifying grievance procedures.

Fewer than 20 percent (67 of 400) of the cases reviewed found nursing homes in compliance. By this we mean discrimination was not substantiated. In over half the Federal and State cases (231 of 400), agencies negotiated settlements wherein the nursing home agreed to take corrective action and a violation was not cited. The one local case was filed in court after the agency found probable cause of discrimination.

Table 5.

| CORRECTIVE ACTIONS COMPARED TO OTHER OUTCOMES¹ | | | |
|--|-----------------------|-----------------------|-----------------------|
| TYPE | FEDERAL | STATE | TOTALS |
| Corrective Action/Violation Cited | 9 | 9 | 18 |
| Corrective Action/Violation Not Cited | 95 | 136 | 231 |
| Subtotals | 104 (67%) | 145 (59%) | 249 (62%) |
| Nursing Home In Compliance | 34 | 33 | 67 |
| Administrative Closure | 3 | 56 | 59 |
| Referred to Other Agency | 0 | 1 | 1 |
| Withdrawn | 1 | 3 | 4 |
| Pending | 14 | 2 | 16 |
| Data Not Available | 0 | 4 | 4 |
| Subtotals | 52 (33%) | 99 (41%) | 151 (38%) |
| TOTALS | 156 (100%) | 244 (100%) | 400 (100%) |

¹ Outcomes for Federal and State cases reviewed.

Agreements resolving a case often specify a timeframe during which the nursing home provides evidence that corrective actions have been taken. This timeframe is called the monitoring period. The length of monitoring periods in 62 OCR cases ranged from 1 month to 2 years with an average of 8.4 months. On the State level,

monitoring in 26 cases (excludes the mass filing) lasted an average of 22 months; some took 3 years. When the 162-case mass filing is included, the average monitoring period for 139 cases was 16 months.

Few patients gained admission.

In the cases reviewed, 62 patients needed placement in nursing homes. As of the time the cases were closed, only 12 patients were admitted. Six of the 12 went to nursing homes involved in the complaint cases and 6 went to other nursing homes. The case documents revealed that another 14 patients died, 5 went to other care settings, 2 withdrew their cases, 1 remained in the hospital, 1 declined the nursing home's offer to be admitted, 1 was asked to reapply for admission, and 1 was in the wrong jurisdiction. The case documents we reviewed did not indicate what happened to the remaining 25 patients.

As mentioned earlier, test cases are filed to determine nursing home access for persons with HIV or AIDS as a special population and not on behalf of an individual patient. Over half the cases reviewed, including the 162-case mass filing, fit this category. Therefore, none of these could result in an admission.

Fines or monetary penalties were rare.

Agencies rarely proposed that nursing homes pay money in connection with substantiated complaints. A civil rights agency in one State imposed a fine against one nursing home. In another State, a licensing agency proposed monetary penalties from \$250 to \$3,000 for four nursing homes. At the Federal level, the OCR does not have authority to assess monetary fines or penalties.

The majority of complaints took over 6 months to resolve.

Two-thirds of the cases reporting length of investigation period (256 of 377 cases) took more than 6 months. The investigation period was from the date the complaint was filed to the date findings were issued or a settlement agreement was signed. This does not include time spent monitoring the nursing home.

While OCR's policy, as mentioned earlier, is to resolve AIDS-related cases within 3 months, the average length of investigation period for 142 cases we reviewed was 6.6 months. Of the 142 cases, only 18 percent (25) were resolved within the required timeframe. (The length of the investigation period was not available for 14 cases.) At the State level, complaint resolution took an average of 12 months. Excluding the 162-case mass filing, the average was 7.4 months.

THE OVERALL COMPLAINT SYSTEM IS DIFFICULT TO USE.

Investigating agencies cannot be identified easily.

Public and private agency respondents had difficulty identifying investigating agencies. As mentioned earlier, the number and type of State agencies which investigate complaints are not consistent from State to State. This can be confusing to potential complainants. Some State agency respondents did not know of other agencies in their own State which investigate complaints.

Many State agency respondents also did not identify OCR as a Federal agency where individuals could file a complaint. This is a problem for complainants who may call a State agency and be told there is no other public investigating agency. The complainant would then believe nothing more could be done and the Federal government is not involved.

On the Federal level, OCR regional offices seemed well aware of State and local human rights agencies, but not as aware of other types of agencies. Nearly half (33 of 72) the State investigating agencies we interviewed were not identified by OCR. If complainants call OCR, however, their cases will be accepted and they will not have to call another agency. On the other hand, complainants might be interested in filing simultaneous cases with other agencies if they knew of that option.

Local private agency respondents said people do not know where or how to file a complaint or even that they have a right to complain. Only 12 of 47 respondents could identify an investigating agency. Six named State agencies and six said they would call OCR. Five of the six respondents identifying OCR had been at AIDS seminars where OCR representatives explained the law, described the complaint process, and distributed complaint forms. The sixth respondent, a physician, learned of OCR from a State agency manager.

Public information does not specifically address nursing home discrimination against persons with AIDS or HIV infection.

Agencies have not been very effective in letting the public know they handle these types of complaints. When available, public information is in the form of posters, pamphlets, and fact sheets. Printed material is usually distributed to other public agencies, nursing homes, and HIV/AIDS service providers. From the perspective of local private agency respondents, the information is not reaching enough patients or the professionals who help them.

