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Report to the Ranking Minority Member, Subcommittee on Post Office and Civil Service, Committee on Governmental Affairs, and the Honorable Ron Wyden, U.S. Senate

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# MEDICAID

# Oversight of Institutions for the Mentally Retarded Should Be Strengthened


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The Honorable David Pryor
Ranking Minority Member
Subcommittee on Post Office and Civil Service
Committee on Governmental Affairs
United States Senate

The Honorable Ron Wyden
United States Senate

Persons with mental retardation or other developmental disabilities who live in large public institutions are often vulnerable to abuse and neglect. Such individuals' mental status can affect their ability to communicate concerns, and many lack family members to advocate on their behalf. As of 1994, more than 62,000 developmentally disabled people lived in 434 large public institutions certified to participate in Medicaid as intermediate care facilities for the mentally retarded (ICF/MR). These facilities received more than $5.3 billion in Medicaid funds in 1994.[1]

Advocacy organizations, the Department of Justice, and others have identified continuing problems with quality of care and protection of residents' rights in some large public institutions for people with developmental disabilities. Justice investigations have identified serious injuries and deaths resulting from physical abuse of residents, inadequate supervision, and failure to evaluate and treat behavioral disorders. Since 1990, Justice investigations have identified dangerous conditions in 17 large public institutions in 10 states, all of which were certified to participate in Medicaid.

Because ICFs/MR are financed mostly with Medicaid funds, the states and the Health Care Financing Administration (HCFA) have primary oversight responsibility for quality of care in these institutions. State agencies conduct annual inspections, called surveys, to assess the quality of care provided and to certify that the institutions continue to meet federal standards. HCFA develops quality standards and monitors state survey efforts to ensure that residents of certified institutions receive adequate protection and care.

[1]Although Medicaid also pays for ICF/MR care in small public facilities and private institutions, the majority of Medicaid funding to support individuals in ICFs/MR goes to large public facilities with at least 16 beds.

Because of your concern that developmentally disabled individuals are at risk of mistreatment in large public ICFs/MR, you asked that we examine the role of HCFA, state survey agencies, and Justice in overseeing quality of care in these public institutions. This report discusses (1) deficient care practices occurring in large ICFs/MR, (2) whether state survey agencies identify all serious deficiencies in these institutions, and (3) weaknesses in HCFA and state oversight of quality of care.

To obtain this information, we interviewed HCFA officials, provider representatives, advocates, researchers, and other experts in the field and reviewed the relevant literature. We analyzed HCFA data on deficiencies in large public ICFs/MR and reviewed a sample of state ICF/MR survey reports. We also interviewed Justice officials and reviewed Justice Department investigation reports and other documentation. We conducted our work between May 1995 and July 1996 in accordance with generally accepted government auditing standards. A more detailed description of our scope and methodology appears in appendix I.

## Results in Brief

Despite federal standards, HCFA and state agency oversight, and continuing Justice Department investigations, serious quality-of-care deficiencies continue to occur in some large public ICFs/MR. Insufficient staffing, lack of active treatment needed to enhance independence and prevent loss of functional ability, and deficient medical and psychiatric care are among those deficiencies that have been frequently cited. In a few instances, these practices have led to serious harm to residents, including injury, illness, physical degeneration, and death.

States, which are the key players in ensuring that these institutions meet federal standards, do not always identify all serious deficiencies nor use sufficient enforcement actions to prevent the recurrence of deficient care. Direct federal surveys conducted by HCFA and Justice Department investigations have identified more numerous and more serious deficiencies in public institutions than have state surveys. Furthermore, even when serious deficiencies have been identified, state agencies' enforcement actions have not always been sufficient to ensure that these problems did not recur. Some institutions have been cited repeatedly for the same serious violations.

Although HCFA has recently taken steps to improve the process for identifying serious deficiencies in these institutions and to more efficiently use limited federal and state resources, several oversight weaknesses

remain. Moreover, state surveys may lack independence because states are responsible for surveying their own institutions. The effects of this potential conflict of interest raise concern given the decline in direct federal oversight of both the care in these facilities and the performance of state survey agencies.

## Background

Most people with mental retardation, cerebral palsy, epilepsy, or other developmental disabilities who reside in large public institutions have many cognitive, physical, and functional impairments. Because their impairments often limit their ability to communicate concerns and many lack family members to advocate on their behalf, they are highly vulnerable to abuse, neglect, or other forms of mistreatment.

As of 1994, more than 80 percent of residents in large public institutions were diagnosed as either severely or profoundly retarded. More than half of all residents cannot communicate verbally and require help with such basic activities as eating, dressing, and using the toilet. In addition, nearly half of all residents have behavioral disorders and require special staff attention, and almost one-third require the attention of psychiatric specialists.

The Congress established the ICF/MR program as an optional Medicaid benefit in 1971 to respond to evidence of widespread neglect of the developmentally disabled in state institutions, many of which provided little more than custodial care. The program provides federal Medicaid funds to states in exchange for their institutions' meeting minimum federal requirements for a safe environment, appropriate active treatment, and qualified professional staff.

In 1994, more than 62,000 developmentally disabled individuals lived in 434 large public institutions certified as ICFs/MR for participation in Medicaid.[2] States operated 392 of these institutions; county and city governments operated 42. The average number of beds in each facility was 170, though facilities range in size from 16 beds to more than 1,000 beds. These institutions provided services on a 24-hour basis as needed. Services included medical and nursing services, physical and occupational therapy, psychological services, recreational and social services, and speech and audiology services.

[2]Some of these ICFs/MR are collocated on a single campus and may be identified as a single institution for other than Medicaid purposes.

Compared with residents in years past, those in large public institutions today are older and more medically fragile and have more complex behavioral and psychiatric disorders. In recent years, states have reduced the number of people living in these large public ICFs/MR by housing them in smaller, mostly private ICFs/MR and other community residential settings. Large public institutions generally are not accepting many new admissions, and many states have been closing or downsizing their large institutions.

