REPORT BY THE

Comptroller General

OF THE UNITED STATES

The Sudden Infant Death Syndrome Program Helps Families But Needs Improvement

Sudden Infant Death Syndrome is the sudden and unexpected death of an apparently healthy infant which cannot be explained by a thorough medical examination. The Department of Health and Human Services' Sudden Infant Death Syndrome Information and Counseling program is helping families deal with the death of their infants. However, grantees have not fully met the program's objectives because of (1) the lack of full cooperation from other organizations, (2) the lack of sufficient guidance from the Department, and (3) the Department's failure to enforce program requirements. The Department also needs to improve its grant and contract award and management procedures.

To help overcome obstacles impeding the extension of Sudden Infant Death Syndrome information and counseling services nationwide, GAO recommends that the Congress consolidate this program with the Maternal and Child Health program.

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COMPTROLLER GENERAL OF THE UNITED STATES
WASHINGTON, D.C. 20548

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The Honorable Mark O. Hatfield, Chairman
Committee on Appropriations
United States Senate

The Honorable Jeremiah Denton, Chairman
Subcommittee on Aging, Family and
Human Services
Committee on Labor and Human Resources
United States Senate

The Honorable Henry A. Waxman, Chairman
Subcommittee on Health and the Environment
Committee on Energy and Commerce
House of Representatives

This report is in response to your Committees' February 22, 1980, joint request that we review the Sudden Infant Death Syndrome Counseling and Information program authorized by part B of title XI of the Public Health Service Act and administered by the Department of Health and Human Services.

The report discusses the performance of selected program grantees and contractors; the extent of voluntary groups' participation in the grantees' project activities; and the Department's program administration, including procedures for awarding and managing grants and contracts.

We obtained written comments from the Department and written or oral comments from the grantees, contractors, and voluntary groups discussed in the report. Their specific comments have been included in the report.

Copies of this report are also being sent to former Committee Chairmen, Senators Warren Magnuson and Alan Cranston. The Committees' offices requested that we make no further distribution of this report, except to the Department of Health and Human Services, until the offices notify us, which we understand will be within a few days after the report's issuance. At that time, we will send copies to other interested Members of Congress, the Office of Management and Budget, other organizations whose activities we discussed in the report, and other interested parties.

Comptroller General
of the United States

REPORT BY THE COMPTROLLER GENERAL OF THE UNITED STATES

THE SUDDEN INFANT DEATH SYNDROME PROGRAM HELPS FAMILIES BUT NEEDS IMPROVEMENT

D I G E S T

Sudden Infant Death Syndrome (SIDS) is the sudden and unexpected death of an apparently healthy infant. It is a particularly perplexing public health problem because of the traumatic impact on families that have lost an infant for no apparent medical reason. Since 1975, the Department of Health and Human Services (HHS) has provided assistance to these families through its SIDS Counseling and Information program.

Grants are awarded to public and nonprofit private entities to help ensure that:

--SIDS cases are identified and confirmed by autopsy which rules out other causes of death.

--Families are promptly notified of the cause of death, given information on SIDS, and offered counseling services.

--The public and professionals likely to come in contact with SIDS victims' families receive information about SIDS and are made aware of the families' emotional problems.

--Appropriate data on SIDS are collected.

--Community groups are involved in the development and operation of SIDS projects.

Between fiscal years 1975 and 1979, HHS awarded about $11 million in grants for the program. As of October 1, 1980, 42 SIDS projects covered 34 States and the District of Columbia entirely and parts of 2 other States.

The SIDS Counseling and Information program is closely coordinated with research sponsored by HHS' National Institute of Child Health and Human Development. The research is aimed at determining the causes of SIDS, identifying infants who have a high risk of SIDS, and preventing SIDS. (See p. 59.)

GAO was asked by three congressional committees to evaluate several aspects of the SIDS Counseling and Information program, including SIDS projects' performance and Federal SIDS program administration, including procedures for awarding and managing project grants and contracts.

SIDS PROJECTS' PERFORMANCE

GAO reviewed 365 case files at 11 projects and interviewed family members of 82 SIDS victims from 10 projects. (GAO was not able to locate family members of SIDS victims from one project.)

GAO could not fully evaluate the effectiveness of the projects' assistance to SIDS victims' families because of a lack of sufficient data at many projects and a lack of HHS performance standards. However, based on the information that was available, SIDS projects generally were making progress in meeting program objectives.

For cases GAO reviewed, autopsies were generally done promptly, and SIDS was recorded on death certificates, when appropriate. Also, the projects generally saw that parents were notified of the cause of death, given information on SIDS, and offered counseling. However, the projects' performance varied considerably in seeing that parents were notified and counseled within the period desired by HHS.

Two major problems were the failure of (1) some medical examiners and coroners to promptly inform the projects of SIDS deaths and (2) many projects to collect sufficient data. (See p. 10.)

Families GAO contacted overwhelmingly believed that the information provided through the SIDS program was helpful to them in dealing with the death of their infant. Several families said that they did not accept or receive SIDS counseling services, but most of those who did believed the services were helpful. (See p. 18.)

Projects successfully conducted SIDS education and training activities, and generally gave community organizations, including voluntary groups, the opportunity to provide advice and consultation to them and to participate in project activities. However, the extent of such participation varied, in part because there were differing interpretations of what was considered "appropriate" involvement of community groups. HHS needs to issue additional guidance in this area. (See p. 20.)

GRANT AWARD AND ADMINISTRATION

HHS generally followed its policies and procedures to ensure competition and objectivity in soliciting applicants and awarding SIDS grants for the period covered by GAO's review. However, HHS' procedures for determining the funding of individual grantees resulted in excessive funding for several projects, and HHS did not follow established procedures for making sure that grantees' unused funds were applied to the next year's funding. (See p. 25.)

HHS can improve the SIDS grant program by issuing additional guidance and/or enforcing existing requirements to assure that grantees (1) develop specific, measurable objectives, (2) collect and report necessary SIDS data, and (3) evaluate their own performance. Shortages of staff and travel funds, together with HHS' failure to require projects to report sufficient data, have precluded HHS' SIDS Program Office from adequately monitoring projects' performance. (See p. 36.)

CONTRACT AWARD AND MANAGEMENT

HHS complied with procurement requirements for publicizing notices of proposed procurements and objectively evaluating proposals for five of the six contracts GAO reviewed. 1/ However, HHS should have (1) more aggressively pursued efforts to award one sole-source contract competitively beyond its first year, (2) more carefully assigned panel members to make technical evaluations of proposals for one contract to avoid the appearance of bias against one competitor, (3) more specifically described its expectations for performance in two contracts, and (4) assured that one contractor complied with contract requirements. (See p. 42.)

EXTENDING SIDS SERVICES NATIONWIDE

A number of obstacles--such as the way the program has been structured, managed, and funded--impeded HHS' efforts to extend the SIDS information and counseling services nationwide, as the Congress intends. Consolidating the SIDS program with the larger Maternal and Child Health program could help resolve some of these problems. (See p. 61.)

RECOMMENDATION TO THE CONGRESS

The Congress should consolidate the SIDS Information and Counseling program and the Maternal and Child Health program authorized under title V of the Social Security Act. (See p. 68.)

1/An unsuccessful competitor for one of the six contracts GAO reviewed has formally protested the contract award, and GAO is considering the protest. Accordingly, GAO's findings in this report exclude this contract. (See p. 42.)

RECOMMENDATIONS TO THE SECRETARY OF HHS

GAO recommends that the Secretary:

--Issue additional guidance on the content of the narrative section of SIDS grant applications and require grant applicants to develop specific, measurable objectives.

--Establish criteria for funding SIDS grantees and make sure that grantees are given only funds which are needed.

--Issue additional guidance to projects regarding (1) appropriate involvement of community groups and (2) data to be collected and reported to HHS.

--Develop performance standards for SIDS projects and evaluate their performance against those standards.

--Improve contract award procedures by ensuring that work requirements are specifically stated in contracts and by issuing instructions relating to bias, or the appearance of bias, in selecting persons to serve on panels reviewing technical proposals.

--Provide adequate staffing for the SIDS program. (See pp. 69 and 70.)

COMMENTS BY HHS AND OTHER ORGANIZATIONS

HHS, two voluntary organizations concerned with SIDS, and the 11 SIDS projects visited commented on a draft of this report. GAO also received comments on excerpts from the draft report from an HHS contractor whose activities were discussed in the report.

HHS generally concurred with GAO's recommendations. (See p. 70.) The two voluntary organizations raised several objections or concerns with the draft report. Their comments are contained in appendixes IX and X. GAO's response to these comments is discussed in chapter 6 of the report and appendix XI.

The SIDS projects GAO visited and HHS' contractor generally commented on matters dealing specifically with their activities which they believed needed clarification. Where appropriate, GAO made the requested clarifications.

Contents

ABBREVIATIONS

BCHS	Bureau of Community Health Services
GAO	General Accounting Office
HHS	Department of Health and Human Services
HSA	Health Services Administration
OMCH	Office for Maternal and Child Health
SIDS	Sudden Infant Death Syndrome

CHAPTER 1

INTRODUCTION

By letter dated February 22, 1980, the Chairmen, Senate Committee on Appropriations; Subcommittee on Child and Human Development, 1/ Senate Committee on Labor and Human Resources; and Subcommittee on Health and the Environment, House Committee on Interstate and Foreign Commerce, requested that we evaluate the Sudden Infant Death Syndrome (SIDS) Counseling and Information program. The Chairmen requested that, as part of our evaluation, we address several specific questions relating to (1) SIDS projects' performance, (2) Federal SIDS program administration, including procedures for awarding and managing project grants and contracts, (3) the performance of two contractors, and (4) the extent of voluntary groups' participation in SIDS project activities.

The SIDS program is authorized under Part B, Title XI, of the Public Health Service Act (42 U.S.C. 300c-11). It is administered by the Department of Health and Human Services (HHS). 2/

WHAT IS SIDS?

SIDS is the sudden and unexpected death of an apparently healthy infant which cannot be explained by a thorough postmortem examination, or autopsy. Each year an estimated 6,000 to 7,000 infant deaths are attributed to SIDS, which is the leading cause of infant death between the ages of 1 and 12 months. SIDS represents a particularly perplexing public health problem because of its traumatic impact on surviving family members who have lost an infant for no apparent medically diagnosable reason. Also, a diagnosis of SIDS, as the cause of death, can be made properly only after a thorough autopsy reveals no other apparent cause of death.

1/During the 97th Congress, the name of this subcommittee was changed to the Subcommittee on Aging, Family and Human Services.

2/On May 4, 1980, a separate Department of Education commenced operating. Before that date, activities discussed in this report were the responsibility of the Department of Health, Education, and Welfare.

FEDERAL PARTICIPATION IN SIDS

Prior to 1975, the Government's involvement in SIDS was limited primarily to research, mainly through HHS' National Institute of Child Health and Human Development. The research focused on many areas, including (1) identifying infants at risk of becoming SIDS victims, (2) exploring approaches to preventing SIDS, and (3) increasing the understanding of the causes of SIDS. Also, HHS awarded a contract for a nationwide survey in 1972 to determine the availability of counseling and information services for SIDS victims' families in various communities. The then president of the National Sudden Infant Death Syndrome Foundation (Foundation) directed the survey. Also, HHS awarded grants and made other efforts in the early 1970s to educate the public and professionals about SIDS. In 1974, HHS awarded a contract to the Foundation to promote SIDS-related activities in communities and to help them establish information and counseling programs.

Initial SIDS legislation

The Sudden Infant Death Syndrome Act of 1974, enacted April 22, 1974 (Public Law 93-270), authorized HHS to award grants and contracts for projects to provide information and counseling to families affected by SIDS and to collect, analyze, and furnish information relating to the causes of SIDS. The act required HHS to develop public information and professional educational materials relating to SIDS and disseminate the information and materials to persons providing health care, public safety officials, and the general public. To carry out these activities, the act authorized the appropriation of funds for fiscal years 1975-77. The program's authorization was extended in 1-year increments until Public Law 95-613, enacted November 8, 1978, extended it through fiscal year 1981.

SIDS Amendments of 1979

Public Law 96-142, enacted on December 12, 1979, made several changes in the SIDS program and specifically required that HHS carry out the program through an identifiable administrative unit. The amendments required that HHS:

--Develop and implement a system for grantees to periodically report to HHS information collected in the operation of their SIDS projects.

--Carry out coordinated SIDS information clearinghouse activities.

--Conduct or sponsor a study on State laws, practices, and systems relating to death investigation and their impact on sudden and unexplained infant deaths.

--Distribute funds equitably among the various regions and ensure that the needs of rural and urban areas are appropriately addressed.

The amendments also require that HHS submit an annual report to the Congress by February 1 of each year. The February 1, 1980, report was to set forth a plan to extend counseling and information services to the 50 States and the District of Columbia by July 1, 1980, and to all possessions and territories by July 1, 1981.

HOW THE PROGRAM CURRENTLY OPERATES

HHS operates the SIDS program by awarding project grants to various public and nonprofit private entities to carry out information and counseling programs for SIDS victims' families and educational programs for the public and professional groups, such as public health nurses, physicians, police officers, and coroners or medical examiners. The following table shows the number of projects HHS funded and the total amount of grant awards by fiscal year. 1/

Fiscal year	Number of projects funded	Amount of grant awards
		(millions)
1975	24	$ 1.8
1976	31	2.0
1977	30	1.8
1978	33	2.5
1979	37	2.8
Total		$10.9

1/In this report, SIDS grant awards refer to the SIDS Counseling and Information program, and program grantees are commonly referred to by HHS and others as SIDS projects. Our review did not include HHS grants awarded for SIDS research.

The $10.9 million in grant awards for SIDS projects represents 89 percent of the $12.2 million the Congress appropriated for the SIDS program for fiscal years 1975-79. HHS spent the other $1.3 million (or 11 percent) for program support and contract activities, except for about $0.1 million that HHS returned to the U.S. Treasury.

The following table shows for fiscal year 1979 the number and amount of SIDS grant awards by type of grantee organization.