The OCR regional managers said they distribute information to public and private agencies, speak before various groups, and work with nursing home associations and HIV/AIDS organizations. The two most frequently mentioned activities were distributing information at workshops (6) and working with nursing home associations (5). Some of OCR's printed material explains Federal law, who is covered and under

what circumstances, and whom to call for help. Resources, however, vary from region to region, and we did not determine if the same material is distributed by every regional office.

Public information at the State level varies by agency type. State licensing agencies and ombudsmen usually send posters or notices about residents' rights to nursing homes. These would not be seen by someone requesting admission, and rarely do the materials mention admission policy, HIV, or AIDS. Civil rights and human rights agencies try to send information to HIV/AIDS service providers but can only do so when their budgets permit. In addition, most of their material is written in agency jargon. For example, a pamphlet might read, "It is unlawful to discriminate in public accommodations against persons who are handicapped or disabled." The public would not know that a nursing home is a public accommodation and that the handicapped include persons with HIV-related conditions.

Some respondents from State agencies and local private agencies suggested that complaint cases be publicized to increase general awareness about this kind of discrimination.

Those in a position to file complaints are reluctant to do so.

Respondents at each government level and in private agencies gave similar reasons why complaint cases are not more numerous. The reason cited most often is that those who make nursing home placements rarely complain. For example, if hospital discharge planners learn that certain nursing homes will not take persons with HIV-related illnesses, those homes will not be called for such patients again. The issue ends there. A 1989 survey of hospital social workers in one State confirmed this phenomenon.¹³

Some State and private local agency respondents said hospital social workers do not want to risk alienating nursing homes by filing complaints. Also, complaints are not filed because social workers are not in a position to determine whether the nursing home's reason for refusing the patient is true. Among the complaints we reviewed, only two were filed by social workers.

Although two-thirds of local private agency respondents (32 of 47) said they have had difficulty placing AIDS patients in nursing homes, only two respondents had filed complaints. One respondent was a physician and the other was a nursing home discharge planner.

Few patients file complaints. State and Federal respondents cited the extent of patients' illness as a primary reason for this. Another reason is patients do not want to make their condition public.

Respondents at each level said the complaint process discouraged people from filing. One respondent said, "Filing a complaint is a lot of work and effort," and many felt

that neither patients nor social workers are able to make filing complaints a priority. Respondents suggested that instead of entering the complaint system, placement staff look for another nursing home or another type of care, discharge the patient, or leave the patient in the hospital.

RECOMMENDATIONS

THE OCR SHOULD LEAD A DEPARTMENTAL INITIATIVE TO IMPROVE PUBLIC INFORMATION.

The OCR has national expertise in the area of nursing home admissions discrimination against persons with HIV or AIDS. It is in the best position to spearhead an information campaign with the participation of other agencies in the Department. The other agencies are the Public Health Service (PHS), the Health Care Financing Administration (HCFA), and the Administration on Aging (AoA). The initiative should target public information to the following audiences: State and local governments, hospitals, HIV/AIDS clinics, health facility discharge planners, medical societies, professional associations, and HIV/AIDS social service and advocacy organizations.

Public information should specifically address two areas. The first is that HIV infection is considered a protected handicap under Federal law. All persons who meet legal requirements for a qualified individual with handicaps are protected from discrimination by nursing homes. The second is which public agencies at each government level investigate complaints of such discrimination. People need to know their rights and where they can file a complaint.

THE OCR SHOULD OFFER TECHNICAL ASSISTANCE TO STATE AND LOCAL GOVERNMENTS.

The OCR has the knowledge and experience that could benefit State and local governments. The OCR has handled more complaints of nursing home admission discrimination against persons with HIV/AIDS than any other agency. It has a national database that specifically identifies and tracks these complaints. It also has Fact Sheets and other printed information that specifically address this type of discrimination. Therefore, OCR should offer technical assistance in these areas.

THE OCR SHOULD MEET ITS 3-MONTH TIMEFRAME FOR AIDS-RELATED COMPLAINTS.

In 1987, OCR recognized the need to expedite AIDS-related cases and established a 3-month timeframe for them. On average, however, the 1989 and 1990 cases we reviewed took over 6 months to resolve. Recently, OCR has considered replacing the 1987 policy with one that gives priority to complaints involving health-endangering situations, regardless of HIV. Until such time as the 1987 policy is officially replaced, we recommend that OCR meet its 3-month timeframe for AIDS-related complaints.

COMMENTS

We received comments on the draft of this report from: the OCR, the PHS, the HCFA, and the AoA. All commented favorably on working together on a Department initiative to provide the public with information. None disagreed with the desirability of sharing expertise and resolving cases faster. But an overriding concern was how to comply with our recommendations with limited resources.

We believe the agencies involved in the initiative (OCR, PHS, HCFA, and AoA) could assist each other in developing creative ways to address this concern since the need for nursing home care for persons with AIDS is likely to increase.

The OCR advised us they are considering a new policy which will require that complaints involving health-endangering situations be given priority over other complaints. The proposed policy would replace the 1987 requirement to resolve AIDS-related cases within 3 months. We continue to recommend that OCR meet the 3-month timeframe on AIDS cases until such time as the policy is officially replaced.

Regarding the agencies' general and technical suggestions, we adopted several which made the narrative clearer but did not alter our meaning or require additional data collection.

The full texts of agency comments are in Appendix D.