## HCFA and State Agency Oversight

HCFA published final regulations for quality of care in ICFs/MR in 1974 and revised them in 1988.[3] To be certified to participate in Medicaid, ICFs/MR must meet eight conditions of participation (CoP) contained in federal regulations. The regulations are designed to protect the health and safety of residents and ensure that they are receiving active treatment for their disability and not merely custodial care.[4] Each CoP encompasses a broad range of discrete standards that HCFA determined were essential to a well-run facility. The CoPs cover most areas of facility operation, including administration, minimum staffing requirements, provision of active treatment services, health care services, and physical plant requirements. (See app. II for a more detailed description of the ICF/MR CoPs.) The eight CoPs comprise 378 specific standards and elements.

HCFA requires that states conduct annual on-site inspections of ICFs/MR to assess the quality of care provided and to certify that they continue to meet federal standards for Medicaid participation. The state health department usually serves as the survey agency. These agencies may also conduct complaint surveys at any time during the year in response to specific allegations of unsafe conditions or deficient care.

If the surveyors identify deficiencies, the institution must submit a plan of correction to the survey agency and correct—or show substantial progress toward correcting—any deficiency within a specified time period. For serious deficiencies, those cited as violating the CoPs, HCFA requires that the institution be terminated from Medicaid participation within 90 days unless corrections are made and verified by the survey agency during a

[3]The current regulations were based in part on standards for institutional care for the developmentally disabled developed by the Accreditation Council on Services for Persons With Developmental Disabilities in the early 1980s.

[4]Medicaid regulations define active treatment as training, treatment, and health and related services that are directed toward (1) the individual's acquiring behaviors necessary for functioning with as much independence as possible and (2) preventing loss of current function.

follow-up visit.[5] If a facility meets all eight CoPs but has deficiencies in one or more of the standards or elements, it may have up to 12 months to achieve compliance as long as the deficiency does not immediately jeopardize residents' health and safety.

HCFA's 10 regional offices oversee state implementation of Medicaid ICF/MR regulations by monitoring state efforts to ensure that ICFs/MR comply with the regulations. HCFA regional office staff directly survey some ICFs/MR—primarily to monitor the performance of state survey agencies. In addition, regional office staff provide training, support, and consultation to state agency surveyors.

## Department of Justice Oversight

The Department of Justice also has a role in overseeing public institutions for people with developmental disabilities. The Civil Rights of Institutionalized Persons Act (CRIPA) authorizes Justice to investigate allegations of unsafe conditions and deficient care and to file suit to protect the civil rights of individuals living in institutions operated by or on behalf of state or local governments.[6] Justice Department investigations are conducted on site by Justice attorneys and expert consultants who interview facility staff and residents, review records, and inspect the physical environment.

The Justice Department seeks to determine whether a deviation from current standards of practice exists and, if so, whether the deviation violates an individual's civil rights. Unlike HCFA, Justice has no written standards or guidelines for its investigations. Justice Department officials told us that the standards they apply are generally accepted professional practice standards as defined in current professional literature and applied by the experts they retain to inspect these institutions.

Since the enactment of CRIPA in 1980, Justice has been involved in investigations and enforcement actions in 38 cases involving large public institutions for the developmentally disabled in 20 states and Puerto Rico. As of July 1996, 13 of these investigations remained ongoing, 17 had been closed or resolved as a result of corrections being made, 7 continued to be monitored, and 1 litigated case was on appeal.

[5]In addition, HCFA requires that a facility be terminated from Medicaid participation within 23 days for any deficiency judged to immediately jeopardize residents' health and safety.

[6]These rights include the right to shelter, clothing, and medical care; the right to be free from harm; the right to freedom from undue restraint; and the right to minimally adequate treatment.

# Deficient Care Practices Continue to Occur in Large Public ICFs/MR

State Medicaid surveys and Justice Department investigations continue to identify serious deficient care practices in large public ICFs/MR. A few of these practices have resulted in serious harm to residents, including injury, illness, physical degeneration, and death.

## Large Public ICFs/MR Violate Medicaid CoPs

As of August 1995, 28 of the 434 large public institutions were out of compliance with at least one CoP at the time of their most recent annual state survey. On the last four annual surveys, 122 of these institutions had at least one CoP violation. (See table 1.) These serious violations of Medicaid regulations commonly included inadequate staffing to protect individuals from harm, failure to provide residents with treatment needed to prevent degeneration, and insufficient protection of residents' rights.

**Table 1: CoP Violations in Large Public Institutions**

| | Annual surveys | | |
|---|---|---|---|
| **Condition of participation** | **Last four** | **Most recent** | **Complaint surveys 1991-94[a]** |
| Governing body and management | 53 | 10 | 5 |
| Client protections | 35 | 6 | 22 |
| Facility staffing | 53 | 6 | 11 |
| Active treatment services | 115 | 18 | 6 |
| Client behavior/facility practices | 10 | 1 | 3 |
| Health care services | 8 | 0 | 1 |
| Physical environment | 3 | 0 | 0 |
| Dietetic services | 5 | 1 | 0 |
| **Total CoP violations in facilities[b]** | **282** | **42** | **48** |

[a]In response to specific complaints, state survey agencies may conduct full or partial surveys in ICFs/MR in addition to the required annual survey.

[b]Some institutions were cited for CoP violations more than once during the 4-year period.

Sources: Annual survey data based on our analysis of HCFA's Online Survey, Certification and Reporting System database containing the results of the most recent and three prior annual surveys of each ICF/MR. These were conducted between December 1990 and May 1995. Complaint survey data for 1991 to 1994 provided by HCFA, Health Standards and Quality Bureau.

Lack of adequate active treatment was the most common CoP violation cited in large public ICFs/MR. Serious active treatment deficiencies were cited 115 times in 84 institutions on the past four annual surveys.[7]

[7]Some institutions were cited for CoP violations more than once during the 4-year period.

Eighteen institutions were cited for this CoP deficiency on their most recent annual survey. Serious active treatment deficiencies cited on the survey reports included, for example, staff's failure to prevent dangerous aggressive behavior, failure to ensure that a resident with a seizure disorder and a history of injuries wore prescribed protective equipment, and failure to implement recommended therapy and treatment to maintain a resident's ability to function and communicate.