	Grant awards	
	Number	Amount
State health department	21	$1,226,176
City or county health department	2	163,960
University or hospital	a/11	1,092,889
Medical association	b/2	220,060
Regional maternal and child health council	1	84,725
	37	$2,787,810

a/One project is operated through a medical examiner's office.

b/These projects are operated through medical examiners' offices.

Of the 37 projects funded in 1979, 28 were statewide projects, and 9 served less than statewide areas. Of these nine projects, three were in New York, three in Texas, two in Illinois, and one in Alabama.

SIDS projects: common purpose, different approaches

SIDS grantees have responsibilities to assure that SIDS cases are identified; the causes of death are confirmed; families are notified, counseled, and provided information on SIDS; appropriate data are collected and reported; and educational and informational activities are carried out.

SIDS projects vary, however, in how they use Federal funds and how they carry out their programs. As appendix I shows, relatively little Federal SIDS funds are identified specifically for counseling families. Most Federal SIDS funds are for staff salaries, and project budgets do not

identify how much of the staff salaries are used for counseling. The projects we visited frequently relied on community resources, such as public health nurses, to visit SIDS victims' families. All project staffs promoted and coordinated SIDS activities and conducted education and training activities. They varied, however, in the extent to which they became directly involved in notifying families that SIDS was the cause of death and providing information and counseling to families. Following are three examples of how SIDS projects see that families are notified and provided information and counseling.

California

This statewide project, located in the State health department, provides no direct services to SIDS families. Coroners' offices make on-scene investigations, perform autopsies, and notify SIDS families of autopsy results. The county coroners refer SIDS cases to local health departments, which provide counseling services to SIDS parents and report the services provided to the SIDS project.

New York City

This project is in the Manhattan medical examiner's office. The project staff examine notices received each morning of all deaths occurring in New York City during the previous 24-hour period to identify any infant deaths. When an autopsy reveals a SIDS death, the project notifies the SIDS family of the autopsy results. For many cases, the project staff counsel parents when they come to identify their infants. The project also notifies the city health department which assigns a nurse to visit the family and sends the project a written report assessing the family's needs.

Dallas, Texas

The project is sponsored by a university. Project staff are in the same building as the Dallas County medical examiner's office, which is also at the university. The project covers 39 counties in Texas. Autopsy results for SIDS cases are reported to the project by the medical examiner or justices of the peace. The project, in turn, notifies the parents. Project staff visit and counsel SIDS families in part of Dallas County and refer cases in the other areas of the county to public health nurses. For SIDS deaths in the

other 38 counties, the project notifies a public health nurse or other party who visits and counsels the family.

HHS' PROGRAM MANAGEMENT

Within HHS, the SIDS Program Office is responsible for the day-to-day operation and management of the SIDS Counseling and Information program. This office is a component of the Office for Maternal and Child Health (OMCH), which is within the Bureau of Community Health Services (BCHS). BCHS is part of the Public Health Service's Health Services Administration (HSA).

Several offices within HSA provide support services to component program offices, including the SIDS Program Office. For example, the Office of Contracts and Grants awards and manages (in terms of Federal procurement requirements) contracts. BCHS' Grants Management Branch handles fiscal and administrative (as opposed to programmatic) aspects of the SIDS grant program and makes formal grant awards.

HHS regional offices are not responsible for administering the program. However, when requested, they assist the SIDS Program Office in such activities as reviewing and evaluating grant applications and monitoring grantee activities.

The National Institute of Child Health and Human Development, a component of HHS' National Institutes of Health, is responsible for sponsoring research aimed at identifying infants at risk of SIDS and preventing SIDS.

VOLUNTARY ORGANIZATIONS INVOLVED WITH SIDS

The Foundation, founded in 1962, and the International Council of Guilds for Infant Survival (Guild), founded in 1964, are two voluntary organizations concerned specifically with SIDS. Each organization has chapters or affiliates around the Nation. Both conducted SIDS counseling, information, and education activities before enactment of the SIDS Act of 1974 and promoted passage of the SIDS legislation.

The activities of the Foundation and the Guild include (1) promoting SIDS legislation, funding, and other activities at the Federal, State, and local levels, (2) raising funds for SIDS research, (3) providing information and education on SIDS to health and other professionals and the public,

(4) providing information and counseling to SIDS-afflicted families, and (5) helping develop and operate federally funded SIDS projects.

Other voluntary groups are concerned with SIDS but do not limit their activities to SIDS. Two such organizations are the Infants' Fight for Life, which raises funds for SIDS research and works with a number of federally funded SIDS projects, and the Compassionate Friends, which provides counseling to SIDS families.

OBJECTIVE, SCOPE, AND METHODOLOGY

The objective of our review was to assess (1) HHS' management of the SIDS program, including the procedures followed in awarding and managing contracts and project grants, (2) the performance of selected federally funded SIDS projects, (3) the performance of two contractors to mobilize community resources for SIDS programs, and (4) voluntary groups' participation in the SIDS program and individual projects' activities.

We reviewed legislation, regulations, policies, procedures, and directives governing the SIDS program, grant administration, and contract procurements. We also reviewed HHS records relating to the operation of the SIDS program, including grant files for all SIDS grants awarded since the inception of the SIDS program and contract files for six SIDS contracts in which the Committees requesting this review expressed interest.

To assess HHS' compliance with grant administration policies and procedures, we (1) attended one grant application review panel meeting to observe the proceedings, (2) interviewed 11 of the 18 voting members of the 1979 and 1980 review panels to obtain their perceptions of the panel review process, (3) reviewed files for 7 grants awarded in 1978 and 7 grants awarded in 1979 to determine HHS' adherence to, and followup on, panel recommendations, and (4) reviewed the grant files for all grants awarded since the inception of the SIDS program to document funding data by project and to determine use made of grantees' yearend unspent funds.

We did audit work at HSA headquarters in Rockville, Maryland, and at 11 federally funded SIDS project offices: Berkeley, California; Tallahassee, Florida; Maywood and Springfield, Illinois; Baltimore, Maryland; St. Louis, Missouri; Lincoln, Nebraska; New York City and Stony Brook, New York; and Dallas and Houston, Texas. Also, we contacted

representatives from 11 States to determine whether the assistance provided by two HHS contractors was helpful.

The Committees' offices asked that we review 5 of the 11 projects selected. The other six were selected to include, also at the request of the Committees' offices, the various types of grantee organizations (see p. 4) and projects with and without problems as perceived by HHS or voluntary organizations concerned with SIDS.

We interviewed HSA officials and staff of the 11 projects selected for review. We also interviewed representatives of State health departments, public health organizations, parent volunteer groups, groups that received training sponsored by the 11 projects, community councils for the 11 projects, and HHS grant application review panel members.

To assess the extent to which the selected grantees met SIDS program objectives for serving SIDS families, we randomly selected and reviewed 293 case files on families residing in the areas served by 10 of the projects during July 1979 through April 1980. We were unable to select a random statewide sample of SIDS families served by the California project because the project had not received case management data from all of the county health departments within the State. From seven of the eight counties within the State with the highest incidence of SIDS, we selected 72 cases for detailed review.

The Committees' offices requested that we interview about 10 SIDS victims' families from each of the 11 projects to determine whether they believed the SIDS information and/or counseling services were helpful. For many reasons, we were unable to contact as many families as the Committees' offices had desired. Following the selection process described below, we contacted 82 families, 35 of which were from the 365 cases we selected for review. The other 47 families we contacted were selected from cases not included in our sample of 365 cases. (See below.)

Our selection process for contacting families was as follows:

--We gave officials of the SIDS projects the opportunity to screen the parents selected for interviews and to delete from our sample family members whom the officials believed were still experiencing unusual trauma resulting from their child's death.

--We sent letters to selected parents who were not identified by project staffs as inappropriate, informing them of our desire to contact them and giving them the opportunity to decline our interview.

--We spoke to representatives of all the families we could locate who did not decline our request for an interview.

--In Nebraska, we were unable to locate any parents we selected, and in California, we interviewed only parents in Los Angeles County. Our efforts to contact families in California were impeded by delays we encountered in obtaining necessary approvals from California State officials. These officials were concerned about confidentiality restrictions and the possibility that some of the parents we would contact might need additional counseling as a result of our discussions. Also, officials from Alameda County refused to approve our parent contacts because they believed that such contacts would upset the parents.

CHAPTER 2

SIDS PROJECTS' PERFORMANCE AS COMPARED TO HHS PROGRAM OBJECTIVES

Federally funded SIDS projects we visited were generally making progress toward implementing the SIDS four-point case management program. (See p. 11.) However, because of the lack of HHS performance standards against which SIDS project activities can be measured and, particularly, in view of the lack of information that existed to document whether or when specific events occurred within the SIDS four-point case management program, we were unable to determine whether 10 of 11 selected SIDS projects were accomplishing program objectives.

Based on information that was available concerning projects' implementation of the program for the cases we reviewed, we found that:

--Autopsies generally were being performed on suspected SIDS victims. Most were being performed in a timely manner.

--SIDS was generally being recorded, when appropriate, as the official cause of death on death certificates.

--Notification of SIDS victims' families occurred in at least 91 percent of the sampled cases. However, in many cases, notification did not occur within HHS' desired time frames, and the performance of individual projects varied substantially.

--Counseling of victims' families occurred in at least 261 (or 72 percent) of the sampled cases. However, in many cases, it did not occur within the time frames suggested by HHS and, again, the performance of projects varied.

The Stony Brook, New York, project almost always met HHS' objectives for the SIDS four-point case management program for the 24 cases it opened during our review. Variations in other projects' performance, as it related to the timeliness with which sequential events in the SIDS four-point case management program occurred, often resulted from differences in the cooperation the projects received

from groups with whom they worked. These groups include medical examiners, coroners, and public health departments.

SIDS victims' families whom we contacted generally believed the projects' information services were helpful to them in dealing with the loss of their child.

The SIDS projects we visited were carrying out their educational and training responsibilities, and the services they provided were generally viewed as helpful by representatives of the recipient organizations we contacted. Although SIDS projects were generally giving community groups the opportunity to provide advice and consultation to them and to help counsel SIDS victims' families, some representatives of voluntary groups concerned about SIDS at several of the projects were dissatisfied with their roles. They would like to have more control or influence over projects' activities and, in some cases, routine access to the names of SIDS victims' families, regardless of whether the families give their permission. HHS needs to develop and issue additional guidance on the appropriate role of voluntary groups to help resolve this problem.

SIDS PROGRAM OBJECTIVES FOR GRANTEES

Under the program, SIDS projects are encouraged to establish case management systems and help assure that:

--Autopsies are performed on all infants who die suddenly and unexpectedly. (Identification)

--SIDS is recorded on the death certificate when appropriate as the official cause of death. (Certification)

--Families of SIDS victims are promptly notified of the cause of the death. (Notification)

--Families are provided additional information and counseling regarding SIDS by knowledgeable persons. (Information and Counseling)

In addition to establishing case management systems which address these four objectives (referred to as the SIDS four-point case management program which was originally developed by the Foundation and subsequently adopted by HHS), projects are to assure that the public and other groups, such as funeral directors, the clergy, firefighters, police, and emergency service personnel, who might have occasion to come

into direct contact with SIDS victims and their families, receive adequate education and training regarding SIDS. Also, each project must have appropriate community representation in developing and operating its activities and collect information on SIDS cases, including case management data.

PROJECTS' CASE MANAGEMENT PERFORMANCE VARIED

As discussed on page 8, we conducted detailed reviews of 365 cases managed by 11 projects to determine the extent to which they were accomplishing the objectives of the SIDS four-point case management program. Conclusive determinations on project performance were difficult to make because HHS' guidance to grantees for individual elements of the case management program is often discussed in terms of goals rather than requirements. This is because HHS recognizes that the projects often must rely on the cooperation of several parties, such as medical examiners or coroners, for prompt notification of SIDS deaths and public health nurses for visiting SIDS victims' families.

In most instances, projects had not established specific goals and objectives by which their case management performance could be measured. Nor had HHS established specific performance standards against which grantees could be evaluated. In addition, our sample cases contained many instances where grantees lacked the documentation needed to identify when individual events related to the four-point program took place.

A discussion of our analysis of sampled cases as they relate to the SIDS four-point case management program follows.

Identification

HHS encourages grantees to assure that autopsies are conducted on suspected SIDS victims within 24 hours after their deaths. Our review of 365 cases at the 11 selected projects showed that autopsies were performed in at least 348 (or 95 percent) of these cases. Autopsies were not performed in eight cases, and we could not determine whether they were performed in the other nine cases. Data were not available in project files indicating the timeliness with which autopsies were performed in 82 of the 348 cases.

In 266 cases where information was available indicating the timeliness of autopsies, they were performed within 24 hours of death, as HHS desires, in 234 cases (or 88 percent), and an additional 19 autopsies were performed within 2 days of the infants' deaths. The other 13 were performed more than 2 days after the infants' deaths.

To the extent possible, based on data available at the projects, we analyzed each project's performance as it related to the identification element of the SIDS four-point case management program. All of the projects met HHS' 24-hour guideline 1/ for timeliness of autopsies, or failed to meet the guideline by not more than 1 day, in at least 80 percent of the cases for which timeliness data were available.

Although most project staff believed they were properly identifying SIDS cases, our review showed that 5 of the 11 projects lacked mechanisms to review all infant death certificates for SIDS cases. Aside from receiving information from medical examiners or coroners, projects can identify SIDS cases by reviewing infant death certificates or autopsy reports. This can also help identify SIDS cases for which medical examiners or coroners fail to notify projects. However, several projects did not or could not review death certificates at all or at the time the certificates were completed. For example, Maryland project staff said that they did not have access to death certificates because of State confidentiality restrictions. According to one of its directors, the Missouri project did not review all infant death certificates for deaths occurring outside the St. Louis area as the certificates were completed because the State Division of Health did not provide it with information on all infant deaths until after the end of the year.