ENDNOTES

1. Centers for Disease Control, "HIV Prevalence Estimates and AIDS Case Projections for the United States: Report Based on a Workshop," *Morbidity and Mortality Weekly Report*, vol. 39, No. RR-16, p. 1 (Atlanta: CDC, November 1990).

2. Dear Colleague letter from James W. Curran, M.D., M.P.H., Assistant Surgeon General, October 1992.

Faulkner and Gray, "CDC Proposes Expanded AIDS Definition," *Medicine and Health*, vol. 45, no. 44, p. 2 (Washington, DC: Faulkner and Gray's Healthcare Information Center, November 1991).

3. A. E. Benjamin, "Chronic Care: Perspectives on AIDS and Aging," *Generations*, p. 19 (Fall, 1989).

A. E. Benjamin and James H. Swan, "Nursing Home Care for Persons with HIV Illnesses," *Generations*, p. 63 (Fall, 1989).

Erwin A. Carner, Ed.D., Jeanette Bressler, MSW, and Wendy Blankfort-Doyle, MA, "AIDS and the Long-term Care System: A Nursing Home Survey," paper delivered at the Gerontological Society of America's 40th Annual Scientific Meeting (Washington, DC, 1987).

General Accounting Office, "AIDS: Delivering and Financing Health Services" (Washington, DC, 1989).

J. David Greenberg, "HIV as a Chronic Disease: Implications for Health Services and Financing," paper delivered at Decatur, GA (Baltimore: Medicaid Bureau, 1991).

G. Kirby Holland and Karen Ohare Conley, "Providing Care for Persons with AIDS in a Long-term Care (Nursing Home) Setting," prepared for Illinois Department of Public Health (Dixon, IL: First Health Care, Ltd., 1988).

Nathan L. Linsk and Reggi Marder, "Facing Nursing Home Resistance in Hospital Discharge Planning for People with HIV Infection" (Chicago: University of Illinois, 1989).

Vincent Mor, "Implications of the AIDS Epidemic for Long Term Care" (Providence: Brown University, 1988).

National Center for Social Policy and Practice, "Beyond the Hospital Door:

Community Resources Available for Persons with HIV Infection or AIDS in the United States" (Chicago: American Hospital Association, 1990).

National Commission on AIDS, "Report of the Working Group on Social/Human Issues to the National Commission on AIDS" (Washington, DC, 1987).

4. See Carner, Bressler, and Blankfort-Doyle.

See General Accounting Office.

Larry Gostin, Lane Porter, Hazel Sandomire, "AIDS Litigation Project: A National Survey of Federal, State, and Local Cases Before Courts and Human Rights Commissions," (Washington, DC: Public Health Service, 1990).

See Greenberg.

See Holland and Conley.

Nan Hunter, "Epidemic of Fear: A Survey of AIDS Discrimination in the 1980s and Policy Recommendations for the 1990s" (New York: American Civil Liberties Union, AIDS Project, 1990).

Intergovernmental Health Policy Project (IHPP), *AIDS, A Public Health Challenge*, vol. 1 (Washington, DC: The George Washington University, October 1987).

See Linsk and Marder.

See Mor.

See National Center for Social Policy and Practice.

See National Commission on AIDS.

Preinspection interviews, August-September 1991.

Public Health Service, "Five State/Local Approaches for Preventing and Resolving HIV-Related Discrimination," 2 vols. (Silver Spring: Birch and Davis Associates, Inc., 1988).

State of New York, "AIDS: New York's Response" (Albany: Department of Health, 1989).

5. Director, Office of Medicaid Management, BQC, to all regional administrators, et al., 16 February 1990.

6. Medicaid Program Review Guide, HIV/AIDS, Fiscal Year 1991 - 1992.
7. Wendy E. Parmet, "AIDS and the Limits of Discrimination Law," *Law, Medicine and Health Care*, pp. 61-72 (Summer, 1987).
8. IHPP, *A Summary of HIV/AIDS Laws from the 1990 State Legislative Sessions* (Washington, DC, January 1991).
9. The 10 metropolitan areas were Baltimore, Baton Rouge, Kansas City, Los Angeles, Memphis, Miami, Newark, New York, San Francisco, and Tulsa.
10. Memorandum and expedited procedures from OCR Director to OCR Regional Managers, October 29, 1987.
11. Agreements were between HUD and the Maine Human Rights Commission, the Minnesota Department of Human Rights, and the Wisconsin Equal Rights Division of the Department of Industry, Labor and Human Relations. The joint investigations were conducted in Maine. Minnesota's complaints were not associated with the Fair Housing Amendments, and Wisconsin has not had any complaints.
12. The five States are Arizona, Nebraska, Nevada, Utah, and Wyoming. An Arizona agency did investigate a complaint in 1991, but it will not do so in the future.
13. See Linsk and Marder.

APPENDIX A

**COMPLAINTS WILL BE INVESTIGATED
BY REGIONAL OFFICES OF
THE OFFICE FOR CIVIL RIGHTS
U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES**

Region I encompasses six States: Connecticut, Maine, Massachusetts, New Hampshire, Rhode Island, and Vermont.

JFK Federal Building
Room 1875
Boston, MA 02203
(617) 565-1340

Region II encompasses two States, New York and New Jersey, as well as Puerto Rico and the Virgin Islands.

26 Federal Plaza
Suite 3312
New York, NY 10278
(212) 264-3313

Region III encompasses the District of Columbia, and Delaware, Maryland, Pennsylvania, Virginia, and West Virginia.