State surveyors also frequently found other CoP violations. They found, for example, residents of one state institution who had suffered severe hypothermia, pneumonia, and other serious illnesses and injuries as a consequence of physical plant deterioration, inadequate training and deployment of professional staff, failure to provide needed medical treatment, drug administration errors, and insufficient supervision of residents. Surveyors determined that the state had failed to provide sufficient management, organization, and support to meet the health care needs of residents and cited the facility for violating the governing body and management CoP.

Other CoP violations found during this period include serious staffing deficiencies and client protection violations. Surveyors of one state institution reported deficiencies such as excessive turnover, insufficient staff deployment, frequent caseload changes, and lack of staff training. In this institution, surveyors also found residents vulnerable to abuse and mistreatment by staff and staff who failed to report allegations of mistreatment, abuse, and neglect in a timely manner. Other staff who were known to abuse residents in the past continued to work with residents and did not receive required human rights training.

State agencies also conduct complaint surveys in large public ICFs/MR in response to alleged deficiencies reported by employees, advocates, family members, providers, or others. State agencies' complaint surveys found 48 serious CoP violations from 1991 through 1994. The most frequently cited CoP violations were client protections, cited 22 times, and facility staffing, cited 11 times. (See table 1.)

State survey agencies generally certify that facilities have sufficiently improved to come back into compliance with federal CoPs. When survey agencies find noncompliance with CoPs, they may revisit the facility several times before certifying that a violation has been corrected. On average, it takes about 60 days for this to occur.

## Deficient Care Can Result in Civil Rights Violations

Since 1990, the Justice Department has found seriously deficient care that violated residents' civil rights in 17 large public institutions for the mentally retarded or developmentally disabled in 10 states. Its investigations have identified instances of residents' dying, suffering serious injury, or having been subjected to irreversible physical degeneration from abuse by staff and other residents, deficient medical and psychiatric care, inadequate supervision, and failure to evaluate and treat serious behavioral disorders.

Justice found, for example, that a resident died of internal injuries in 1995 after an alleged beating by a staff member in one state institution that had a pattern of unexplained physical injuries to residents. In addition, the Department found that in the same facility a few years earlier, a moderately retarded resident suffered massive brain damage and lost the ability to walk and talk due to staff failure to provide emergency care in response to a life-threatening seizure. In another state institution, Justice found facility incident reports from 1992 and 1993 documenting that some residents were covered with ants and one resident was found with an infestation of maggots and bloody drainage from her ear. In another facility, Justice found that a resident was strangled to death in an incorrectly applied restraint in 1989.

We reviewed Justice's findings letters issued since 1990 for 15 institutions. The most common serious problems identified were deficient medical and psychiatric care practices, such as inadequate diagnosis and treatment of illness; inappropriate use of psychotropic medications; excessive or inappropriate use of restraints; inadequate staffing and supervision of residents; inadequate or insufficient training programs for residents and staff; inadequate therapy services; deficient medical record keeping; and inadequate feeding practices.

States rarely contest Justice's findings in court. Only two CRIPA cases involving large public ICFs/MR have been litigated. Department officials told us that the prospect of litigation usually prompts states to negotiate with Justice and to initiate corrective actions. The Department resolved 11 CRIPA cases without having to take legal action beyond issuing the findings letter because the states corrected the deficiencies. In another 12 cases involving large public ICFs/MR, states agreed to enter into a consent decree with the Department.[8] About half of these latter cases required a civil contempt motion or other legal action to enforce the terms of the decree.

[8]Consent decrees are judicially sanctioned agreements between parties in dispute. In these cases, they generally specify the actions that the state agrees to take, the time frames for implementing them, and the type and form of follow-up monitoring to take place.

## State Survey Agencies Have Not Identified All Serious Deficiencies

State survey agencies may be certifying some large public ICFs/MR that do not meet federal standards. Although state survey agencies have the primary responsibility for monitoring the care in ICFs/MR on an ongoing basis, HCFA surveyors and Justice Department investigators have identified more deficiencies—and more serious deficiencies—than have state survey agencies.

Federal monitoring surveys conducted by HCFA regional office staff identified more numerous or more serious problems in some large public ICFs/MR than did state agency surveys of the same institutions. According to HCFA, federal surveyors noted significant differences between their findings and those of the state survey agencies in 12 percent of federal monitoring surveys conducted in large public ICFs/MR between 1991 and 1994. HCFA surveyors determine that significant differences exist when, in their judgment, they have identified serious violations that existed at the time of the state agency survey that the state surveyors did not identify.

When conducting monitoring surveys, HCFA regional office staff use the same standards and guidelines as state agency surveyors. These federal surveys are designed to assess the adequacy of state certification efforts in ensuring that ICFs/MR meet federal standards, and, for public facilities, the effectiveness of delegating to states the responsibility for surveying and monitoring the care provided in their own institutions.

Justice also identified more deficiencies—and more serious deficiencies—in some large public ICFs/MR than did state survey agencies. Although some deficient care practices found by Justice were also noted on state agency surveys of the same institutions, others were not noted by state surveyors. For example, Justice found seriously deficient care that violated residents' civil rights in 11 state institutions it investigated between 1991 and 1995. Of these 11, state agency surveys cited only 2 for a CoP deficiency even though the state surveys were conducted within a year of Justice's inspection. The types of serious deficiencies often cited in Justice reports but not in state agency surveys of the same institution included deficiencies in medical practices and psychiatric care, inappropriate use of psychotropic medications, and excessive use of restraints.

## Several Factors Weaken HCFA and State Oversight Efforts

Several factors have contributed to the inability or failure of HCFA and state survey agencies to identify and prevent recurring quality-of-care deficiencies in some large public ICFs/MR. First, states have not identified all important quality-of-care concerns because of the limited approach and resources of Medicaid surveys. Second, enforcement efforts have not been sufficient to ensure that deficient care practices do not recur. Third, because states are responsible for both delivering and monitoring the care provided in most public institutions, state agency surveys of these institutions may lack the necessary independence to avoid conflicts of interest. Finally, a decline in direct HCFA oversight has reduced HCFA's ability to monitor problems and help correct them. Although HCFA has recently begun to implement several initiatives to address some of these weaknesses, others remain unresolved.