Certification

SIDS was generally recorded as the cause of death, when appropriate, on victims' death certificates for the cases we

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1/Draft SIDS program guidelines were issued in February 1976. Although these guidelines never were formally approved by HHS, the SIDS Program Office considers them to be in effect and expects the projects to follow them.

reviewed. 1/ Projects helped facilitate this by, in some cases, paying for autopsy-related expenses for suspected SIDS victims and by meeting with medical examiners, coroners, or others to encourage recording SIDS on death certificates when appropriate.

SIDS was listed as the official cause of death in 330 of the 365 sampled cases we reviewed. Project files lacked documentation of the cause of death in 26 cases (13 in California). In the other nine cases, other official causes of death were listed or the cause of death had not yet been reported.

Notification

Activities relating to notification of victims' families that SIDS was the official cause of an infant's death are important to bereaved families, since they are assured that the death was not a result of lack of care or any medical condition which the family could have been aware of or prevented.

HHS regulations (42 C.F.R. 51a.505(a)(6)) require grantees to arrange for or provide prompt notification to SIDS victims' families and state that such notification should occur, where possible, within 24 hours of the diagnosis of cause of death.

Our review of the 365 sampled cases showed that victims' families were notified of the cause of their infants' deaths in at least 331 cases (91 percent). However, of 259 cases where information was available to show both whether and when victims' families were notified, 129 cases (50 percent) indicated that families were notified within 2 days of infants' deaths. In 60 cases, families were notified between 2 and 7 days, and in 65 cases, families were notified more than 7 days after the victims' deaths. Project files, as of the date we reviewed them, indicated that in 5 cases, families had not been notified of the cause of the infants' death.

1/In Maryland we reviewed the medical examiner's certificate which is used to prepare the official death certificate. Our review did not include an evaluation of all infant death certificates or an assessment of whether all SIDS deaths occurring in projects' service areas were being properly identified.

Information was not available to show the timeliness with which families were notified in 106 (or 29 percent) of the 365 cases sampled. The 106 included 77 for which timeliness data were not available and 29 for which notification information was not available. Case files in California, Missouri, and Florida projects accounted for 87 of the 106 cases with missing notification data.

Projects' performance in notifying victims' families varied widely, as shown in the following table.

Frequency with Which Projects Met HHS Timeliness Guidelines for Notification of Victims' Families

Percent of sampled cases (note a)	Within 2 days of death (HHS criteria)	Within 7 days of death
	(Number of projects)	
Less than 50	4	1
50-75	3	2
76-100	3	7

a/Includes only cases where information was available to determine the timeliness of notification activities. Sampled cases in the Florida project contained so little data regarding the timeliness of family notification that we could not assess the project's performance.

Two reasons for delays in parent notification were failure of the medical examiner, coroner, or other officials to promptly notify projects of SIDS cases or refusal of some medical examiners to authorize the project to notify the parents until special laboratory studies were completed. Such studies can take several days or weeks.

For example, in the Dallas project some delays in notifying families of SIDS victims who lived outside Dallas County were due to the failure of an official from those areas to promptly inform the project about the deaths. As another example, the Maryland medical examiner's office would not permit the project to contact SIDS victims' families for 6 of the 30 cases we reviewed until special laboratory studies were completed. These studies were completed 12 to 30 days after death. The medical examiner's office believed that these

studies were necessary to confirm the cause of death and considered the cases to be pending until the laboratory studies were completed. Maryland project staff told us that they were aware of this situation for some time and had been working with the medical examiner's office to determine whether counseling should be offered on a case-by-case basis. They said that a formal procedure for routinely handling pending cases was established in April 1980. 1/

Counseling

Professionals in the SIDS area have varying opinions as to the optimum time lapse which should occur between an infant's death and the counseling of SIDS victims' families. HHS' program guidance to grantees states that, if possible, counseling should occur within 1 to 2 weeks following an infant's death.

Information on counseling was available in 342 of the 365 case files we reviewed. The files showed that families were counseled in 261 (or 76 percent) of the 342 cases. Reasons for counseling not being provided in the other 81 cases included

--projects could not locate SIDS victims' families (35 cases);

--families refused counseling (30 cases); and

--other reasons, such as counseling services were not available where victims' families lived, or the project found out about the case too late for counseling to be considered appropriate (16 cases).

Grantees in Maryland; Maywood and Springfield, Illinois; Houston, Texas; California; and Florida had particular difficulty in counseling victims' families for the reasons noted above.

1/According to HHS' SIDS program director, HHS expects projects to contact families to help them deal with the sudden deaths of their infants in cases where SIDS is suspected, but additional studies are needed to confirm the cause of death.

We could not determine from the project files when counseling occurred in 42 of the 261 cases. For the other 219 cases, counseling was performed

--within 14 days of death in 135 cases (62 percent),

--between 15 and 28 days of death in 52 cases (24 percent), and

--after the 28th day of death in 32 cases (15 percent).

Our analysis of the timeliness with which projects counseled victims' families showed that their performance varied widely as it did in the notification program element. The following table summarizes this analysis.

Frequency with Which Projects Met HHS' Timeliness Guidelines for Counseling Victims' Families

Percent of sampled cases (note a)	Within 14 days of death (HHS criteria)	Within 28 days of death
	(Number of projects)	
Less than 50	5	0
50 to 75	2	3
76 to 100	4	8

a/Includes the 219 cases where information was available to determine the timeliness of counseling activities.

Several reasons account for SIDS victims' families not receiving counseling within HHS' desired time frames:

--The failure of coroners or medical examiners to promptly notify the project or public health departments about SIDS deaths. (See p. 15.)

--The inability of project staff or public health nurses to promptly locate or contact families to arrange for a home visit.

--The time needed to send SIDS case information to the organization responsible for making home visits.

Reasons for the projects' lack of information on whether or when counseling occurred include the failure of (1) projects' to routinely collect this information and (2) some public health departments to report counseling visits to the projects or to report them promptly. Most projects lacked the information necessary to determine if or when counseling or other components of the SIDS four-point case management program occurred. In several cases, such as in Missouri and Nebraska, project staff told us that they did not routinely collect case management information because they have not received specific instructions from HHS on the information to collect.

In addition, projects do not always receive the full cooperation from public health nurses who often are relied upon to perform home visits and submit reports of these visits to them. For example, public health nurses in some areas served by the projects in Missouri, Dallas, and California did not always submit reports of their visits to SIDS victims' families or did not always send them promptly.

When we began our fieldwork, five projects did not have adequate followup procedures to assure counseling was provided in all cases. 1/ During our review, representatives from two of these projects--Springfield, Illinois, and Loyola University--told us that they were establishing or improving followup systems.

FAMILIES' PERCEPTION OF PROJECTS' INFORMATION AND COUNSELING SERVICE

We talked with 82 SIDS victims' families to determine whether they believed the information and counseling they received, under the auspices of the projects, were helpful to them. Of these families: 2/

1/These projects were Springfield and Loyola, Illinois; California; Missouri (for areas outside of St. Louis); and Dallas, Texas.

2/We were unable to locate any families served by the Nebraska project.

--74 said the information they received was helpful.

--36 said the counseling service provided was helpful.

--9 said the counseling service was not helpful, and 19 said they had refused counseling services.

--18 indicated they were not offered or did not receive counseling services. (These included eight families who said that they wanted counseling.)

In summary, most families we contacted found the information they received to be helpful. Of those who accepted counseling services, most said it, too, was helpful. Others did not believe such counseling was necessary because they were supported by other parties. Most families with whom we spoke were reassured to know that a program such as the SIDS program existed and that help was available if they needed it.

Of the 82 family representatives we talked to, 22 said they had accepted assistance from other parents or voluntary groups, such as the Guild or the Foundation. Eighteen of these families believed that this assistance helped them.

In a few cases, family members identified problems they perceived with the program. For example, seven parents from five projects said that the persons who visited them came too late to be very helpful. (Five of the seven family members were included in our case sample, and of the five, project records showed that four were visited within 12 days of the date their infants died; one was visited 65 days after this date.)

PROJECTS ARE TRAINING COMMUNITY GROUPS

In addition to implementing the four-point program, projects are required to assure that community group resources receive training on SIDS-related matters. Groups to be trained include, but are not limited to, coroners, medical examiners, police, firefighters, funeral directors, ambulance attendants, emergency medical technicians, voluntary organizations, and public health nurses.

Grantees were training various groups at each project we visited. Representatives of groups we contacted at each project found the training helpful in treating SIDS families. For example, during fiscal year 1979, the St. Louis project conducted 54 training programs. Groups this project trained most frequently included nursing students, community or public health nurses, police cadets, and emergency room staffs. According to an official of the St. Louis medical examiner's office, almost all of the new police officers in the city and St. Louis County have received SIDS training. The director of the State fire school said the SIDS project presents a program three or four times a year for new emergency medical technicians and firefighters. He also said that the program has been very helpful.

APPROPRIATE ROLE OF VOLUNTARY GROUPS NEEDS TO BE CLARIFIED

The appropriate role of volunteer groups as it relates to SIDS project activities has been the subject of controversy between project officials and voluntary groups. This controversy has centered essentially on two issues:

--The extent to which voluntary groups should influence project activities through their involvement in project advisory councils.

--The manner and extent to which voluntary group members should participate in counseling SIDS victims' families.

Much of this controversy results from differing interpretations of HHS' regulations by project staff and voluntary group members.

Project community councils

Public Law 96-142 requires that each SIDS grant applicant provide for "appropriate" community representation (including involvement of voluntary groups with a demonstrated interest in SIDS) in developing and operating its project. SIDS program regulations (42 C.F.R. 51a.506) require that each grantee establish a community council consisting of between 9 and 15 members. At least one-third of the members are to be representatives of the community being served, including representatives of parents' groups or other voluntary civic or community organizations. The councils are to meet at least six times a year. The role of the councils is to advise and discuss with project staff project performance and functions.

During our visits to the 11 projects and through discussions with 63 members of their community councils, we found that:

--Generally, the projects had the required community representation on the councils. Most councils met at least five times during recent 12-month periods preceding our visits. One project council, however, had held only one meeting.

--Most project council members with whom we talked believed they had sufficient input into project functions.

--Several Guild or Foundation group members of councils said that they had not had sufficient influence over the projects' activities. Some Foundation representatives believed that they should have more direct control over project activities.

Of the 63 community council members we interviewed, 17 were either Foundation or Guild members. Of the 17, 7 from five projects were not satisfied with their involvement in project activities. Although the extent of community group involvement varied among the projects, we believe that Guild and Foundation representatives did have the opportunity to consult with or advise projects. Following are two examples that illustrate the level of satisfaction council members had with their input to project activities.

Nebraska

As of May 1, 1980, the Nebraska project's community council consisted of 12 members, including 3 representatives from the Foundation's Nebraska chapter. We interviewed two of the Foundation's three representatives on the council as well as three other council members who were professionals concerned with SIDS.

One of the Foundation council members indicated that the council had sufficient input into project activities. The other Foundation council member said that she had only limited input. She indicated that the Foundation would like more control over project activities by being able to nominate all the candidates for the community council. Also, she said that she did not support the selection of two new parents who

were being added to the council because they were not active in the Foundation and would not present the perspective she wanted.

The other three council members we interviewed indicated that they were satisfied with their involvement in project activities and that the council as a whole has influence over the project. For example, one said that in his view the project staff treated the council as though it ran the project.

Dallas

As of May 1980, the Dallas project's community council consisted of 15 members. Of the 15, we interviewed 2 Guild members, a parent of a SIDS victim, and 3 professionals concerned with SIDS. In addition, we interviewed a member of a local Foundation chapter that was inactive at the time of our fieldwork; she was not, however, a member of the project's council. The parent and the professional members we interviewed were satisfied with their roles on the council and their involvement in the project. For example, the parent said that she helps project staff visit families and conduct training programs. The Foundation representative said that her chapter, when it was active, had a good working relationship with the project. The two Guild council members were dissatisfied because of problems they were having obtaining the names of SIDS victims' families without the families' consent.

Use of parents for counseling

SIDS program regulations (42 C.F.R. 51a.505) require projects to offer counseling services to families affected by SIDS through persons who are qualified by training and experience. These persons include project personnel and, as necessary or appropriate to meet the families' needs, other counseling resources within the community. Further, the regulations require that projects have mechanisms to refer families affected by SIDS to other official and voluntary resources, including organized parents' groups. On the other hand, the regulations (42 C.F.R. 51a.511) provide that projects must treat victims' families personal information as confidential and must not release such information without the person's consent except as otherwise authorized by law or necessary to provide services.

Each of the 11 projects visited had arrangements to provide SIDS victims' families with referrals to other SIDS parents, either through arrangements with organized voluntary groups concerned with SIDS or individual parents. However, voluntary groups at three projects--Loyola, Dallas, and Maryland--believed that they were not given adequate opportunities to provide counseling.

A major issue is the voluntary groups' complaints that the projects will not routinely provide them with the names of SIDS cases. The projects, in accordance with SIDS program regulations or other confidentiality requirements, have refused to provide the names unless the family of the SIDS victim gives permission. In Maryland and Dallas, information can be obtained from the medical examiners' offices. However, voluntary groups were not satisfied with this arrangement because they wanted the names sent or telephoned to them.

Representatives from two Foundation chapters in the Chicago area expressed dissatisfaction with the opportunities the Loyola project has given them to counsel parents. For example, one of the representatives believed that public health nurses were not informing SIDS victims' families about the Foundation and that, when the project makes a referral, it does so only after the nurse contacts the family.

The Loyola project director stated that in accordance with HHS' regulations he cannot release the names of SIDS victims' families to the Foundation chapters without the families' permission. He added that public health nurses who visit families are expected to ask the families if they would like to talk to other parents of SIDS victims. The nurses are expected to indicate the families' preference on the home visit report they submit to the project. Project staff said that, if the family wants to talk to another SIDS parent, the project refers the family to the Foundation.

Two projects we visited relied on SIDS parents' groups to provide counseling in some areas, which was not always provided. The California project was relying on the Foundation's San Diego chapter to provide such counseling. According to the chapter president, the chapter did not reach all population segments, such as low-income groups. At the time we completed our fieldwork, the project and the chapter were taking steps to help correct these problems.