3535 Market St.
Room 6300
Philadelphia, PA 19104
(215) 596-5381

Region IV encompasses eight States: Alabama, Florida, Georgia, Kentucky, Mississippi, North Carolina, South Carolina, and Tennessee.

101 Marietta Tower
Room 1504
Atlanta, GA 30323
(404) 331-2779

Region V encompasses six States: Illinois, Indiana, Michigan, Minnesota, Ohio, and Wisconsin.

105 West Adams
16th Floor
Chicago, IL 60603
(312) 886-2359

Region VI encompasses five States: Arkansas, Louisiana, New Mexico, Oklahoma, and Texas.

1200 Main Tower
Room 1360
Dallas, TX 75202
(214) 767-4056

Region VII encompasses four States: Iowa, Kansas, Missouri, and Nebraska.

601 East 12th Street
Room 248
Kansas City, MO 64106
(816) 426-7277

Region VIII encompasses six States: Colorado, Montana, North Dakota, South Dakota, Utah, and Wyoming.

1961 Stout Street
Room 840
Denver, CO 80296
(303) 844-4774

Region IX encompasses four States: Arizona, California, Hawaii, and Nevada.

50 United Nations Plaza
San Francisco, CA 94103
(415) 556-8367

Region X encompasses four States: Alaska, Idaho, Oregon, and Washington.

2201 Sixth Avenue
Mail Stop RX-11
Seattle, WA 98121
(206) 553-0473

APPENDIX B

STATE PUBLIC AGENCIES THAT WILL INVESTIGATE COMPLAINTS

ALABAMA

Department of Human Resources
Office of Civil Rights and
Equal Employment
50 Ripley Street
Montgomery, AL 36130-1801
(205) 242-1550

ALASKA

State Commission for
Human Rights
800 A Street
Suite 202
Anchorage, AK 95501
(906) 276-7474

ARKANSAS

Department of Human Services
Office of Long Term Care
Post Office Box 8059
Little Rock, AR 72203
(501) 682-8487

CALIFORNIA

Department of Health Services
Office of Civil Rights
714 P St., Room 1050
Sacramento, CA 95814
(916) 657-1411

COLORADO

State of Colorado
Civil Rights Division
1560 Broadway, Suite 1050
Denver, CO 80202
(303) 894-2997

Department of Health
Health Facilities Division
4210 East 11th Avenue
Denver, CO 80220-3716
(303) 692-2800

CONNECTICUT

Commission on Human Rights
and Opportunities
90 Washington Street
Hartford, CT 06106
(203) 566-3352

Department of Aging
175 Main Street
Hartford, CT 06106
(203) 566-7770

Office of Protection and Advocacy
for Persons with Disabilities
60-B Weston Street
Hartford, CT 06120
(203) 297-4300

DELAWARE

State of Delaware
Division of Aging
Millford State Service Center
11/13 Church Avenue
Millford, DE 19963
(302) 422-1386

Office of Health Facility
Licensing and Certification
3000 Newport Gap Pike
Wilmington, DE 19808
(302) 995-6674

DISTRICT OF COLUMBIA

Department of Consumer and
Regulatory Affairs
Health Facilities Division
614 H Street, Northwest
Room 1014
Washington, DC 20001
(202) 727-7201

District of Columbia
Office of Human Rights
and Minority Business
2000 14th Street, Northwest
Washington, DC 20009
(202) 939-8740

FLORIDA

Department of Health and
Rehabilitative Services
Office of Civil Rights
1317 Winewood Boulevard
Building 3, Room 203
Tallahassee, FL 32399
(904) 487-1901

Department of Health and
Rehabilitative Services
Office of Licensure and Certification
2727 Mahon Drive
Tallahassee, FL 32308
(904) 487-2527

Long-Term Care Ombudsman Council
1320 South Dixie Highway
3rd Floor
Coral Gables, FL 33146
(305) 663-2085

GEORGIA

Department of Human Resources
Office of Regulatory Services
878 Peachtree Street, NE
Atlanta, GA 30309
(404) 894-5137

HAWAII

Department of Health
Hospital and Medical Facilities Branch
1270 Queen Emma Street
Honolulu, HI 96813
(808) 586-4077

IDAHO

Department of Health and Welfare
Bureau of Facility Standards
450 West State Street
Boise, ID 83720-5450
(208) 334-6626

ILLINOIS

Department of Human Rights
623 Stratton Building
Springfield, IL 62706
(217) 785-5119

INDIANA

Civil Rights Commission
32 East Washington Street
Suite 90
Indianapolis, IN 46204
(317) 232-2600

IOWA

Civil Rights Commission
Grimes State Office
507 10th Street
Des Moines, IA 50319
(515) 281-4121

Department of Inspection
and Appeals
Health Facilities Division
Lucas Office Building
2nd Floor
Des Moines, IA 50319
(515) 281-4233/4125

KANSAS

Human Rights Commission
Landon State Office Building
Suite 851S
900 South West Jackson
Topeka, KS 66612-1258
(913) 296-3206

KENTUCKY

Commission on Human Rights
701 West Mohammed Ali Boulevard
Post Office Box 69
Louisville, KY 40201-0069
(502) 588-4024

Office of Inspector General
Division of Licensing and Regulations
CHR Building, 4th Floor E
275 East Main Street
Frankfort, KY 40621-0001
(502) 564-2800