### Medicaid Surveys' Approach and Resources May Hinder Problem Identification

Differences between the approach and resources of Medicaid surveys and Justice Department investigations may explain why Medicaid surveys have not always identified the serious deficiencies that Justice investigations have. State surveyors examine a broad range of facility practices, environmental conditions, and client outcomes to ensure minimum compliance with HCFA standards. Surveys are generally limited to a review of the current care provided to a sample of residents in an institution, are conducted annually, and may last 1 to 2 weeks at a large public institution.

In contrast, Justice Department investigations are intended to determine whether civil rights violations exist. They generally focus on deficient care practices about which Justice has received specific allegations, often related to medical and psychiatric care. Such investigations may include a review of care provided to all individuals in a facility, extend over several months, and include an examination of client and facility records covering several years to assess patterns of professional practice.

The professional qualifications and expertise of individuals conducting state agency surveys and Justice's investigations also differ. State surveyors are usually nurses, social workers, or generalists in a health or health-related field. Not all have expertise in developmental disabilities. Although HCFA recommends that at least one member of a state survey team be a qualified mental retardation professional (QMRP), 17 states had no QMRPs on their survey agency staffs as of March 1996.[9] Justice's

[9]Medicaid regulations define a QMRP as an individual who (1) has at least 1 year of experience working directly with people with mental retardation or other developmental disabilities and (2) is a physician, registered nurse, or an individual with a bachelor's degree in a health or human services-related discipline.

investigators are usually physicians, psychiatrists, therapists, and others with special expertise in working with the developmentally disabled. According to HCFA and Justice officials, Justice Department investigators generally can better challenge the judgment of professionals in the institution regarding the care provided to individual residents than can state surveyors.

HCFA officials acknowledged that the differences between Medicaid surveys and Justice investigations could explain some of the differences between their findings. They told us, however, that they have begun to implement several changes to the survey process to increase the likelihood that state surveys will identify all serious deficiencies. These include new instructions to surveyors for assessing the seriousness of deficiencies, increased training for surveyors and providers, and implementation of a new survey protocol intended to focus more attention on critical quality-of-care elements and client outcomes.

The new survey protocol reduces the number of items that must be assessed each year and places greatest emphasis on client protections, active treatment, client behavior and facility practices, and health care services. The new protocol gives surveyors latitude, however, to expand the scope of a facility's survey if they find specific problems. HCFA's pilot test of the new protocol showed that although surveyors identified fewer deficiencies overall than with the standard protocol, they issued more citations for the most serious CoP violations. HCFA is conducting training for state surveyors and providers on this new protocol and plans to monitor certain aspects of its implementation.

## Medicaid Enforcement Efforts Are Insufficient

Even when state survey agencies identify deficiencies in large public ICFs/MR, state enforcement efforts do not always ensure that facilities' corrections are sufficient to prevent the recurrence of the same serious deficiencies. Although state survey agencies almost always certify that serious deficiencies have been corrected, they subsequently cite many institutions for the same violations. For example, between December 1990 and May 1995, state survey agencies cited 33 large public institutions for violating the same CoP on at least one subsequent survey within the next 3 years. Moreover, 25 were cited for violating the same CoP on one or more consecutive surveys.

HCFA officials told us that the sanctions available to the states under Medicaid have not always been effective in preventing recurring violations

and are rarely used against large public ICFs/MR. Only two possible sanctions are available under the regulations for CoP violations: suspension—that is, denial of Medicaid reimbursement for new admissions—or termination from the program.[10] Medicaid regulations do not contain a penalty for repeat violations that occur after corrective action.

Denying reimbursement to large public institutions for new admissions is not a very relevant sanction because many of these institutions are downsizing or closing and are not generally accepting many new admissions. Furthermore, terminating a large institution from the Medicaid program is counterproductive because denying federal funds may further compromise the care of those in the institution. No large public institutions were terminated from Medicaid for reasons of deficient care and not reinstated from 1990 through 1994, the period for which data were readily available.

HCFA officials told us that they were particularly concerned about institutions where surveyors found repeat violations of the same CoPs. Although the officials have not explored the usefulness of other sanctions or approaches to enforcement for large public ICFs/MR, they told us that the newly implemented survey procedure was intended to better identify the underlying causes of facility deficiencies, possibly reducing repeat violations.

## State Oversight of ICFs/MR Lacks Independence

A potential conflict of interest exists because states both operate large public ICFs/MR and certify that these institutions meet federal standards for Medicaid participation. States can lose substantial funds if care is found to be seriously deficient and their institutions lose Medicaid certification. The state survey agency, usually a part of a state's department of health, conducts surveys to determine whether ICFs/MR are in compliance with quality standards. It reports and makes its recommendation to the state Medicaid agency, which makes the final determination of provider certification. Medicaid rules do not require any independent federal or other outside review for a state's ICF/MR to remain certified.

HCFA officials, provider representatives, and advocates have expressed concern that this lack of independence compromises the integrity of the survey process. HCFA regional officials told us of instances in which state

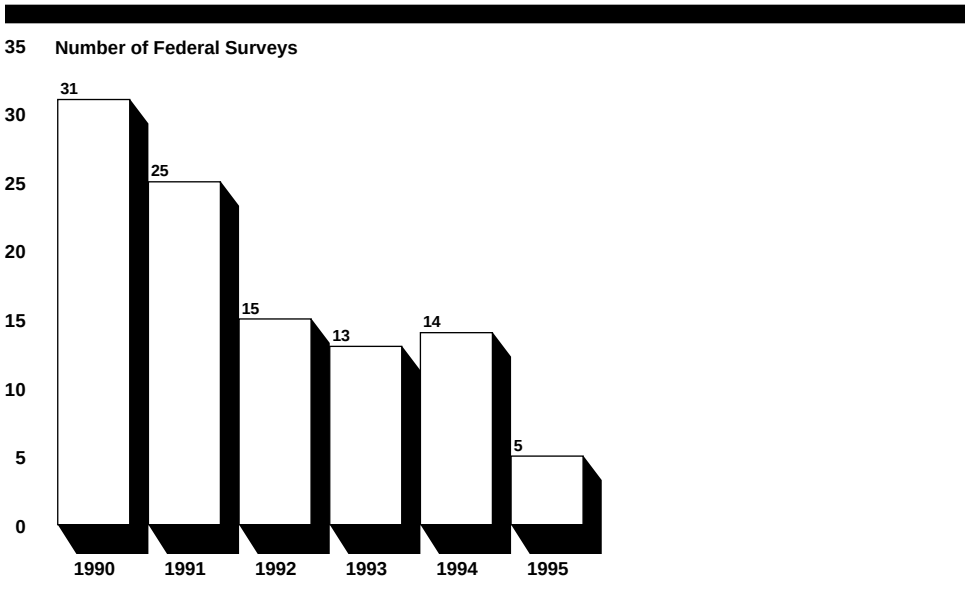
[10]Termination includes not renewing an annual provider agreement or discontinuing an agreement before its expiration date.