According to a representative from the Kansas City Health Department, his agency did not begin counseling SIDS victims' families until January 1980. He said he had understood that the local Foundation chapter was handling SIDS cases, but later learned it was not very active and had neglected many cases. Consequently, the health department began providing counseling services.

In discussing these problems, the SIDS program director agreed that additional HHS guidance on appropriate community involvement of SIDS parents' groups in the development and operation of projects is needed, in terms of both project and voluntary groups' roles and responsibilities. She said that HHS expects the community councils to be advisory and expects SIDS projects to follow Federal, State, and other confidentiality requirements on the release of names of SIDS cases. Further, she said that projects should not release the names of SIDS victims or their families without parental permission unless this is necessary in their professional judgments to (1) provide services when the projects cannot locate families or (2) handle or prevent an emergency, such as a potential suicide. Also, since January 1977, the National SIDS Foundation has also had a formal policy supporting the privacy and confidentiality of SIDS victims' families.

In commenting on a draft of this report (see app. V) HHS said that it is in the process of developing guidance on appropriate involvement of community groups in project activities and that this guidance will be implemented in fiscal year 1982.

CHAPTER 3

IMPROVEMENTS NEEDED IN GRANT AWARD AND ADMINISTRATION

The SIDS Program Office generally followed the policies and procedures established within HSA to ensure that grants were awarded on a competitive and objective basis. However, HHS (1) awarded excessive funds to several projects in years after their initial grant award, (2) did not provide grantees sufficient guidance material for several aspects of SIDS program operations, and (3) did not adequately monitor grantee performance. Federal SIDS grant funds that could have been used to initiate other SIDS programs sat idle. Also, several grantees were not complying with program requirements or established guidelines, and HHS lacked assurance that SIDS programs were being carried out effectively.

To correct these problems, HHS needs to improve the funding allocation process for SIDS program grantees, expedite development and issuance of guidelines on several aspects of program operations, and strengthen monitoring of grantee compliance with program requirements and guidelines.

SOLICITATION, REVIEW, AND APPROVAL OF GRANT APPLICATIONS

During fiscal years 1978 and 1979, the SIDS Program Office generally followed HHS' established policies and procedures governing the solicitation and approval of SIDS grant applications. With the exception of one grant application, the office followed the recommended funding priorities set by grant review panels established to objectively evaluate grant applications. In all but 2 of 14 grant awards that we reviewed in detail, the office followed up on application deficiencies identified by review panels. According to the SIDS program director, the exceptions were due to oversight.

HHS grant award requirements and procedures

HHS policies and procedures governing the award of SIDS project grants are contained in several documents. These include the Public Health Service's supplemental chapters to the HHS Grants Administration Manual and the SIDS program

regulations, program guidelines, and the SIDS Program Objective Review Procedures. These documents set forth specific policies and procedures in such areas as the solicitation of competing grant applications, objective review of applications, and assurances that applicants can effectively carry out their responsibilities.

To maximize competition in SIDS grant solicitation, HHS is to publish information in the "Federal Register" announcing its solicitation of grant applications. To assure objectivity in the application review process, the SIDS Program Office, with OMCH approval, is to establish an objective review panel to evaluate and rate each application in accordance with established criteria. At least half of the panel members must be from outside BCHS. All circumstances must be avoided that might involve a conflict of interest, the appearance of such a conflict, bias, or prejudice by panel members.

Review panel members evaluate assigned applications; comment on funding levels; vote on whether to recommend approval, disapproval, or deferral; and individually give a numerical score to each application recommended for approval. The SIDS Program Office tabulates the panel members' numerical scores and ranks the applicants. This ranking and results of the panel's vote on approval, disapproval, or deferral serve as a recommendation to the SIDS Program Office. If applicants are not funded in accordance with the panel's recommendations and the ranking, the SIDS Program Office is to document the reasons for the deviation.

The SIDS Program Office relies heavily on the grant application review panels to assure that applicants are representative of and responsive to the needs of SIDS parents in the community and that the applicants can effectively carry out their responsibilities. Review panel members are to use their judgment in evaluating and rating individual SIDS program elements to be addressed in applications. The panels use the following major criteria: (1) definition of the problem in the service area, (2) definition of goals and objectives, (3) project organization and budget, (4) identification of SIDS cases, (5) information and counseling services, and (6) informational and educational activities. Applicants seeking a renewal or continuation grant must also submit a performance report comparing accomplishments to the goals established.

One of the specific items panel members are to look for is letters of endorsement from community organizations, including parent volunteer group organizations. Applicants are also required to identify the anticipated membership of the project's community council, at least one-third of which must be representative of the community being served, including representatives of parent volunteer groups. Existing grantees must also submit copies of minutes of council meetings.

Policies and practices on types of grantees and geographic service areas

SIDS program regulations (42 C.F.R. 51a.503(a)) state that any public or nonprofit private entity is eligible to apply for a SIDS project grant. Program guidelines provide that each applicant define its proposed service area. The SIDS Program Office has not developed or implemented a formal policy that limits grant eligibility to certain types of organizations or organizations proposing to serve a specified geographic area, such as an entire State. The office prefers to work through State health departments for statewide projects--as long as they are willing and able to effectively implement SIDS programs--and encourages such applications. However, regardless of whether the applicant is a State health department, the office generally relies on grant review panels to evaluate the merits of each new or competing continuation application and follows the panel's recommendations.

Types of organizations applying for and receiving grants

During fiscal years 1978-80, HHS received 122 applications from various types of organizations for SIDS counseling and information project grants. Of these, 113 (or 93 percent) were approved and 109 (or 89 percent) were funded. As the following table shows, health departments constituted most of the SIDS project grantees, but several other types of organizations have also been approved and funded.

Disposition of SIDS Grant Applications

	Fiscal year		
	1978	1979	1980
Approved and funded:			
State health department	18	21	26
City or county health department	2	2	1
University or hospital	10	11	12
Medical association	2	2	2
Regional maternal and child health council	1	1	1
Total	a/33	37	42
Approved but not funded:			
State health department	-	3	-
University or hospital	-	1	-
Total	-	4	-
Disapproved:			
State health department	1	-	-
County health department	1	-	-
University or hospital	2	1	1
Private foundation	2	-	-
Funeral director	-	-	1
Total	6	1	2
Total applications received	39	42	44

a/Includes three applications approved in fiscal year 1977 but not funded until fiscal year 1978.

Service areas

Of the 37 projects funded during 1979, 28 were statewide projects. In both New York and Texas, HHS awarded three grants for separate service areas within the States; in Alabama, one project served part of the State; and in Illinois, two grantees served separate areas but together served the entire State. One of these, the Loyola project served one county in Indiana

in addition to nine counties in Illinois. Although multistate projects are acceptable, the SIDS Program Office does not encourage them because of problems projects would have in dealing with different political jurisdictions.

HHS has received more than one application to provide services to the same geographic area only three times. On one occasion in 1975, both a children's hospital and the State health department applied to provide services for the entire State of Nebraska. The panel approved and HHS funded both. HHS did not reapprove either in 1976 because the hospital and the health department could not work together cooperatively. HHS' award of two grants for Nebraska appears questionable because HHS did not require the two grantees to specifically identify separate areas within the State of Nebraska. Also, the combined funding--about $135,000--seems excessive in relation to the estimated 50 SIDS deaths in Nebraska, even though the children's hospital was also to serve residents in several Iowa counties.

Grant review panels established and used as required

During 1978-80, HHS convened panels of 9 to 12 voting members to evaluate applications. It assured that various disciplines were represented and that volunteer groups participated. Represented on the panel were persons with a professional interest in SIDS, such as doctors, public health nurses, medical examiners, coroners, funeral directors, police officers, firefighters, social workers, and employees of SIDS projects; parent volunteer group members, and BCHS and other HHS officials. The composition of the SIDS grant review panels for 1978-80 follows:

Panel member affiliation	Number of panel members 1978	1979	1980
Persons with professional interest in SIDS	7	6	3
Parent volunteer group members	2	2	2
BCHS staff	2	1	2
Other HHS staff	1	1	2
	12	10	9

Our interviews with 11 members of the 1979 and 1980 panels showed that panel members (1) believed that they were given sufficient information to evaluate and rank the applications, (2) were generally satisfied with the overall results of the review process, and (3) did not believe HHS attempted to influence their decisions. 1/ Some panel members stated that they found applications difficult to review because they were unstructured, too lengthy, and/or incomplete.

Our review confirmed the panel members' comments. HHS gives prospective grantees extensive instructions on information to include in their grant applications; however, it has not established a standard format for the narrative part of the applications. As a result, applications are voluminous and information is often not organized consistently. Some applications contain several hundred pages and either include essential information throughout the application or exclude it altogether. A standard application format for the narrative part of grant applications or additional guidance for applicants could reduce the time needed to review applications, could make it easier to determine whether the application contains essential information, and should help ensure that applicants address all essential requirements. In commenting on a draft of this report, HHS said that it agreed that additional guidance to SIDS grant applicants should be prepared.

Established procedures generally followed

We reviewed all 78 SIDS program grant applications received in fiscal years 1978 and 1979 to determine whether the SIDS Program Office (1) followed review panel recommendations on approval or disapproval and (2) funded applicants according to panels' rankings. Twenty-four of the 78 applications were for noncompeting continuation grants and, therefore, were not subject to panel review. The office followed review panel recommendations on approval or disapproval for all of the other 54 applications which were for new or competing continuation grants. Except in one instance, the office followed the panel recommendations regarding the ranking of approved applicants in determining priorities for

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1/The 11 members interviewed included 4 voluntary group members, 5 persons with a professional interest in SIDS, and 2 HHS staff, 1 of which was from BCHS.

funding. Also, in all but 2 of 14 grant awards that we evaluated further, the office followed up on application deficiencies identified by review panels.

In 1979, both the Oklahoma and Idaho projects were funded and Oregon was not, even though it was approved and received a higher ranking by the panel. Also, the Alabama project received a higher ranking than Idaho. HHS' SIDS program director said she gave Oklahoma a higher priority because it had applied for funds in 1978 and had been disapproved. Idaho was funded ahead of Oregon and Alabama because Idaho had requested only about $15,000, and it did not appear as though sufficient funds were available for the Oregon or the Alabama project, which had requested a substantially higher amount. However, the SIDS program director overlooked documenting the reasons for not following the panel's ranking, as required.

We further evaluated 14 of the 70 grant awards made during fiscal years 1978 and 1979 to determine whether panel members were identifying problems and whether the SIDS Program Office was following up on the problems identified. 1/

Panel members identified numerous problems and raised many questions on various aspects of the applications reviewed, using review criteria established by the SIDS Program Office. The table on the following page summarizes the frequency with which panel members raised questions or identified problems with selected aspects of applications for the 14 grant awards we reviewed.

The SIDS Program Office failed to follow up and assure that 2 of the 14 applicants provided written responses to questions raised or requests for additional information sought by the panel. According to SIDS Program Office staff, this resulted from oversight.

1/The 14 grant awards we reviewed more extensively included those for the 11 projects visited and 3 additional first-time awards made by HHS.

Program element on which questions were raised	Number of applications on which questions were raised
Advisory council	11
Counseling services/referrals	11
Project organization/staff including letters of endorsement from community groups	10
Plan for continuing after Federal funds cease (note a)	9
Identification of cases/autopsies, notify parents	9
Informational and educational activities	7
Plan to monitor quality of services	6
Plan for evaluation of program effectiveness	5

a/HHS expects projects to develop plans for continuing operations after Federal funding ends, although SIDS authorizing legislation does not specify that the SIDS program is a "seed" money program. (See p. 63.)

Failure of an applicant to meet all requirements does not necessarily preclude it from receiving an award. For example, in 1980, the grant review panel noted that Nebraska's application lacked a letter of support from the Foundation chapter in that State and recommended that HHS request the applicant to provide one. Although the Program Office requested such a letter from the Nebraska project, it did not expect to receive one because of conflicts between the project and the Foundation chapter, which had made several complaints about the project. The SIDS program director said that she did not recommend disapproval of Nebraska's application on this point because the review panel evaluated the project's overall plan and program and believed the project merited approval.

IMPROVEMENTS NEEDED IN FUNDING ALLOCATION PROCESS

The SIDS Program Office has not developed sufficient criteria or guidelines for judging the appropriate funding levels for SIDS projects. Consequently, it is difficult to

determine conclusively whether grantees are appropriately funded. However, some projects may be receiving excessive funding in relation to the number of SIDS cases in their service areas and the funding received by other projects having similar numbers of SIDS cases.

Many projects did not use all of the funds granted to them in fiscal year 1978 and before. HHS did not adequately consider this factor when it refunded those projects in fiscal year 1979, thereby compounding the overfunding of those projects while other approved projects remained unfunded.

Additional guidance or criteria on grant amounts needed

SIDS program regulations (42 C.F.R. 51a.507) provide that grant awards will be based on HHS' estimate of the amount necessary for proper performance. With the exceptions of costs for autopsy-related activities (up to $350 per autopsy), and costs for public health nursing home visits, the SIDS Program Office has not established guidelines or criteria for making such an estimate. SIDS Program Office staff and grant review panel members use their judgment in recommending funding levels for other activities. In some instances, the office believes it must adhere to reimbursement policies established by applicants. For example, indirect costs are reimbursed at an established rate.

Projects serving small geographic areas or areas with a low incidence of SIDS sometimes received larger grants than projects responsible for more cases or a larger service area. For example, during 1979 the Springfield, Illinois, SIDS project received about $48,500 to serve an estimated 114 families in an area of 50,000 square miles. The Maryland SIDS project received $107,500, or more than twice as much, to serve an estimated 112 families in an area of 11,000 square miles. The New York City project received about $125,500 to serve an estimated 212 SIDS families, while the Stony Brook project, also in New York, received almost as much, $110,000, to serve an estimated 59 families. California received about $166,500 to serve an estimated 758 families. (The estimated number of families to be served is based on 2 SIDS deaths for every 1,000 live births.)