LOUISIANA

Department of Social Services
Civil Rights Bureau
546 Main Street
Baton Rouge, LA 70801
(504) 342-2700

MAINE

Human Rights Commission
State House, Station 51
Augusta, ME 04333
(207) 289-2326

MARYLAND

Commission on Human Relations
20 East Franklin Street
Baltimore, MD 21202-2274
(410) 333-1717

MASSACHUSETTS

Commission Against Discrimination
1 Ashburton Place
Room 1305
Boston, MA 02109
(617) 727-3990 Ext. 211

MICHIGAN

Department of Civil Rights
1200 6th Street
Detroit, MI 48226
(313) 256-2628

Department of Health
Health Facility Licensing
and Certification
3423 North Logan
Martin Luther King Boulevard
Lansing, MI 48909
(517) 335-8491

MINNESOTA

Department of Human Rights
7th Pl. and Minnesota St.
500 Bremer Towers
St. Paul, MN 55101
(612) 296-5667

MISSISSIPPI

Division of Medicaid
Office of Long-Term Care
Robert E. Lee Building, Suite 801
239 North Lamar Street
Jackson, MS 39201-1399
(601) 359-6050

MISSOURI

Commission on Human Rights
Post Office Box 1129
Jefferson City, MO 65102-1129
(314) 751-3325

MONTANA

Human Rights Commission
1236 6th Avenue
Post Office Box 1728
Helena, MT 59624-1728
(406) 442-5506

NEW HAMPSHIRE

Department of Health and
Human Services
Bureau of Health Facilities
Administration
6 Hazen Drive
Concord, NH 03301-6527
(603) 271-4471

Department of Health and
Human Services
Long-Term Care Ombudsman
6 Hazen Drive
Concord, NH 03301-6505
(603) 271-4375

NEW JERSEY

Department of Health
Division of Health Facilities Evaluation
300 Whitehead Road
Trenton, NJ 08625-0367
(609) 588-7758

Department of Law and
Public Safety
Division on Civil Rights
CN 089
Trenton, NJ 08625-0089
(609) 984-3091

NEW MEXICO

Department of Labor
Human Rights Division
1596 Pacheco Street
Sante Fe, NM 87502
(505) 827-6838

Department of Health
Office of Licensing
and Certification
525 Camino De Los Marquez
Suite 2
Sante Fe, NM 87502
(505) 827-4200

NEW YORK

State of New York
Division of Human Rights
Office of AIDS Discrimination Issues
55 West 125 Street
New York, NY 10027
(212) 870-8607

NORTH CAROLINA

Department of Human Resources
Division of Medical Assistance
1985 Umstead Drive
Post Office Box 29529
Raleigh, NC 27626-0529
(919) 733-6681

NORTH DAKOTA

Department of Health
Division of Disease Control
State Capitol
Bismark, ND 58505
(701) 224-2378

OHIO

Department of Health
Division of Health Facility Regulations
Complaint Unit
246 North High Street
Post Office Box 118
Columbus, OH 43266-0118
(614) 644-1952

OKLAHOMA

State Health Department
Special Health Services
1000 Northeast 10th Street
Oklahoma City, OK 73117-1299
(405) 271-6868

Department of Human Services
Medical Services Division
P. O. Box 25352
Oklahoma City, OK 73125
(405) 557-2539

Department of Human Services
Aging Services Division
Long-Term Care Ombudsman
P.O. Box 25252
Oklahoma City, OK 73125
(405) 251-6734

Human Rights Commission
Jim Thorpe Building
Room 480
2101 North Lincoln Boulevard
Oklahoma City, OK 73105-4904
(405) 521-2360

OREGON

Long-Term Care Ombudsman
Building B, Suite 9
2475 Lancaster Drive, NE
Salem, OR 97305
(503) 378-6533

Department of Human Resources
Senior and Disabled Services
313 Public Service Building
Salem, OR 97310
(503) 378-3751

PENNSYLVANIA

Human Relations Commission
101 South Second St., Suite 300
P. O. Box 3145
Harrisburg, PA 17105-3145
(717) 783-6481

RHODE ISLAND

Commission for Human Rights
10 Abbott Park Place
1st Floor
Providence, RI 02903-3768
(401) 277-2661

SOUTH CAROLINA

Human Affairs Commission
Post Office Drawer 4490
Columbia, SC 29240
(803) 253-6322

Health and Human Services
Finance Commission
1801 Main Street
Columbia, SC 29201
(803) 253-6374

SOUTH DAKOTA

Department of Human Rights
222 East Capitol Avenue
c/o Capitol Building
500 East Capitol Avenue
Pierre, SD 57501-5070
(605) 773-4493

TENNESSEE

Department of Health
Division of Health Care Facilities
Office of Civil Rights Compliance
283 Plus Park Boulevard
Nashville, TN 37219-5407
(615) 367-6318

TEXAS

Department of Health
Bureau of Long Term Care
1100 West 49th Street
Austin, TX 78756-3199
(512) 458-7709

VERMONT

Department of Aging and Disability
Division of Licensing and Protection
103 South Main Street
Waterbury, VT 05671-2306
(802) 241-2345

Human Rights Commission
133 State Street
Montpelier, VT 05633-6301
(802) 828-2480

VIRGINIA

Department of Medical
Assistance Services
Division of Quality Care Assurance
600 East Broad Street
Suite 1300
Richmond, VA 23219
(804) 786-7933