surveyors were pressured by officials from their own and other state agencies to overlook problems or downplay the seriousness of deficient care in large state institutions. Of concern to the state officials in these instances was the imposition of sanctions that would have cost the state federal Medicaid funds. HCFA regional office staff may mitigate the effects of potential conflicts of interest by training surveyors, accompanying state surveyors during their inspections, or directly surveying the institutions themselves.

## Federal Oversight Has Declined Dramatically

Direct federal oversight has declined dramatically in recent years despite its importance for independent monitoring of the care provided in large public institutions and the performance of state survey agencies. HCFA's primary oversight mechanism has been the federal monitoring survey, which assesses state agency determinations of provider compliance. As shown in figure 1, the number of federal monitoring surveys conducted in large public ICFs/MR has declined from 31 in 1990 to only 5 in 1995.

**Figure 1: Federal Monitoring Surveys in Large Public ICFs/MR, 1990-95**




Source: HCFA's Online Surveys Certification and Reporting System.

HCFA began surveying large public ICFs/MR in response to congressional hearings in the mid-1980s that detailed many instances of poor quality and abusive conditions in Medicaid-certified institutions for the developmentally disabled. In 1985, HCFA hired 45 employees, about half of whom had special expertise in working with persons with developmental disabilities, to conduct direct federal surveys. Officials from HCFA and Justice, providers, and experts told us that this effort helped improve the quality of care in many institutions and stimulate improvements to the state survey process.

The recent decline in federal oversight, however, has increased the potential for abusive and dangerous conditions in these institutions. HCFA officials told us that regional office staff have neither conducted sufficient reviews nor acted on facility deficiencies in recent years because of competing priorities and resource constraints. According to these officials, resources previously used for federal surveys of ICFs/MR have been diverted to allow compliance with requirements for increased federal monitoring surveys of nursing facilities and for other reasons.[11] Regional office officials report that these resource constraints have limited their current review efforts to mostly private ICFs/MR of six beds or less.

HCFA regional office staff are now less able to identify deficiencies or areas of weakness and to provide targeted training or other support to state surveyors. State survey agencies have recently reported a decline in the number of serious CoP violations in large public ICFs/MR. Yet without direct monitoring, HCFA cannot determine whether this decline is due to real improvements in conditions or to decreased vigilance or competence on the part of state agency surveyors.

Although HCFA officials have expressed concern about the current level of direct federal oversight of state survey agencies and large public ICFs/MR, they have no plans to increase resources for these efforts. Instead, HCFA officials told us they are examining ways to better target their limited oversight resources. While they are planning to improve their use of existing data for monitoring purposes, they also plan to develop a system of quality indicators to provide information on facility conditions on an ongoing basis. These officials told us that they expect this system of quality indicators to be operational in about 4 years.

[11]The Omnibus Budget Reconciliation Act of 1987 required HCFA to conduct federal surveys in 5 percent of nursing facilities annually.

## Conclusions

The ICF/MR program—intended to provide a safe environment with appropriate treatment by qualified professional staff—serves a particularly vulnerable population of individuals with mental retardation and other developmental disabilities in large public ICFs/MR. Most of these institutions comply with Medicaid quality-of-care standards. Serious deficiencies continue to occur, however, in some institutions despite federal standards, oversight by HCFA and state agencies, and continuing investigations by the Department of Justice.

States are the key players in ensuring that ICFs/MR meet federal standards. Although their oversight includes annual on-site visits by state survey agencies to all large public ICFs/MR, these agencies have not identified all instances of seriously deficient care. HCFA reviews and Justice Department investigations have identified some instances of deficient care, including medical care, that were not reported in state surveys. Furthermore, serious deficiencies continue to recur in some of these institutions.

Effective federal oversight of large public ICFs/MR and the state survey agencies that inspect them requires that the inspection process be well defined and include essential elements of health care, active treatment, and safety; that enforcement efforts prevent the recurrence of problems; that surveyors be independent; and that HCFA officials have sufficient information to monitor the performance of institutions and state survey agencies. The approach and resources of Medicaid surveys, the lack of effective enforcement mechanisms, the potential conflicts of interest occurring when states are charged with surveying the facilities they operate, and the decline in direct federal monitoring efforts have all weakened oversight of large public ICFs/MR and state survey agencies.

HCFA has begun to implement changes to the structure and process of state agency surveys of ICFs/MR. The new approach to surveys may result in identifying more serious deficiencies in large public institutions. This change, and others that HCFA is implementing to more efficiently use limited federal and state resources, may also reduce the impact of some of the other weaknesses we have identified. Nonetheless, the lack of independence in state surveys coupled with little direct federal monitoring remains a particular concern. HCFA needs to strengthen the oversight of its ICF/MR program and collect sufficient information in a timely manner to assess the effectiveness of the new approach in identifying and ensuring the correction of deficient care.

## Recommendations

To improve HCFA's oversight of large public ICFs/MR, we recommend that the Administrator of HCFA

- assess the effectiveness of its new survey approach in ensuring that serious deficiencies at large public ICFs/MR are identified and corrected;
- take steps, such as enhanced monitoring of state survey agencies or direct inspection of institutions, to address the potential conflict of interest that occurs when states are both the operators and inspectors of ICFs/MR; and
- determine whether the application of a wider range of enforcement mechanisms would more effectively correct serious deficiencies and prevent their recurrence.