We recognize that determining the proper amount of funding for grantees is complicated and that such a determination must consider a number of factors. These include the extent to which services are already in place; the type of death investigation system to be used; the degree of coordination from medical examiners, coroners, counselors, and others; the size of the service area; the amount of non-Federal funding available; and program effectiveness. Our review did not include an assessment of all these factors. We believe, however, that HHS needs to reevaluate the relative project funding levels to determine their reasonableness, particularly with respect to the number of estimated SIDS cases and the size of the areas to be served.

The SIDS program director said that she plans to evaluate SIDS project funding in relation to several factors, including the longevity of the project, size of the service area, other available resources, and number of cases in the service area. She said that she will recommend that BCHS take appropriate action based on her findings.

Unspent funds available for use

Since fiscal year 1975, SIDS grantees, in the aggregate, have consistently been unable to use the entire amounts of their project grants. Grantees funded in fiscal years 1975-78 annually did not spend between 10 and 35 percent of their approved budgets. (Expenditure reports for budgets approved in 1979 were not available during our fieldwork.) For example, of 33 grantees funded in fiscal year 1978, 28 previously funded grantees did not spend about $470,200 (or 19 percent) of their approved budgets of over $2.4 million. Also, five new grantees did not spend about $171,500 (or 58 percent) of their approved budgets of $295,000. Staffs at 6 of the 11 projects we visited attributed their lack of use of funds primarily to their inability to hire staff. They said that they either could not locate appropriate persons or faced hiring freezes.

During fiscal years 1976-78, the SIDS Program Office offset a major portion of the grantees' previously unobligated funds against their requests for refunding, thereby freeing other funds for use as needed. However, in 1979, HHS did not adequately track grantees' use of the previous years' funds and failed to apply substantial unused funds to the next period's grant awards.

HHS regulations (45 C.F.R. 74.108) governing grant administration require grantees to either (1) report promptly when a grant is expected to exceed needs by more than $5,000 or 5 percent of the grant, whichever is greater, or (2) include an estimate of expected unused funds in their applications for the next period's funding. Public Health Service instructions to SIDS grantees also require them to estimate unobligated funds in their applications for continuing grants, which are due about 3 months before the end of the budget period. SIDS grantees are further required to submit a financial status report showing actual unused funds within 3 months after the end of their budget year.

Of the 33 applications for continuing grants in 1979, 10 did not contain an estimate of anticipated unused funds from the previous grant year, and 23 reported estimated unused funds totaling $366,000. HHS offset against grantees' next year's (fiscal year 1979) funding only $142,000 of the $749,000 SIDS grantees actually did not spend. BCHS instructed grantees to carry over the remaining $607,000 in their accounts during the next year, and told them that these funds were not available for rebudgeting but could be applied to their fiscal year 1980 funding. The funds, therefore, remained unused in the grantee accounts for 2 years.

Representatives from BCHS' Grants Management Branch told us that in 1979 they discontinued (1) enforcing the requirement that grantees report their estimated unused funds and (2) offsetting reported estimates against the next period's grant awards. The branch discontinued these practices because of differences between estimated and actual unused funds from previous years. They said that they wanted to ensure that grantees would not have insufficient funds if their estimates of unspent funds were overstated. The SIDS program director told us that she had not realized such a substantial amount had not been applied to the next year's funding.

During 1979 HHS approved four applications totaling $307,000 that were not funded because the Program Office was unaware that funds were available. In addition, one prospective applicant said it refrained from applying because it did not believe sufficient funds would be available.

HHS NEEDS TO PROVIDE BETTER PROGRAM GUIDANCE TO GRANTEES AND TO IMPROVE ITS EVALUATIONS OF THEIR PERFORMANCE

SIDS projects were not always complying with program requirements or were having difficulty carrying out their responsibilities. The SIDS Program Office's ability to effectively evaluate grantees' performance has been hindered by several problems. These include the:

--Lack of specific, measurable goals and objectives for individual grantees.

--Failure of grantees to collect or report necessary program data.

--SIDS Program Office's (1) lack of staff and travel funds to conduct adequate site visits, (2) lack of approval to require periodic reporting by grantees, and (3) failure to see that annual project performance reports contain sufficient information and that projects conduct required self-evaluations.

To help resolve these problems, HHS needs to issue additional program guidance in a number of areas, provide for more systematic monitoring of grantees' performance, assure that grantees comply with regulations and instructions, and where possible, assist projects having difficulty gaining cooperation from health departments, coroners, medical examiners, or others.

More specific, measurable objectives needed for projects

SIDS program regulations (42 C.F.R. 51a.514(a)) require grantees to establish goals and compare accomplishments to them, and the SIDS Program Office expects applicants and grantees to develop objectives to be accomplished within specified time frames. However, the office has neither developed specific guidance defining those aspects of program operations for which measurable objectives are required nor insisted that applications contain measurable objectives in important program areas, such as the SIDS four-point case management program. Consequently, many applicants have not developed such objectives, making HHS' evaluation of their performance difficult.

Of the 11 projects we visited, only 2 presented quantifiable goals and objectives and methods and time frames for accomplishing them. For example, the Springfield, Illinois, project's fiscal year 1981 application states:

--60 percent of the deaths are reported to the project within 5 days (there are no time frame goals for the other 40 percent).

--99 percent of the infants dying of SIDS are autopsied.

--100 percent of the cases have SIDS on the death certificate.

--90 percent of the victims' families are notified of autopsy results within 30 days.

--100 percent of the victims' families will be offered counseling.

--90 percent of the groups likely to respond first to families' calls for assistance will be trained to describe at least eight characteristics of a humane, professional approach to SIDS families.

Although the Springfield project presented goals and objectives in measurable terms, its goals did not always comply with HHS requirements for performance. For example, SIDS program regulations provide for notifying victims' families of autopsy results within 24 hours, if possible, not 30 days.

Goals or objectives developed by other projects we visited were often not stated in measurable terms or were stated in such general terms that their attainment would be difficult to measure. For example, one of the goals/objectives in the Stony Brook project's 1979 application was to increase the awareness and sensitivity of the general public to alleviate misconceptions about SIDS. In commenting on a draft of this report, the Stony Brook project director said that the project does evaluate its activities but that he agrees with the need to establish more measurable objectives.

To assure that projects develop goals and objectives that can be used to measure accomplishments and that are within its expectations, HHS should establish guidelines outlining those aspects of program operations requiring specific, measurable

goals and objectives. Also, HHS should specify minimum performance standards for critical program areas, particularly for projects not considered to be in a startup phase.

Problems in the collection and use of data

SIDS program regulations (42 C.F.R. 51a.505(a)(9) and (10)) require projects to collect demographic, epidemiological, and case management data for SIDS cases in their areas and to provide these data to appropriate public officials and interested members of the public. SIDS program guidelines define several specific kinds of data grantees' should collect, including death investigation data, characteristics of SIDS victims, and data on information, educational, and counseling activities.

As discussed in chapter 2 (see p. 10), most projects we visited were not collecting case management data necessary to determine whether they were meeting all program requirements.

On the other hand, several projects were collecting considerable epidemiological and other SIDS-related data that were apparently not being used. Although the SIDS Program Office has provided guidance to projects on the type of data to collect, it has not assured that they collect case management data necessary to evaluate their performance, nor has it told them what to do with the epidemiological and demographic data they collect.

The California project illustrates the problem. The data collection form developed by the project for use by public health nurses does not request sufficient information on the timeliness of services. On the other hand, the form requests information which (1) project personnel believe is unneeded, (2) is unused, and (3) takes time to complete. The project was experiencing significant problems persuading county health departments to submit or fully complete these forms. Project officials said they intend to eliminate the unneeded questions on the form.

Quarterly statistical reports

In 1976, BCHS developed a quarterly statistical reporting format which it expected all SIDS grantees would use to report their projects' activities. The proposed reporting format was

designed to gather data on SIDS cases and on project educational activities. However, SIDS program staff could not initially obtain clearance from the Public Health Service for using the reports. The SIDS program staff finally resolved the Public Health Service's objection to the frequency with which projects would have to submit the reports. However, the staff discontinued efforts to secure HHS' formal approval for reports because of uncertainty over how long the SIDS program itself would be continued and because, according to the SIDS program director, the SIDS reporting system was not considered a high priority within HHS.

Although some projects voluntarily submit these reports, the SIDS program director said that she does not have adequate staff to systematically and routinely analyze reports that are submitted. However, she added that the reports are used to help plan site visits, assess potential problem areas, and determine the progress of individual projects.

Uniform reporting system

Public Law 96-142 requires HHS to develop and implement a system for periodic reporting and dissemination of information collected under SIDS grants and contracts. HHS has not implemented such a uniform data collection and reporting system; however, it plans to design and implement such a system within the next year. The SIDS program director said that HHS is sponsoring two studies which will help define what SIDS data are needed and feasible to collect under such a reporting system. One is an evaluation of SIDS projects, and the other is a study sponsored by the National Institute of Child Health and Human Development to help identify risk factors for SIDS.

Annual performance reports

Although SIDS program regulations (42 C.F.R. 51a.514) require grantees to submit annual performance reports showing comparisons of accomplishments to established goals, the SIDS Program Office has not required that these reports contain information on the timeliness of services. Consequently, these reports generally do not contain sufficient information to compare progress toward meeting all elements of the four-point management system with measurable goals established for the year.

Scope and frequency of site visits limited

The SIDS Program Office has not made enough site visits to adequately monitor grantee performance, and reports on site visits it did make were frequently incomplete. According to the SIDS program director, insufficient staff and travel funds for in-house staff or program consultants precluded her office from making enough visits.

According to data provided by the SIDS program director, her office made 63 site visits to monitor projects between July 1975 and August 1980. However, based on the data, five projects initially funded in fiscal year 1976 had not been visited as of August 1980 and seven projects initially funded in fiscal year 1975 had not been visited since 1976.

Also, site visit reports frequently lacked sufficient information to determine whether projects complied with program requirements for the four-point SIDS management program. Our review of 19 site visit reports filed between April 1977 and January 1980 showed that only 4 contained information on how frequently parents were notified of the cause of death and only 2 commented on the promptness of such notification. Only six commented on how frequently parents were counseled, and none contained information on the timing of such counseling. According to the SIDS program director, site visits are supposed to include an assessment of the four-point management program performance. However, staff members making visits frequently either did not have time to make these assessments because of other problems that had to be addressed or did not document their findings if no problems were found.

As a result of insufficient monitoring, the SIDS Program Office has frequently been unable to identify and help resolve problems at projects, assess their performance and compliance with requirements, or verify the correctness of information in project applications.

To illustrate, several projects we visited were experiencing problems in complying with one or more aspects of the four-point SIDS management program which HHS may have been able to help resolve. For example, the Florida project could not track parent notification because it was not promptly informed of SIDS deaths and was not collecting information on parent notification from medical examiners. If the SIDS

Program Office had monitored projects more thoroughly, it could have identified this problem and helped the project take corrective action.

Contractor evaluation of projects

To enhance its evaluation of SIDS projects, in 1979, HHS awarded a contract for an evaluation of 33 projects. The evaluation is to include an assessment of case management, educational, and other activities. The contractor's final report was due in December 1980, but is now not expected until February 1981. (See p. 53.)

Grantee self-evaluations infrequently done

Although SIDS program guidance provides that grantees must periodically evaluate their activities, 5 of the 11 projects we visited did not perform such evaluations. The SIDS Program Office needs to provide more detailed guidance to grantees defining what types of evaluations are expected and to monitor grantees more closely to see that they carry out appropriate evaluations.

Those projects we visited that did perform evaluations did not do so routinely or did not cover all critical aspects of program operations. For example, in 1976 and 1977, the Houston, Texas, project evaluated program activities, but did not evaluate the quality of project services. Although the Maryland project had evaluated some aspects of its operations, it had not systematically evaluated the timeliness with which autopsies were being performed or SIDS victims' families were being notified or counseled in relation to HHS' desired time frames.

Our interviews with SIDS parents demonstrated the importance of and the benefits that can result from self-evaluations. A few parents we contacted identified problems that needed to be corrected or studied further. For example, some parents said that some nurses (1) visited them too late to be of much help, (2) were not very knowledgeable about SIDS, or (3) were not sensitive to the parents' grief. In addition, a few of the parents needed or desired followup services.

CHAPTER 4

IMPROVEMENTS NEEDED IN HSA'S ADMINISTRATION OF CONTRACTS RELATING TO SIDS

Since 1974, HSA has awarded 13 contracts (each for over $10,000) totaling about $1.4 million for such activities as the production of films regarding SIDS, toxicological studies, analyses of State death investigation laws and systems which affect SIDS programs, mobilization of resources for SIDS programs, evaluation of SIDS grant projects, and provision of a clearinghouse for SIDS informational and educational materials.

As indicated on page 7, we reviewed six contracts awarded by HSA. One of these contracts--for a study of State death investigation laws and systems--has recently been formally protested to our Office by an unsuccessful offeror. Our office is considering this protest; therefore, our comments relating to HSA's contracting procedures and practices are based on information we developed for the other five contracts.

Our review of the five contracts showed that HSA complied with procurement regulations for publicizing notices of proposed procurements, objectively and equitably evaluating proposals, and negotiating with all offerors whose proposals were determined to be acceptable.

However, we believe that HSA, in negotiating and administering its two contracts for the mobilization of SIDS resources within specified States, should have:

- --More aggressively pursued efforts to award the original sole-source contract competitively beyond its first year.
- --More carefully assigned panel members to technically evaluate contract proposals in order to avoid the appearance of bias against one offeror. (We found no evidence, however, that the evaluations were, in fact, biased against the unsuccessful offeror.)
- --More specifically described, in its contract terms, the scope of work it required and more forcefully assured that the contractor complied with the contract requirements.

In addition, HSA did not, in its initial contract work scope for its evaluation contract, specify that the contractor was to report the results of its evaluation of case management and educational activities on a project-by-project basis.