Department for Rights of Virginians
with Disabilities
101 North 14th Street, 17th Floor
Richmond, VA 23219
(804) 225-2042

Department of Health
Division of Licensure
and Certification
3600 West Broad Street
Suite 216A
Richmond, VA 23230
(804) 367-2100

Department for the Aging
Office of Long-Term Care Ombudsman
700 East Franklin St., 10th Floor
Richmond, VA 23219
(804) 225-3141

WASHINGTON

Human Rights Commission
711 South Capitol Way
Suite 402
Evergreen Plaza Building
Olympia, WA 98504-2409
(206) 753-0884

Department of Social and
Health Services
Office of Equal Opportunity
Post Office Box 45839
Olympia, WA 98504
(206) 753-0970

WEST VIRGINIA

Department of Health and
Human Services
Health Facility Licensure
and Certification
Capitol Complex
Building 3, Room 535
1900 Kanawha Boulevard
Charleston, WV 25305
(304) 558-0050

Human Rights Commission
1321 Plaza Gast Room 104/106
Charleston, WV 25301-1400
(304) 558-2616

WISCONSIN

Board on Aging and Long Term Care
214 N. Hamilton St.
Madison, WI 53703-2118
(608) 266-8944

Department of Health and
Social Services
Division of Health
Bureau of Quality Compliance
Facilities Regulation Section
1 West Wilson Street
P. O. Box 309
Madison, WI 53701-0309
(608) 266-2055

Department of Industry, Labor
and Human Relations
Equal Rights Division
P. O. Box 8928
201 East Washington Avenue
Madison, WI 53708
(608) 266-1997

APPENDIX C

LOCAL PUBLIC AGENCIES THAT WILL INVESTIGATE COMPLAINTS¹

KANSAS CITY, MISSOURI

Kansas City Human Relations Department
414 East 12 St.
Kansas City, MO 64106
(816) 274-1194

LOS ANGELES, CALIFORNIA

HIV/AIDS Discrimination Unit
City Attorney's Office
200 N. Main St., Suite 1600
Los Angeles, CAL 90012
(213) 237-1901

NEW YORK, NEW YORK

NYC Commission on Human Rights
40 Rector St., 9th Floor
New York, NY 10006
(212) 306-7465

SAN FRANCISCO, CALIFORNIA

San Francisco Human Rights Commission
1170 Market Street
Suite 500
San Francisco, CA 94102
(415) 252-2500

¹ Based on our contacts in 10 metropolitan areas.

APPENDIX D

FULL TEXTS OF COMMENTS FROM HHS AGENCIES

| | |
|---|------|
| Office for Civil Rights..... | D-2 |
| Public Health Service..... | D-5 |
| Health Care Financing Administration..... | D-7 |
| Administration on Aging..... | D-11 |



DEPARTMENT OF HEALTH & HUMAN SERVICES

Office of the Secretary

Office for Civil Rights
Washington, D.C. 20201

| | |
|-----------|-------|
| EG | _____ |
| PDEG | _____ |
| DIG-AS | _____ |
| DIG-HI | _____ |
| DIG-OI | _____ |
| AIG-MP | _____ |
| OGC/IG | _____ |
| EX SEC | _____ |
| DATE SENT | 5/13 |

with attachment

MEMORANDUM

DATE : 12 MAY 1993

FROM : Ronald G. Copeland
Acting Director
Office for Civil Rights

Ronald G. Copeland

SUBJECT: OCR Comments on OIG Draft Report: "HIV/AIDS: Nursing Home Discrimination Complaints," OEI-03-91-00960.

TO : Bryan B. Mitchell
Principal Deputy Inspector General
Office of the Inspector General

As a follow-up to the comments we made in the March 8 exit conference between OCR and OIG staff, I am forwarding our comments on the OIG Draft Report: "HIV/AIDS: Nursing Home Discrimination Complaints."

The Report makes three recommendations. The first two are already being carried out to the degree possible under our current budget restraints.

RECOMMENDATION #1:

The Office for Civil Rights supports a Departmental public information initiative, and we would welcome a lead role in such an effort with PHS, HCFA and AoA. Such an effort would require considerable beefing-up of OCR's public information capabilities (staff and resources). OCR is already distributing thousands of fact sheets in six foreign languages (including Spanish, Vietnamese and Haitian-Creole). These fact sheets offer specific, easily understood information on types of discrimination as well as complaint filing procedures. But more publications, newspaper and radio campaigns (not to mention TV public service announcements), and all the other elements of a successful public information effort are prohibitively expensive. We should also be certain that these public information efforts do not displace efforts on Title VI, Hill-Burton and the ADA.

OCR COMMENTS, p. 2RECOMMENDATION #2:

The OCR already undertakes efforts to provide technical assistance to State and local governments, as well as to nursing homes (as in Region III's current program of assistance through a State-wide association of Pennsylvania nursing homes). We are constantly exploring ways to improve our technical assistance initiatives, including a possible notification system to State agencies and AIDS advocacy groups. Budgetary constraints remain a major inhibitor to doing more.

As we stated in the exit conference, OCR does not question the goals set forth in recommendations 1 and 2; however, we are concerned that the implication is that we are resistant, if not derelict (i.e.: The OCR "should offer technical assistance"). In some way, the report should address the problems with available and anticipated resources.