## Agency Comments

HCFA and the Justice Department reviewed a draft of this report and provided comments, which are reproduced in appendixes III and IV. Both agencies generally agreed with the information provided in this report. In their comments, HCFA and Justice recognized the need for improvements in government oversight of the ICF/MR program to ensure adequate services and safe living conditions for residents of large public institutions. HCFA also provided technical comments, which we have incorporated as appropriate.

HCFA is implementing a new survey approach and in its comments agreed with our recommendation that it should assess the effectiveness of this approach. To monitor the implementation of its new approach, federal surveyors will accompany state surveyors on a sample of facility surveys, including a minimum of one large public institution in each state. HCFA plans to analyze the results of these monitoring surveys to determine, among other things, whether the new protocol, as designed, is applicable to large public institutions. These are steps in the right direction. Given the serious problems we have identified in ICFs/MR and in state survey agency performance, we believe HCFA must move quickly to determine whether the new survey process improves the identification of serious deficiencies at large public institutions and make appropriate adjustments if it does not.

In its comments, HCFA did not propose specific measures to address our recommendation on the potential conflict of interest that occurs when states are both operators and inspectors of ICFs/MR. HCFA stated that resource constraints have resulted in a significant reduction of on-site federal oversight of state survey agencies and of care in large public ICFs/MR. We believe that HCFA's plan to increase its presence in the field as

part of monitoring implementation of the new survey protocol may reduce the impact of potential conflicts of interest at some institutions. However, HCFA must find a more lasting and comprehensive solution to strengthen the independence of the survey process by program improvements or reallocation of existing resources to enhanced monitoring or direct inspection of institutions.

HCFA agreed with our recommendation that it determine whether a wider range of enforcement actions would bring about more effective correction of serious deficiencies and prevent their recurrence. HCFA plans to assess whether a wider range of mechanisms would be appropriate for the ICF/MR program on the basis of an evaluation of the impact of alternative enforcement mechanisms for nursing homes due to the Congress in 1997.

As arranged with your offices, unless you publicly announce its contents earlier, we plan no further distribution of this report until 30 days from its date of issue. We will then send copies to the Secretary of the Department of Health and Human Services; the Administrator, Health Care Financing Administration; the U.S. Attorney General; and other interested parties. Copies of this report will be made available to others upon request.

If you or your staff have any questions about this report, please contact me at (202) 512-7114 or Bruce D. Layton, Assistant Director, at (202) 512-6837. Other GAO contacts and contributors to this report are listed in appendix V.

William J. Scanlon
Director, Health Financing
and Systems Issues

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## Abbreviations

| | |
|---|---|
| CoP | condition of participation |
| CRIPA | Civil Rights of Institutionalized Persons Act |
| HCFA | Health Care Financing Administration |
| HHS | Department of Health and Human Services |
| ICF/MR | intermediate care facility for the mentally retarded |
| ICFs/MR | intermediate care facility for the mentally retarded |
| QMRP | qualified mental retardation professional |

# Scope and Methodology

To address our study objectives, we (1) conducted a review of the literature; (2) interviewed federal agency officials, provider and advocacy group representatives, and national experts on mental retardation and developmental disabilities; (3) analyzed national data from inspection surveys of intermediate care facilities for the mentally retarded (ICF/MR); and (4) collected and reviewed HCFA, state agency, and Justice Department reports on several state institutions.

We interviewed officials or representatives from the Health Standards and Quality Bureau of HCFA; HCFA regional offices; the Administration on Developmental Disabilities; the President's Committee on Mental Retardation in HHS; the Civil Rights Division in the Justice Department; the National Association of State Directors of Developmental Disabilities Services, Inc.; the National Association of Developmental Disabilities Councils; the National Association of Protection and Advocacy Systems; the Accreditation Council on Services for People With Disabilities; and the Association of Public Developmental Disabilities Administrators.

Data reviewed at HCFA consisted of automated data and reports submitted by states and regional offices. We analyzed national data from HCFA's Online Survey, Certification and Reporting System for state and federal ICF/MR surveys conducted between December 1990 and May 1995. Information from surveys conducted before December 1990 was not available at the time of our review. We limited our analysis of HCFA and state data on deficiencies to information about institutions participating in Medicaid as of August 1995. We also reviewed state agency survey reports for 12 large public ICFs/MR, 5 of which were also the subject of Justice investigations between 1991 and 1995.

We reviewed Justice's records since 1990, including findings letters, consent decrees, court filings and actions, and other supporting documentation and analyses related to enforcement of the Civil Rights of Institutionalized Persons Act.

We conducted our work between May 1995 and July 1996 in accordance with generally accepted government auditing standards.

# Conditions of Participation

Following are the eight conditions of participation for intermediate care facilities for the mentally retarded (ICF/MR), as prescribed by the Secretary and contained in federal regulations.

## Governing Body and Management

The standards that must be addressed under this condition include the following: the facility must (1) have a governing body that exercises general control over operations; (2) be in compliance with federal, state, and local laws pertaining to health, safety, and sanitation; (3) develop and maintain a comprehensive record keeping system that safeguards client confidentiality; (4) enter into written agreements with outside resources, as necessary, to provide needed services to residents; and (5) be licensed under applicable state and local laws.

## Client Protections

To comply with this condition, the facility must (1) undertake certain actions and provide mechanisms to protect the rights of residents; (2) adequately account for and safeguard residents' funds; (3) communicate with and promote the participation of residents' parents or legal guardians in treatment plans and decisions; and (4) have and implement policies and procedures that prohibit mistreatment, neglect, or abuse of residents.

## Facility Staffing

Standards for facility staffing include requirements that (1) each individual's active treatment program be coordinated, integrated, and monitored by a qualified mental retardation professional; (2) sufficient qualified professional staff be available to implement and monitor individual treatment programs; (3) the facility not rely upon residents or volunteers to provide direct care services; (4) minimum direct care staffing ratios be adhered to; and (5) adequate initial and continuing training be provided to staff.