CONTRACT AWARD PROCEDURES

HHS procurement regulations require that all negotiated contracts be conducted competitively unless compelling and convincing reasons justify sole-source procurements. Where noncompetitive awards are justified, action must be taken to avoid the need for subsequent or continuing noncompetitive procurements.

To protect the public interest and to increase competition, Federal Procurement Regulations (41 C.F.R. 1-1.10) also require that, with certain exceptions, proposed procurements, both competitive and noncompetitive, of more than $5,000 be published in the "Commerce Business Daily." Interested parties request and receive a request for proposals from the procuring agency and submit proposals for contracts.

Proposals received by HHS are to be reviewed by a panel of technical evaluators in accordance with criteria contained in the request for proposals. The technical evaluators are to prepare reports that reflect the ranking of the proposals, identify each proposal as acceptable or unacceptable, and discuss the strengths and weaknesses of each proposal. The report is to include technical reasons supporting a determination of unacceptability with regard to any proposal.

Following the evaluations, the contracting officer, with technical assistance as appropriate, is required to determine those offers in "a competitive range"--those offerors with which there is a possibility of improvement to the point of being acceptable for award. The contracting officer is also required to negotiate with the offerors in the competitive range to firm up agreements covering the work to be performed, its cost, and other contract terms as necessary.

To finalize negotiations, the contracting officer asks offerors for a "best and final offer" by a designated date. After receipt of the final offers, the contracting officer is to select, for award, the offeror whose proposal provides the greatest advantage to the Government.

Also, to the extent possible, HHS is to make efforts to award contracts to small businesses owned by socially and economically disadvantaged persons. Contracts are awarded to the Small Business Administration as authorized by section 8a of the Small Business Act of 1953, as amended (15 U.S.C. 637(a)). These awards are, in turn, usually subcontracted without competition to organizations identified by the Small Business Administration as owned or controlled by socially and economically disadvantaged persons.

CONTRACTS AWARDED FOR SIDS ACTIVITIES

Since inception of the SIDS program through October 1, 1980, 13 contracts totaling about $1.4 million have been awarded as follows:

Type of award	Number of contracts	Amount awarded
Noncompetitive (sole source)	4	$ 541,863
Competitive	5	400,028
Small Business--section 8(a)	4	413,491
	13	$1,355,382

Because of the Committees' interest in particular contracts awarded by HSA for SIDS activities, controversy surrounding several of them, and the fact that two of the contracts are designed to assist HSA in meeting specific requirements in the SIDS Amendments of 1979, we selected six contracts for review. The table below summarizes these contracts:

Type of contract	Contractor	Type of SIDS program activity	Contract amount
Noncompetitive	National Sudden Infant Death Syndrome Foundation, Inc.	Mobilization of resources for SIDS programs	$264,547
Competitive	Lawrence Johnson & Associates, Inc.	Mobilization of resources for SIDS program	124,242
Competitive (note a)	Lawrence Johnson & Associates, Inc.	Study of State death investigation laws and systems	106,713
Small Business--section 8(a)	Lawrence Johnson & Associates, Inc.	Develop methodology to evaluate effectiveness of SIDS projects	86,000
Small Business--section 8(a)	Lawrence Johnson & Associates, Inc.	Evaluate effectiveness of SIDS projects	183,584
Small Business--section 8(a)	InterAmerica Research Associates	Provision of a clearinghouse for SIDS information	114,998

a/This contract was formally protested in September 1980 by an unsuccessful offeror.

HSA followed requirements for publicizing notices of proposed procurements and evaluating proposals

Our review showed that HSA followed the required procedures for publishing notices of proposed procurements in the "Commerce Business Daily." In this way, HSA properly notified interested firms of its intention to award SIDS contracts. The Federal Procurement Regulations provide exceptions to the publishing requirements which HSA used when it did not publish notices of its intention to contract under section 8(a) of the Small Business Act.

We also found that HSA complied with procurement regulations governing the technical evaluation of proposals. Where required:

--Requests for proposals were issued.

--Technical evaluation review panels were convened.

--Documentation in the contract files reflected the rankings of competitive proposals and discussions of the strengths and weaknesses of each proposal, including the reasons supporting determinations of unacceptability of certain proposals.

Also, discussions were held and documented, as required, with all offerors whose proposals were determined to be acceptable.

HSA PROBLEMS REGARDING MOBILIZATION CONTRACTS

HSA awarded a contract, effective September 30, 1976, to the Foundation to mobilize resources within States and areas that were not covered by SIDS grants. The Foundation was to mobilize community resources for SIDS programs through informational and educational activities. The contract was awarded on a sole-source basis.

In awarding the contract, HSA stated in the "Commerce Business Daily" that it intended to negotiate a sole-source contract. In justifying the sole-source award, BCHS stated that the Foundation was in a unique positon to conduct mobilization activities because of its organization, ability, and past experiences with SIDS, including work performed under a previous Federal contract.

Competition possible but contract extended

During the second year of the Foundation's contract, HSA continued the sole-source award even though it was aware that there was no longer assurance that the Foundation was the only contractor capable of meeting contract requirements. HSA staff members said that they were aware of other organizations with the apparent capabilities to perform the required services.

Nevertheless, the sole-source contract with the Foundation was continued by means of six separate contract modifications until April 1979. HSA justified the continuation of the sole-source award by stating that the contract with the Foundation was originally awarded for 2 years and that the contractor performed satisfactorily during the first year. According to the contracting officer, the contract extensions beyond the second year were approved to keep mobilization work going while a competitive request for proposals was being developed and the competitive proposals were being evaluated and negotiated.

We believe that HSA, to comply strictly with the regulations--which require avoiding the need for subsequent, continuing noncompetitive procurements--should have more aggressively pursued efforts to award the mobilization contract competitively, particularly in view of the knowledge that other organizations may have been able to perform the work HSA desired.

Award of competitive mobilization contract

Before awarding a competitively negotiated mobilization contract to Lawrence Johnson & Associates (hereafter referred to as Johnson & Associates) in April 1979, HSA published its notice of proposed procurement in the "Commerce Business Daily" and sent requests for proposals to 88 prospective offerors. Two organizations, the Foundation and Johnson & Associates, submitted proposals. HSA convened a technical evaluation panel to review each proposal in conformance with the evaluation criteria published as part of the request for proposals. The panel found the Foundation's proposal to be unacceptable, and HSA proceeded to negotiate with and award the contract to Johnson & Associates.

Immediately after the award of the contract, the Foundation protested to HHS alleging that HSA's contract award process was unfair because:

--The Foundation previously held the contract as a sole-source contractor and was told by a BCHS official that its contract would be continued.

--The Foundation was not notified directly and in a timely manner of the request for proposals.

In addition, Foundation officials later complained to us that the HSA review panel included OMCH staff who had reason to be very unhappy with the Foundation.

We reviewed the Foundation's complaints and found those material to the outcome of the contract award process to be without merit for the following reasons:

--Pursuant to the terms of its last modification, the Foundation's contract expired on April 20, 1979, and was not again extended. HSA procurement personnel determined that the requirement should be satisfied competitively rather than by sole-source award or a modification of the Foundation's contract. The HSA official who acknowleged telling the Foundation that its contract would be extended was not authorized to make such a statement. Also, Federal procurement laws and regulations require as much competition as practicable.

--Even though the Foundation was not directly notified concerning the request for proposals, a notice was published in the "Commerce Business Daily." Moreover, we found no evidence that HSA consciously failed to expressly notify the Foundation regarding the forthcoming procurement. Also, documents show that the Foundation was aware of the request for proposals at least 2 weeks before the date proposals were due.

--Although two of the three panel members who reviewed the technical proposals had previous disagreements with the Foundation, we found no evidence that the proposals were not evaluated objectively and equitably.

Regarding the last of the Foundation's allegations, the HSA contracting officer and the SIDS program director told us that they were not aware of any HHS requirement which specifies that technical evaluation panel members be excluded because of their prior dealings with prospective contractors. We believe that HSA should establish procedures, such as those it has for its grant program, which require that panel members who may have reason to have, or may appear to have, a bias involving any of the competitors be excluded from technical evaluation panels.

Problems in HSA's management of Foundation's mobilization contract

We noted two principal problems with HSA's management of the Foundation's mobilization efforts under its contract. In some instances, the terms of the contract, as awarded by HSA, were not sufficiently specific; as a result, the Foundation did not perform certain activities as HSA had expected. In other instances, HSA did not compel the Foundation to fully comply with the contract requirements, including those related to products that were to be delivered to HSA.

According to both HSA and Foundation officials, a basic philosophical difference of opinion existed throughout the contract period between HSA and the Foundation concerning the best approach to follow in mobilizing SIDS resources. HSA officials believed that the best approach for mobilization was generally through the health departments of States which did not yet have, but were willing and able to implement, a SIDS program. On the other hand, the Foundation believed in a more community-oriented approach and, accordingly, was not inclined to aggressively pursue its contract efforts through health departments to the extent desired by HSA.

In preparing the contract, HSA structured its language to accommodate both philosophies. Moreover, according to the SIDS program director, it did not--until 6 months after the effective date of the contract--approve a specific project design. The design included a list of States in which the Foundation was to concentrate its mobilization efforts and a methodology for the conduct of the contract activities. The Foundation did not, in many instances, concentrate its efforts in States and areas which HSA considered to be deserving of priority attention. Also, it did not always focus its efforts through State health departments but rather often enlisted support largely from local organizations, including universities and other private organizations.

In April 1978, HSA included in a contract modification agreed to by the Foundation, a list of 18 specifically targeted States which HSA believed should receive priority attention. However, it again permitted the Foundation the flexibility to continue its activities in nontargeted areas. HSA continued to be dissatisfied with the Foundation's approach in the targeted areas and with the fact that the Foundation continued

to concentrate efforts in nontargeted areas. However, according to BCHS representatives, HSA never formally informed the Foundation of its dissatisfaction.

We also noted several instances in which the Foundation did not fully comply with the terms of its contract with HSA, including those related to products it was required to deliver. For example:

--The Foundation submitted only 7 of the required 10 quarterly progress reports. The reports submitted did not contain all the information HSA required but rather contained substantial amounts of information related to the Foundation's non-contract-related activities. As a result, HSA was not able to adequately evaluate the Foundation's performance as it related to specifically agreed-to contract activities.

--The Foundation submitted numerous vouchers for payment under the contract which should have indicated to HSA that the Foundation was carrying out substantial efforts in nontargeted areas. In this regard, many trips made by Foundation personnel to nontarget areas were reimbursed by HSA under the contract.

--The Foundation failed to submit to HSA a draft of its final report and did not submit the final report itself on the results of its efforts under the contract until October 1980. As a result, the subsequent mobilization contractor, Johnson & Associates, lacked the benefit of much of the information obtained by the Foundation under HSA's previous contracts. This slowed implementation of Johnson & Associates' contract work.

Even though HSA experienced difficulties with the Foundation, such as those described above, it continued to make payments to the Foundation throughout the contract period and ultimately paid all but about $9,600 of the agreed-to $265,000.

In October 1980, about 18 months after the end of the contract period, the Foundation submitted a final report to HSA. In commenting on a draft of our report, the Foundation stated that all the information contained in its final report was submitted to the Senate Subcommittee on Child and Human Development and appears in a Senate hearing record that

was available to the subsequent contractor. Johnson & Associates representatives stated that they had this document but that the information in it on the Foundation's mobilization work was not current and did not contain sufficient details on specific mobilization activities undertaken or organizations contacted. HHS' SIDS program director concurred with this assessment of the situation by the Johnson & Associates' representatives. Furthermore, the Foundation's final report contained more details and more current information than the earlier report reprinted in the Senate Subcommittee's report.

In discussing their dealings with the Foundation, HSA representatives stated that, in retrospect, they believed the contract should have been more specific concerning what HSA expected of the Foundation. They also stated that, while they probably should have been more stringent in enforcing contract requirements, they were sensitive to the fact that the Foundation had substantial experience in dealing with SIDS activities and was influential in both the upper levels of management within HHS and with congressional groups. When the Foundation disagreed with HSA representatives' decisions, it did not hesitate to contact these groups, which in turn, made numerous inquiries to HSA representatives. Accordingly, HSA representatives said that they did not force the contractor to meet all of the contract's terms and conditions and HSA expectations. A BCHS official stated that, because the SIDS effort was relatively new from the Federal involvement viewpoint, the Foundation's assistance was needed and appreciated to get the Federal program off to a good start.

Foundation officials recognized that they had not delivered to HSA all of the products required under the contract and did not pursue the mobilization efforts in the manner HSA desired. However, they stated--and BCHS concurred--that, particularly during the first year of the contract, HSA did not provide the Foundation sufficiently specific guidance as to what it wanted. They added that HSA did not help the Foundation make contacts with State health departments. Finally, the Foundation was continuously dissatisfied with not only HSA's administration of the contract, but also its overall management of the entire SIDS program, and therefore did not submit the final report on the results of its work until 18 months after the contract period ended.

The SIDS program director believed that, despite the numerous difficulties with its management of various aspects of the Foundation's contract, the Foundation was generally effective in mobilizing SIDS resources.

HSA's mobilization contract with Johnson & Associates, Inc.

In April 1979, HSA awarded its second mobilization contract on a competitive basis to Johnson & Associates, a social behavioral science research firm headquartered in Washington, D.C. The general terms of the contract were very similar to those previously included in the Foundation's contract. Johnson & Associates was to (1) visit targeted States and work with State health departments and others and (2) submit to HSA quarterly reports and other documentation of its mobilization efforts. The contract was for only a 1-year period as compared to the 2-1/2-year period covered by the Foundation's contract.

During the 1-year contract period, Johnson & Associates made initial visits to all but 3 of the 19 targeted areas. Initial visits were not made to three States because either (1) a State-funded SIDS program was already in place or (2) the States were not interested in establishing a federally assisted SIDS program. Ten of Johnson & Associates' initial visits were made during the last quarter of the contract period. Johnson & Associates attributed this to (1) the Foundation's failure to submit information to HSA which HSA had said would be available, (2) difficulties encountered in contacting the HSA project officer for approvals it needed to proceed, and (3) additional time and effort required to make arrangements for two regional meetings for which HSA changed the time, location, and number of persons to be invited.