RECOMMENDATION #3:

The OIG report acknowledges our experience in dealing with AIDS cases nationally and our ability to track them in our data base. On the other hand, it points out our failure to meet the 90-day time frame we established ourselves. The report does not indicate why this deficiency has occurred (see our earlier comments). We suggest that the report highlight the effects of our range of enforcement responsibilities, the increased volume of complaint receipts coupled with a diminution of resources.

The OCR recognizes the time-frame problem and has developed new processing guidelines in the revised Investigative Procedures Manual. Copy attached for your ready reference.

GENERAL COMMENTS

In discussing the investigative process, the report does not address the enforcement capability of OCR. The report implies that compliance agreements are OCR's sole means of enforcing the law. This was also a recurring criticism of the OIG's report on our Hill-Burton activities.

On page 13, in the paragraph "Fines and Monetary Penalties were Rare," the OIG suggests that OCR willfully refrains from imposing fines. The report should note that OCR has no authority to impose fines.

OCR COMMENTS, p. 3

GENERAL COMMENTS (con't.)

The report refers to OCR as the Office OF Civil Rights, not the Office FOR Civil Rights.

The use of the word "respondents" (pp. 11 and 14) is unclear and confusing. When referring to OCR, the report should use the words "regional manager(s)."

Attachment



Memorandum

Date . MAY 19 1993

From Acting Assistant Secretary for Health

Subject Office of Inspector General (OIG) Draft Report "HIV/AIDS: Nursing Home Discrimination Complaints," OEI-03-91-00960

To Acting Inspector General, OS

Attached are the Public Health Service comments on the subject OIG draft report. We have provided comments on the report's recommendations that are directed to the Office for Civil Rights, as well as suggested narrative changes to clarify certain statements from a public health perspective.

Audrey F. Manley
 Audrey F. Manley, M.D., M.P.H.

Attachment

| | |
|-----------|-------|
| IG | _____ |
| PDIG | _____ |
| DIG-AS | _____ |
| DIG-EI | _____ |
| DIG-GI | _____ |
| AIG-MP | _____ |
| OGC/IG | _____ |
| EX SEC | _____ |
| DATE SENT | 5/21 |

RECEIVED
 OFFICE OF INSPECTOR
 GENERAL
 1993 MAY 21 11 41 56

PUBLIC HEALTH SERVICE (PHS) COMMENTS ON THE OFFICE OF
INSPECTOR GENERAL (OIG) DRAFT REPORT "HIV/AIDS: NURSING
HOME DISCRIMINATION COMPLAINTS," OEI-03-91-00960

We have reviewed the findings and conclusions in this draft report. Although there are no recommendations directed specifically to PHS, we offer the following comments.

We concur with the first recommendation which calls for the Office for Civil Rights (OCR) to lead a Departmental initiative with PHS, the Health Care Financing Administration, and the Administration on Aging to improve public information about the occurrence of this type of information and where to file complaints. If it becomes an OCR priority to initiate and lead this effort, we will be willing to assist them in this endeavor.

We support in principle the report's second and third recommendations that OCR offer technical assistance to State and local governments, and meet its three month time frame for resolving AIDS-related complaints. However, while we support the sharing of expertise and expedited resolution of AIDS-related complaints, we recognize that implementation of the OIG recommendations could be impacted by OCR's staffing levels and budgetary resources. Therefore, we defer to OCR's position regarding the feasibility of implementing these recommendations.

Finally, we offer the following suggested wording to help clarify an item in the report. On pages i and 1, the report states that "AIDS takes on characteristics of long-term illness..." and "... AIDS is beginning to take on the characteristics of a long-term disease..." We suggest that it would be more appropriate to state that "[W]ith therapeutic advances that both improve survival and quality of life, persons with HIV and AIDS will need the full range of health care services similar to those available to sufferers of other chronic illnesses."



Memorandum

Date **JUN 11 1993**

From **Bruce C. Vladeck
Administrator**

Subject **Office of Inspector General (OIG) Draft Report: "HIV/AIDS: Nursing Home Discrimination Complaints," (OEI-03-91-00960)**

To **Bryan B. Mitchell
Principal Deputy Inspector General**

We reviewed the above-referenced draft report which examined the handling of nursing home discrimination complaints filed against nursing homes that do not admit persons with the human immunodeficiency virus (HIV) or acquired immune deficiency syndrome (AIDS).

We commend OIG for its extensive examination of the data and for providing several useful insights on the issue of nursing home discrimination against persons with HIV or AIDS.

HCFA concurs with the recommendation contained in the report. Our detailed comments are attached for your consideration. Thank you for the opportunity to review and comment on this draft report. Please advise us if you agree with our position on the report's recommendation at your earliest convenience.

Attachment



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Comments of the Health Care Financing Administration (HCFA)
on the Office of Inspector General (OIG) Draft Report:
HIV/AIDS: Nursing Home Discrimination Complaints
(OEI-03-91-00960)

Recommendation

The Office for Civil Rights (OCR) should lead a departmental initiative with the Public Health Service, Health Care Financing Administration, and Administration on Aging to improve public information about the occurrence of nursing home admission discrimination against persons with human immunodeficiency virus (HIV) or acquired immune deficiency syndrome (AIDS), and where to file complaints.