## Active Treatment

Regulations specify that each resident receive a continuous active treatment program that includes training, treatment, and health and related services for the resident to function with as much self-determination and independence as possible. Standards under this condition include (1) procedures for admission, transfer, and discharge; (2) requirements that each resident receive appropriate health and developmental assessments and have an individual program plan developed by an interdisciplinary team; (3) requirements for program plan

implementation; (4) adequate documentation of resident performance in meeting program plan objectives; and (5) proper monitoring and revision of individual program plans by qualified professional staff.

## Client Behavior and Facility Practices

Standards under this condition specify that the facility (1) develop and implement written policies and procedures on the interaction between staff and residents and (2) develop and implement policies and procedures for managing inappropriate resident behavior, including those on the use of restrictive environments, physical restraints, and drugs to control behavior.

## Health Care Services

To meet the requirements of this condition, the facility must (1) provide preventive and general medical care and ensure adequate physician availability; (2) ensure physician participation in developing and updating each individual's program plan; (3) provide adequate licensed nursing staff to meet the needs of residents; (4) provide or make arrangement for comprehensive dental care services; (5) ensure that a pharmacist regularly reviews each resident's drug regimen; (6) ensure proper administration, record keeping, storage, and labeling of drugs; and (7) ensure that laboratory services meet federal requirements.

## Physical Environment

Requirements under this condition include those governing (1) residents' living environment, (2) size and furnishing of resident bedrooms, (3) storage space for resident belongings, (4) bathrooms, (5) heating and ventilation systems, (6) floors, (7) space and equipment, (8) emergency plans and procedures, (9) evacuation drills, (10) fire protection, (11) paint, and (12) infection control.

## Dietetic Services

Standards under this condition are designed to ensure that (1) each resident receives a nourishing, well-balanced, and varied diet, modified as necessary; (2) dietary services are overseen by appropriately qualified staff; and (3) dining areas be appropriately staffed and equipped to meet the developmental and assistance needs of residents.

# Comments From the Health Care Financing Administration

DEPARTMENT OF HEALTH & HUMAN SERVICES

Health Care Financing Administration

The Administrator
Washington, D.C. 20201

AUG - 5 1996

**TO:** William J. Scanlon
Director, Health Systems Issues
General Accounting Office

**FROM:** Bruce C. Vladeck
Administrator

**SUBJECT:** GAO Draft Report,"Medicaid: Oversight of Institutional Care for the Mentally Retarded Should Be Strengthened"

We appreciate the opportunity to review your draft report to Congress concerning the oversight of institutional care for the mentally retarded. Our comments are attached; should you have any questions or require any additional information, kindly contact Ron Miller of the Executive Secretariat at (410) 786-5237.

Attachment

Comments of the Health Care Financing Administration (HCFA) on the General Accounting Office (GAO) Draft Report, "Medicaid: Oversight for the Mentally Retarded Should be Strengthened"

Overview

HCFA is pursuing an ongoing, long-term effort to continuously improve the intermediate care facility for the mentally retarded (ICF/MR) program. This effort has recently resulted in the issuance of a comprehensive update to the interpretive guidelines, and the drafting, pilot testing, and implementation of a revised survey protocol. We are currently involved in a nationwide training program to train all ICF/MR surveyors on this revised survey protocol. We have funded a major study of the ICF/MR program to determine what direction HCFA should take to develop quality enhancement systems for services to people with developmental disabilities. Throughout each of the efforts, we have arranged for the input and participation of our partners and stakeholders in this Medicaid program.

Two of the initiatives described above are pertinent to this report.

HCFA has recently revised the current survey process. State surveyors still survey onsite each year to directly examine the providers' compliance with the ICF/MR requirements. The revisions are designed to direct surveyors to focus their attention on the experiences of individuals who reside in the facility, by requiring more observations of, and interviews with, the individuals who are served. We have identified 52 fundamental outcomes which individuals are expected to experience as a result of the ICF/MR benefit. The revisions also give surveyors guidance in the form of Compliance Principles, directed at determining Condition of Participation level compliance. This should result in more consistent compliance decisions. This enhanced survey process will be implemented nationally by October 1, 1996.

HCFA is also in the process of developing a long range survey and certification improvement initiative, using quality indicators. We do not anticipate implementation of this system of oversight before FY 2000. The future system will necessitate the establishment of a comprehensive data base of facility-submitted performance and resident characteristics information.

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Based on the evaluation of this data, using quality indicators, the survey and certification system will provide facilities with feedback about their performance on a regular basis. The feedback will include comparisons with their own prior performance and with other facilities in the state, region, and nation, thus providing facilities with information they can use to implement continuous quality improvement efforts.

As a result of this effort, surveyors will flag problem areas before going onsite, and may schedule specialists, as indicated by the flags, for that survey. Surveyors will conduct focused surveys for two purposes: to verify the accuracy of the data provided (random) and to look at problem areas flagged by the data (specific). It is expected that this method of oversight will also lead to the identification and sharing of "best practices" information between facilities.

HCFA will utilize the data base and quality indicators to assess trends in state certification activities in ICFs/MR, including publicly funded, large facilities. This will provide a more effective way of targeting resources to potential problems.

The above two steps are distinct attempts to move towards the ongoing improvement of services that HCFA sees as a multi-step effort to strengthen services in ICFs/MR.

GAO Recommendation

To improve HCFA's oversight of large public ICFs/MR, we recommend that the Administrator of HCFA:

-- assess the effectiveness of its new survey approach in ensuring that serious deficiencies at large public ICFs/MR are identified and corrected;

HCFA Comment

We agree, and have designed an implementation monitoring plan which requires that Federal surveyors accompany state surveyors on implementation monitoring and support surveys (IMSS) in 2 percent of the facilities in each region, with a minimum number of 2 small facilities and at least one large public facility in each state. Federal surveyors will compile and analyze the results of these surveys, with one area of analysis focusing on whether the protocol, as designed, is applicable to large public facilities.