Our review showed that Johnson & Associates generally met the reporting requirements of the contract and attempted to pursue its mobilization efforts generally through State health departments as HSA desired. Johnson & Associates also blamed the delay it experienced in making the initial visits for its failure to (1) conduct more followup visits and (2) execute required memorandums of agreements with States to commit resources to SIDS efforts. It also said that the States were reluctant to make commitments to execute such memoranda during the limited amount of time the contractor was able to spend with them.

The BCHS project officer told us that Johnson & Associates performed satisfactorily under the contract and was extremely responsive to the expectations of the SIDS Program Office. BCHS believed that the contractor was effective in mobilizing SIDS resources, but had not generated as many mobilization results as the Foundation. The project officer said that the Foundation had had extensive previous experience in the SIDS area, that Johnson & Associates had only a 1-year mobilization contract compared to the Foundation's 2-1/2-year contract, and that Johnson & Associates did not have the benefit of the Foundation's final report.

Representatives from four States which were contacted by both the Foundation and Johnson & Associates told us they were generally satisfied with the assistance provided by both contractors.

HSA CONTRACTS FOR EVALUATION OF SIDS GRANTEES

In September 1977, HSA, under section 8(a) of the Small Business Act, awarded an $86,000 contract, through the Small Business Administration, to Johnson & Associates to develop a methodology for comprehensively evaluating grantees' progress in implementing the SIDS program and to carry out the evaluation. The contractor submitted a methodology acceptable to HSA in June 1978, but did not do the evaluation under the September 1977 contract.

About 15 months later, HSA, again through the Small Business Administration under section 8(a), awarded a $153,760 contract to Johnson & Associates for the evaluation of the SIDS program. The delay between the development of the study methodology and HSA's award of the second contract was caused primarily by delays in obtaining approvals within HHS and the Office of Management and Budget for using a questionnaire which the contractor planned to have sent to the families of SIDS victims. Under the second contract, the contractor was to:

--Visit 33 SIDS grantees to (1) interview projects' staffs, (2) obtain grantee data on SIDS cases handled and training and information activities performed, and (3) make arrangements for the review and administration of the questionnaire which the contractor planned to have sent to SIDS victims' families.

--Collect data on SIDS deaths from HHS' National Center for Health Statistics.

--Interview staff members in HSA regarding its administration of the SIDS program.

The contract called for Johnson & Associates to submit reports on the results of its visits to grantees concerning arrangements necessary to obtain local clearances on the questionnaire for SIDS victims' families, quarterly reports of progress made under the contract, a draft of the final report by September 28, 1980, and a final report by November 28, 1980.

By letter dated May 1, 1980, the HSA contracting officer authorized the contractor to use existing contract funds to revise the questionnaire for SIDS families and sampling plan in accordance with recommendations made by HHS' National Center for Health Statistics. In September 1980, HSA notified the contractor that it was deleting from the contract all requirements dealing with the contractor's administration of the questionnaire. These requirements were deleted because of continuing difficulties encountered in trying to obtain internal HHS and Office of Management and Budget clearances for the administration of the contract. In October 1980, HSA modified the contract to extend completion dates for the draft and final reports by 1 month and increase the cost by $29,824 to $183,584.

Johnson & Associates had visited all but 3 of the 33 SIDS grantees within the time required by the contract but in most instances was quite late in submitting reports of those visits to HSA. It did, however, submit the quarterly reports in a timely manner. As of January 26, 1981, the contractor had not yet submitted its final report, and HSA expects to receive it in mid-February 1981.

The scope of work included in HSA's contract with Johnson & Associates did not specify that the contractor was to report the results of its evaluation of case management and educational activities on a project-by-project basis. Our discussions with contractor officials indicated that Johnson & Associates planned to develop its report on an overall program basis and did not intend to identify the grantees. Johnson & Associates officials considered the information they had obtained from individual grantees to be confidential and believed the contract did not require the grantees to be identified. We advised HSA officials of the contractor's intention concerning this matter since HSA apparently believed

grantees would be identified in the report. Subsequently, HSA unilaterally modified the contract to require reporting of case management and training activity data on a project-by-project basis.

HSA CONTRACT FOR SIDS INFORMATION CLEARINGHOUSE ACTIVITIES

Public Law 96-142 required HHS to carry out clearinghouse activities to collect information pertaining to SIDS and to disseminate the information to the public, health and educational institutions, professional organizations, voluntary groups, and other interested parties. The amendments authorized HHS to enter into contracts to carry out the clearinghouse activities.

In July 1980, HSA awarded a 12-month, $114,998 contract to the Small Business Administration for establishing and operating a national clearinghouse for SIDS and related information. The Small Business Administration subcontracted the work to InterAmerica Research Associates.

The contract work scope provides for InterAmerica to:

--Develop and establish a clearinghouse system.

--Collect and disseminate SIDS-related information and educational materials to SIDS projects, providers of health care, public safety officials, and the public.

--Maintain and update mailing lists of SIDS projects, professionals interested in SIDS, State health departments, and voluntary groups concerned with SIDS.

--Establish and maintain a library of SIDS reference materials and studies relating to, among other things, death investigation systems, personnel training, and preventive techniques.

--Establish and maintain a data base of SIDS information using information sources of health libraries.

--Prepare a bibliography of literature concerned with SIDS.

--Prepare and distribute four issues of an Information Exchange Bulletin containing education techniques and materials to be shared among SIDS grantees, HHS, and voluntary organizations.

The contract work scope further provides that information in the clearinghouse is to be patient/family oriented rather than highly technical or research oriented.

In our opinion the work scope of the clearinghouse contract, if adequately carried out by the contractor, will provide the necessary means to meet the requirements of Public Law 96-142.

CHAPTER 5

STRUCTURE AND MANAGEMENT OF SIDS PROGRAM

HHS has established an identifiable administrative unit to manage the SIDS program, as required by Public Law 96-142, and this unit has coordinated its activities with those of the National Institute of Child Health and Human Development. However, HHS has not always provided adequate staffing for the SIDS program. Also it does not appear that HHS will be able to assure the availability of complete, nationwide SIDS information and counseling services under the current SIDS program structure, management, and funding levels.

SIDS PROGRAM ORGANIZATION AND STAFFING

Although HHS has established a specific administrative unit--the SIDS Program Office--to manage the program as required by law, the unit has not been adequately staffed to carry out all of its responsibilities effectively. As discussed in chapter 3, insufficient staffing has been one of the factors impeding the ability of the SIDS Program Office to monitor grantee performance adequately, thereby necessitating the award of a contract to evaluate SIDS grantees.

The original SIDS authorizing legislation--Public Law 93-270--did not require HHS to establish a specific organizational unit to manage the SIDS program. The legislation did not mention program staffing levels. In its report (S. Rep. 95-283) on the fiscal year 1978 appropriations bill, the Senate Committee on Appropriations expressed concern about HHS' inadequate staffing for the SIDS program and stated that 6 of 250 additional HSA positions for which it was providing funding were to be clearly identified for the SIDS program.

In 1979, the Senate Committee on Labor and Human Resources, in its report (S. Rep. 96-102) on S. 497, which eventually became Public Law 96-142, also expressed concern about fragmented and inadequate staffing for the SIDS program. It noted that HHS had not clearly identified the six positions cited by the Senate Appropriations Committee for the SIDS program.

Public Law 96-142 required HHS to manage the SIDS program through an identifiable administrative unit. The law also required that HHS provide this unit with the full-time professional and clerical personnel as well as the services of consultants and support personnel necessary to implement the SIDS program effectively.

SIDS administrative unit

In October 1977, HHS established a working group to administer the SIDS program. This working group was subsequently designated as the SIDS Program Office. In April 1978, HHS formally delegated the authority to implement relevant sections of Public Law 93-270 to the director of this office.

SIDS program staffing levels

Since its inception, HHS has administered the program by using a combination of full-time and part-time personnel within HSA, OMCH, the SIDS Program Office, and regional office staff. HHS has not identified six full-time positions within the SIDS Program Office or elsewhere specifically for SIDS. HHS has interpreted the six positions specified by the Senate Appropriations Committee to be full-time-equivalent positions--a combination of full- and part-time positions which are equivalent to six full-time positions. In September 1980, HHS identified four full-time--three professional and one secretarial--positions within the SIDS Program Office and several part-time positions within various other HHS offices designated for SIDS which total two full-time-equivalent positions, as shown in the following chart.

Office	Full-time-equivalent positions for SIDS
BCHS:	
SIDS Program Office	4.0
Grants Management Branch	1.0
Financial Management Branch	.1
Program Information Branch	.3
Division of Policy Development	.2
OMCH (other than SIDS Program Office)	.1
Subtotal	5.7
HHS regional offices	.3
Total	6.0

The SIDS Program Office also receives support services from personnel in HSA's Office of Contracts and Grants, but this support was not included in HHS' computation of the six full-time-equivalent positions.

HHS' actual full-time professional staffing for the SIDS program has fluctuated from none to three since April 1974. Between October 1978 and October 1980, the program staffing consisted of at least two full-time professionals; and for short intervals, three. As of October 6, 1980, the SIDS Program Office consisted of two full-time professionals. The Program Office receives its principal support services from one grants management specialist in BCHS' Grants Management Branch. This specialist works full time on SIDS.

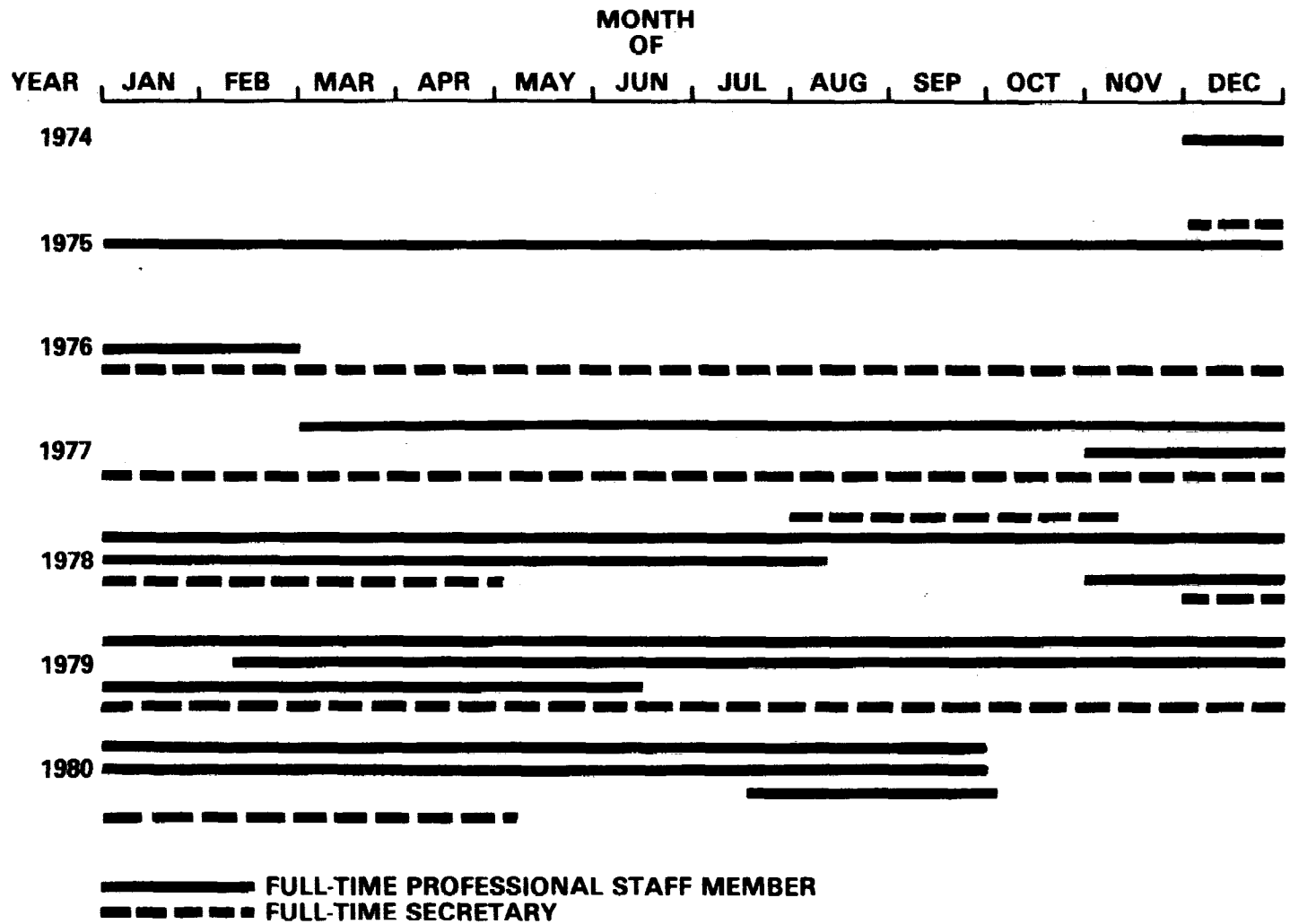
The chart on the following page shows the number of HHS full-time staff members assigned to the SIDS program since April 1974.

The SIDS program director believes that a staffing complement of three full-time professionals and one full-time secretary for the SIDS Program Office is reasonable to support program activities as long as assistance is provided by other HHS staff and consultants on a part-time basis. She said, however, as indicated in chapter 3, that staffing has been insufficient to enable her office to adequately monitor SIDS grantees. She added that, if her office (1) had been able to require grantees to report periodically case management and educational activity data (see p. 38) and (2) consistently had three full-time staff with sufficient training and experience and adequate travel funds, HHS could have done, in-house, most of the evaluation of SIDS projects ultimately contracted out to a private firm. (See p. 53.)