HCFA Response

We concur with the recommendation. We recognize the general need for more intensive use of outreach materials to improve access to HIV/AIDS-related care under Medicaid and would be happy to work with OCR. We have already begun preliminary work within HCFA to consider how HCFA central office and regional office (RO) staffs can help develop State and local outreach materials and more closely coordinate with OCR.

In addition, HCFA has been taking a variety of actions to address HIV/AIDS discrimination:

- o In the May/June 1988 issue of Public Health Reports, former HCFA Administrator William Roper wrote an article called "Making Fair Decisions About Financing Care for People With AIDS." In the article, Dr. Roper indicated that a central principle guiding HCFA in the fight against HIV/AIDS is that "care must never be denied to a person who has contracted AIDS or HIV infection."
- o OCR discussed referral procedures and trends in complaints during HCFA's annual regional coordinators' meeting in 1989.
- o In a February 16, 1990, memorandum to the ROs, HCFA outlined the legal basis for pursuing discrimination complaints, procedures for referrals to OCR, and possible remedies. The ROs subsequently conveyed this information to the States.

Page 2

- o On May 1, 1992, HCFA obtained and disseminated an opinion from the Office of the General Counsel indicating that Medicaid managed care providers may not disenroll a recipient with HIV/AIDS against that person's will.
- o A number of ROs have reported their active involvement with their OCR and Public Health Service counterparts in referring, documenting, and helping to negotiate reported cases of HIV/AIDS-related discrimination. Preliminary analysis of State Medicaid program reviews in the area of HIV/AIDS confirms that HCFA RO coordinators have been active in addressing discrimination.

While this recommendation is consistent with our previous activities and plans with respect to HIV/AIDS discrimination, budgetary considerations may constrain the actual volume of materials HCFA can produce and distribute directly, given the variety of audiences listed in the report. Model materials developed either by HCFA or by the States themselves may provide a useful alternative.

General Comments

OIG points out that of the 62 individuals seeking admission, the eventual status of 25 was unknown. This is an indication that more accountability by the investigating agencies is needed. According to the report, relatively few complaints are filed nationwide and there is widespread lack of awareness about the investigating agencies. The credibility and future success of local, State, and Federal agencies in resolving complaints will be hindered if the few complainants they do serve "fall through the cracks."

Based on the facts presented in this report, a further recommendation OIG might consider is that agencies which handle complaints about HIV/AIDS discrimination in nursing home admissions should emphasize correcting current violations, as well as preventing future discrimination. The fact that the average length of OCR's investigation period to resolve AIDS discrimination cases is nearly 7 months (more than twice their goal) is of great concern. It would perhaps be interesting and enlightening if the study looked in detail at the causes for discrimination. This is not to suggest that any cause for discrimination is justifiable, but the cause of the discrimination itself could serve as a prompt to finding solutions. For example, if persons with AIDS are being denied access to nursing homes because of ignorance or fear, training and education may be a remedy. However, if these individuals are denied services for other reasons, such as the cost of their care, or a facility's inability to provide the types of care needed, then the recommendations offered by the study may not alleviate discrimination problems.

Technical Comments

Page 1: It might be useful to note in the background section how discrimination in nursing homes compares to HIV/AIDS discrimination with other provider groups. It may set a proper context for nursing home discrimination by indicating how many and what the nature of complaints are against other providers, such as health maintenance organizations, dentists, general practitioners, etc.

Page 11: The report states that of 62 complainants seeking admission, only 12 were admitted. While it is vital that facilities against which complaints are filed take corrective action to prevent future discrimination (e.g., review admission policies or maintain a record of reasons certain applicants are not admitted), the fact that the complainants need to find placement in nursing homes is a serious matter. OIG might consider conducting a detailed analysis to examine why "typical corrective actions" do not include getting the person with AIDS into a nursing home.



DEPARTMENT OF HEALTH & HUMAN SERVICES

Office of the Secretary
Administration on Aging

Washington, D.C. 20201

TO: Bryan B. Mitchell
Principal Deputy Inspector General

FROM: Deputy Commissioner on Aging

SUBJECT: OIG Draft Report: "HIV/AIDS: Nursing Home
Discrimination Complaints," OEI-03-91-00960

Thank you for the opportunity to review the above-referenced draft report. The report addresses a critical subject, and the purpose, background, findings and recommendations are clearly presented.

We suggest only the following minor changes:

- On page 5, paragraph 1, change "federally funded nursing homes" to "nursing facilities which participate in the Federal Medicare and Medicaid programs." This will clarify that technically the residents, not the homes, receive Federal funding. (The homes are certified to participate in these federally-funded programs. Also, the 1987 nursing home reform law uses the term "nursing facility" for homes previously designated as skilled or intermediate care facilities.)
- On page 6, paragraph 4, change the first sentence to specify the type of complaints referred to — complaints regarding HIV/Aids discrimination in admissions — to avoid any possible confusion on the part of the reader.
- The finding on page 11 — "Fewer than 20% of cases reviewed found nursing homes in compliance" — should be included in the Executive Summary. The summary now refers only to cases requiring "corrective action", but the term "compliance" conveys a more descriptive concept for those not familiar with the usual Office for Civil Rights' approach.

Many State Long-Term Care Ombudsmen and attorneys in the Network on Aging have developed strategies for resolving complaints about nursing home discrimination in admissions due to the applicant's physical condition. This experience may be useful to the work of any departmental task force which may be formed in response to this report. We look forward to participating in such a group to address the important subject of this report.

John F. McCarthy
John F. McCarthy