We expect to continue our efforts to improve the effectiveness of the survey system. The President's 1997 budget request provided for funds to begin the process of identifying, developing, and implementing quality indicators, and designing and implementing the

data collection, storage and retrieval methods necessary to implement a data driven survey and monitoring system that uses quality indicators. A data driven survey and monitoring system provides for an ongoing off-site analysis of facility performance using information submitted by the facility. Onsite reviews will focus on areas of potential performance problems as well as validation of submitted information. As part of this effort, we will assess the ability of the indicators to provide accurate information about serious deficiencies in large public ICFs/MR.

GAO Recommendation

-- take steps such as enhanced monitoring of state survey agencies or direct inspection of facilities to address the potential conflict of interest that occurs when states are both the operators and inspectors of ICFs/MR; and

HCFA Comment

With our constrained resources, we continue to monitor the states' activity through limited onsite surveys, complaint follow up surveys, and our general oversight of all state activity. Congress has reduced the President's budget (Federal administrative costs budget) requests for HCFA for the past 3 years, and resources have been cut from all components of HCFA, while the number of Medicare and Medicaid facilities which require surveys has grown dramatically. This has resulted in a significant reduction of onsite Federal oversight of states' performance in certifying ICFs/MR.

GAO Recommendation

-- determine whether the application of a wider range of enforcement mechanisms would bring about more effective correction of serious deficiencies and prevent their recurrence.

HCFA Comment

HCFA has implemented a menu of various enforcement mechanisms for nursing homes. These alternate remedies include: directed in-service training; directed plan of correction; denial of payment for new admissions; civil money penalties; and, temporary management. A report evaluating the effectiveness of this effort is due to Congress in 1997. Based on the evaluation of the impact of alternate remedies in nursing homes, we will assess whether it is likely that a wider range of enforcement mechanisms for the ICF/MR program would bring about more effective correction of serious deficiencies and prevent their recurrence. If necessary, a legislative proposal will be developed.

# Comments From the Department of Justice

**U.S. Department of Justice**

Civil Rights Division

Office of the Assistant Attorney General

*Washington, D.C. 20035*

August 6, 1996

William J. Scanlon
Director, Health Financing and
Systems Issues
U.S. General Accounting Office
NGB/Room 500
441 G Street, N.W.
Washington, D.C. 20548

Dear Mr. Scanlon:

Thank you for the opportunity to review and comment on a draft of the United States General Accounting Office's report entitled Medicaid: Oversight of Institutional Care for the Mentally Retarded Should Be Strengthened. The report raises significant issues about the critical need for appropriate governmental oversight to ensure adequate services and living conditions in the more than 400 large public institutions across this nation currently serving more than 62,000 people with mental retardation and other developmental disabilities.

The Civil Rights of Institutionalized Persons Act (CRIPA), 42 U.S.C. § 1997 et seq., gives the Attorney General of the United States the authority to protect the fundamental rights of individuals living in a wide variety of publicly operated institutions, including facilities serving people with mental retardation, psychiatric hospitals and other mental health facilities, nursing homes, juvenile correctional facilities, jails, and prisons. Under CRIPA, the Department has investigated conditions in some 250 institutions across the nation based upon allegations of widespread abuse, neglect, and other dire and unlawful conditions. As you note in your report, the Department has repeatedly found seriously deficient conditions in public facilities certified to participate in Medicaid as intermediate care facilities for people with mental retardation (ICFs/MR). These conditions have resulted in death, significant injury, and physical deterioration. The Department has been instrumental over the years in remedying these harmful conditions and inadequate care and treatment in ICFs/MR as well as other facilities, including nursing homes and juvenile and adult correctional facilities, in which a growing number of people with developmental disabilities are institutionalized and are suffering similar abuse and neglect.

Federal, state, and local governments must be vigilant in identifying deficient conditions that exist in public facilities and equally vigilant in ensuring that they are corrected. This effort must be a shared governmental responsibility in order to put an end to continuing abuse and other serious violations of basic rights. Under CRIPA, the Department attempts to work cooperatively with state and local governments to address these problems. This approach has resulted in voluntary correction of deficient conditions in approximately half of the facilities where the Department has found violations during a CRIPA investigation. In the vast majority of other facilities where a CRIPA investigation has identified systemic violations of residents' rights, the Department has entered into a court supervised agreement with the state or local jurisdiction to ensure that necessary corrective action is taken.

As your report indicates, the Department has traditionally identified a greater number of serious deficiencies through its CRIPA investigations of ICFs/MR than state agencies have identified in such facilities through their Medicaid surveys. Moreover, as you point out, enforcement actions taken by state agencies have not been sufficient to ensure that the deficiencies are corrected and do not recur. These failures to identify and address problems on a state level have contributed to the need for CRIPA enforcement action by the Department in a number of large public facilities for people with developmental disabilities. Because legal action under CRIPA is a vehicle of last resort, we agree that a greater effort must be placed on other avenues of governmental oversight.

The Department will continue its strong program under CRIPA to protect the rights of all persons who live in public facilities, including those with mental retardation and other developmental disabilities. Your report focuses attention on critical issues about improving other areas of governmental oversight of services for people with developmental disabilities that must be addressed. We believe your identification of underlying problems and needed solutions is a significant contribution to a resolution of these important issues.

Sincerely,

Deval L. Patrick
Assistant Attorney General
Civil Rights Division

# GAO Contacts and Staff Acknowledgments

## GAO Contacts

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## Staff Acknowledgments

In addition to those named above, the following team members made important contributions to this report: James Musselwhite and Anita Roth, evaluators; Paula Bonin, computer specialist; Karen Sloan, communications analyst; George Bogart, attorney-advisor; and Leigh Thurmond and Jamerson Pender, interns.

# Related GAO Products

Medicaid: Waiver Program for Developmentally Disabled Is Promising But Poses Some Risks (GAO/HEHS-96-120, July 22, 1996).

Financial Management: Oversight of Small Facilities for the Mentally Retarded and Developmentally Disabled (GAO/AIMD-94-152, Aug. 12, 1994).

Medicaid: Federal Oversight of Kansas Facility for the Retarded Inadequate (GAO/HRD-89-85, Sept. 29, 1989).

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