Coordination of SIDS-related activities

Personnel from the SIDS Program Office and the National Institute of Child Health and Human Development have a good working relationship and frequently coordinate activities. They have cooperated in planning and holding conferences and collaborated on carrying out mutually beneficial activities and preparing annual reports. For example, the SIDS Program Office and some SIDS program grantees assisted in an Institute-sponsored SIDS epidemiological study, and the Institute worked with the SIDS Program Office in planning its SIDS information clearinghouse activities.

FULL-TIME HHS STAFF POSITIONS ASSIGNED TO THE SIDS COUNSELING AND INFORMATION PROGRAM APRIL 1974 TO OCTOBER 1980



EXTENDING SIDS SERVICES NATIONWIDE

Public Law 96-142 required HHS to have a plan, on or before February 1, 1980, to extend counseling and information services to all States and the District of Columbia by July 1, 1980, and to all U.S. possessions and territories by July 1, 1981. The plan HHS developed did not detail how it would assure that SIDS services are extended to geographic areas without such services. Moreover, as of July 1, 1980, the SIDS program had not been extended to all States. As the program is currently structured and operated, the SIDS Program Office does not have sufficient appropriations to fund projects which would cover all unserved areas. Nor has it had sufficient leverage or influence to achieve nationwide services.

There are several means by which SIDS informational and counseling services could be extended nationwide. For example, making the SIDS program a "seed" money program may be one way to help HHS carry out congressional intent. Such an approach assumes, however, that grantees can find sufficient funding from other sources.

Another approach to assure a nationwide program could be to consolidate the SIDS program with the Maternal and Child Health program authorized under title V of the Social Security Act (42 U.S.C. 701), and specify minimum levels of SIDS services as a condition of receiving formula grant funds under title V.

SIDS services coverage and obstacles to extension

As of July 1, 1980, SIDS grantees covered 29 States entirely and 2 partially. As of October 1, 1980, 42 SIDS grantees covered 34 States and the District of Columbia entirely and parts of 2 States. Thus, as of October 1, 14 States, parts of 2 States, and the possessions and territories were not covered by a SIDS program grantee.

Lack of a SIDS grant, however, does not necessarily mean that no SIDS-related information, educational, or counseling activities exist in these areas. Most of the States without Federal SIDS program funds have some elements of the four-point management program. For example:

--According to Oregon State officials, all infants dying suddenly and unexpectedly are autopsied, SIDS is cited on the death certificate, and parents are notified of autopsy results. Counseling is offered by the local public health departments and by parent volunteer groups. The deputy medical examiner further stated that all SIDS parents in the State receive some counseling and at least 50 percent, possibly 75 percent, receive home visits, although these are not well-documented.

--In Kansas, the State Department of Health and Environment has been identifying SIDS cases for statistical purposes since 1952. However, because no State law requires autopsies, department officials are concerned that SIDS cases may not always be identified. SIDS information, counseling, and educational activities are occurring in various areas in the State, but department officials stated they did not know how many families had received counseling services. The Foundation has been active in encouraging and conducting SIDS activities in Kansas.

Major obstacles impeding the extension of SIDS services to noncovered areas or strengthening services in areas with some SIDS services are lack of funds and insufficient interest by organizations in some areas.

--First, HHS has estimated that about $5.5 million in Federal funds would be required to extend services nationwide compared to its 1980 appropriation of about $2.8 million. 1/

--Second, in nine States no organization has applied for a SIDS grant. For example, Virginia State health officials have not applied because they do not consider SIDS a high priority and they believed that public health nurses already had heavy workloads.

SIDS authorizing legislation does not require States to provide SIDS services, and HHS' efforts to encourage organizations in States with no or limited SIDS services to initiate or improve them have not always been successful.

1/Because of HHS' lack of criteria for funding SIDS projects, we did not evaluate HHS' estimate.

SIDS as a "seed" money program

SIDS authorizing legislation does not specify a maximum time period for which a grantee can receive SIDS funding or whether SIDS funding for grantees should decrease over time. However, HHS seems to support the "seed" money concept by expecting grantees to seek alternative funding sources and eventually reduce reliance on Federal funding. However, the SIDS Program Office has not (1) issued specific requirements, instructions, or guidelines to grantees or applicants specifying how long it will finance projects and at what level, (2) required grantees or applicants to develop realistic plans or take substantive action to obtain other funding sources, as provided for in program guidelines, or (3) formally notified grantees that it will decrease funding levels over time. As a result, grantees generally have not developed or implemented realistic plans for reducing reliance on Federal funds.

According to SIDS program regulations (42 C.F.R. 51a. 507(b)(4)), one of the matters HHS is to consider in determining funding priorities is how applicants intend to see that services are maintained after Federal funding ends. SIDS program guidelines provide that applications are to contain a projection of how services will be continued after Federal funding ceases and a plan for community support for services beyond the project period. Also, one of the criteria given to grant review panel members by the SIDS Program Office pertains to long-range goals for continuing services when Federal funding ends.

Despite these requirements and instructions, many projects we visited were not reducing their dependence on Federal financing. For example, California's approved Federal budget was about $137,500 in fiscal year 1975 and about $166,450 in fiscal year 1980. The New York City project's approved Federal budget was about $101,500 in fiscal year 1976 and about $111,000 in fiscal year 1980.

Representatives from only three of the projects we visited--all State health departments--believed that services would not be severely impaired by the withdrawal of Federal funds. On the other hand, representatives of the other eight projects--four universities or medical schools; one medical examiner; two public health departments; and one other private, nonprofit agency--believed that services would not

continue at the same level if Federal funds were withdrawn. Most of the eight said that some services, mainly autopsies, would continue.

For example, the dean of one medical school stated that the school probably would not pick up the cost of operating the project because it was not research oriented. Another university's grant application claimed the project had begun to ensure continuation of services beyond Federal funding; however, the project coordinator stated that no discernible actions had been taken. The director at another project believed that it would be difficult to obtain alternative financing unless HHS gave him formal notice that Federal funding would be discontinued or decreased.

Potential for consolidating SIDS and Maternal and Child Health programs

Under the Maternal and Child Health program, State health departments receive both formula and project grant funds--amounting to about $237 million in fiscal year 1980--to reduce infant mortality and otherwise promote the health of mothers, infants, and children. 1/ Under the program, States are required to extend services statewide. Almost all States reallocate some of their Federal Maternal and Child Health program funds to local health departments. These health departments employ public health nurses who are relied upon heavily to provide information and counseling services to SIDS families.

A consolidation of the SIDS program with the larger Maternal and Child Health program could have the following advantages:

--Greater assurance that SIDS information and counseling services are provided more consistently.

--Greater program stability while retaining flexibility to involve various types of organizations in SIDS activities.

--Reduction in the number of health programs.

1/Excludes funding for Crippled Children's Services, also authorized under title V.

Greater assurance that SIDS services are provided more consistently

Linking SIDS services with the Maternal and Child Health program could provide greater assurance that certain services are provided more consistently. For example, nurses in three Illinois county health departments had not agreed to provide SIDS counseling requested by the Springfield project. Elsewhere, public health nurses are not always reporting on counseling provided, and project personnel do not always have access to death certificates to help identify SIDS cases. If SIDS services were required of title V grantees, State health departments could have more leverage over local resources, such as local health departments, which do not now always fully cooperate because their involvement is often voluntary.

Greater program stability and flexibility retained

In addition, the Maternal and Child Health program should provide greater stability and continuity to the SIDS program because title V authorizing legislation does not expire at set intervals, while the SIDS authorizing legislation does. Furthermore, the SIDS program could have flexibility in that organizations other than State health departments could continue to participate in the program through subgrants or contracts from those health departments. State health agencies could be required to ensure that adequate SIDS services are provided. They would not necessarily have to provide the services or coordinate activities themselves.

Reduce the number of health programs

Consolidating the SIDS and Maternal and Child Health programs would also help reduce the number of separate Federal programs having similar or closely related objectives. This problem is more fully discussed in our January 21, 1980, report to the Congress "Better Management and More Resources Needed to Strengthen Federal Efforts to Improve Pregnancy Outcome" (HRD-80-24). In that report, we made several recommendations aimed at improving the management of Federal and State Maternal and Child Health programs. In addition, we recommended that over the long run and to the extent possible, the

Congress consolidate programs funding similar types of activities aimed at women and infants into one Maternal and Child Health program. We specifically identified the SIDS program as a candidate for such consolidation.

CHAPTER 6

CONCLUSIONS AND RECOMMENDATIONS

CONCLUSIONS

Conclusive determinations concerning the effectiveness of SIDS projects in carrying out the SIDS four-point management program are difficult to make because many projects we visited lacked sufficient data on one or more elements of the program and because of the absence of performance standards. However, we believe that, in general, SIDS projects were making progress in meeting program objectives--particularly in view of the extent to which they have to rely on the cooperation of other parties.

Families we contacted overwhelmingly believed that the information aspect of the SIDS program helped them deal with the death of their infants. Not all families contacted used SIDS counseling services, but most of those who did thought they were helpful.

In our opinion, HHS needs to improve the administration of its SIDS grant program as it relates to its (1) grant application review and approval process and (2) management of grantees' activities after grant awards have been made.

With respect to its review and approval process for SIDS grant applications, we believe HHS needs to develop additional guidance on the content of the narrative section of SIDS grant applications. Also, prospective grantees should be required to submit specific, measurable objectives for those aspects of their operations which HHS considers to be critical to an effective SIDS program. HHS also needs to establish criteria for funding SIDS grantees, giving more consideration to the number of SIDS cases in the grantees' service areas and the need for Federal funding in these areas.

With respect to HHS' postaward grant administration, we believe that:

--SIDS grantees need additional guidance on (1) the appropriate involvement of community groups in developing and operating project activities and (2) the collection of case management and other data necessary to evaluate progress toward meeting program objectives.

--HHS needs to develop standards for measuring SIDS projects' performance and to evaluate project performance against those standards.

--Federal funds not used by SIDS program grantees should be applied to their next year's funding.

To improve its contract award procedures, we believe HHS should issue instructions such as those applicable to its grant programs, which prohibit panels reviewing contract technical proposals from including persons who might be biased or who might have the appearance of being biased for or against any competitor. In addition, we believe that HHS should more clearly specify its requirements and expectations in its scope of work statements for contracts.

To permit more thorough and frequent monitoring of SIDS grantees, HHS should assure that the SIDS Program Office is appropriately staffed on a continuing basis.

In our opinion, several obstacles impede the extension of SIDS information and counseling services nationwide, as the Congress intends. Making the SIDS program a "seed" money program may be one way to help HHS carry out congressional intent to see that SIDS information and counseling services are extended nationwide. However, this assumes that sufficient funding to continue services could be obtained from other sources.

We believe that a better approach would be to consolidate the SIDS program with the Maternal and Child Health program authorized under title V of the Social Security Act. We believe that this would have the added advantages of (1) encouraging States that have not assured the availability of SIDS services to do so, (2) helping to overcome the reluctance of some local health departments to cooperate with SIDS projects, (3) ensuring a relatively stable funding source, and (4) linking SIDS activities with other maternal and child health services. Such a consolidation would require legislative action.

RECOMMENDATION TO THE CONGRESS

We recommend that the Congress consolidate the SIDS Information and Counseling program and the Maternal and Child Health program authorized under title V of the Social Security Act.

RECOMMENDATIONS TO THE SECRETARY OF HHS

We recommend that the Secretary:

1. Issue additional guidance on the content of the narrative section of SIDS grant applications and require grant applicants to submit specific, measurable objectives for those aspects of operations critical to an effective program. In this regard, HHS should also issue guidance to applicants on the types of objectives appropriate for new and continuing projects and assure that projects evaluate their own performance as required.

2. Establish criteria for funding SIDS grantees, considering such factors as the number of SIDS cases in their service areas and the need for Federal funding in those areas.

3. Issue guidelines on projects' appropriate use of community groups, including volunteers. These guidelines should include a clear statement of

   (a) the types of activities appropriate for community groups,

   (b) the circumstances under which the groups can be used, and

   (c) projects' responsibilities for ensuring appropriate use of the groups.

4. Issue additional guidance to projects concerning case management and epidemiological data they are to collect and submit, periodically evaluate these data, and ensure that only data which are needed and used are collected.

5. Develop standards for measuring SIDS projects' performance and evaluate project performance against those standards.

6. Enforce requirements that grantees promptly report to HHS when they will not be spending all of the funds they were awarded and assure that future grant awards are offset with unexpended fund balances.

7. Issue instructions--such as those applicable to the SIDS grant program--which prohibit panels reviewing contract technical proposals from including persons who might have reason to be biased, or might have the appearance of being biased, against any competitor. In making this recommendation, it is not our intention to preclude HHS from including persons on review panels who have some knowledge of the competitors.

8. Assure that the scope of work statement in each contract provides adequate specificity regarding HHS' requirements and expectations.

9. Assure that the SIDS Program Office is appropriately staffed on a continuing basis to permit it to periodically evaluate grantees' performance and compliance with program requirements.

COMMENTS BY HHS AND OTHER ORGANIZATIONS AND OUR EVALUATION

We received written comments on a draft of this report from HHS, the Foundation, the Guild, and the Loyola, Stony Brook, and Maryland SIDS projects. These comments are included as appendixes to this report. Other SIDS projects provided oral comments. Representatives from Johnson & Associates also provided oral comments on those parts of our draft report that discussed their activities. A discussion of the comments received from HHS, the Foundation, and the Guild follows. The other organizations generally directed their comments to specific matters in our draft report dealing with their activities that they believed needed clarification. Where appropriate, we modified our report to reflect their concerns.

HHS

HHS generally concurred with our recommendations and reported corrective actions it has initiated. However, HHS said that it could not implement one of the corrective actions we proposed in our draft report because it believed that Office of Management and Budget instructions preclude it from doing so. We had suggested that HHS develop a standard SIDS grant application format. Instead, HHS said that it would develop additional guidance for grant applicants. We believe that additional guidance could serve the same purpose as a standard grant application format and modified our recommendation accordingly.

National SIDS Foundation

The Foundation characterized our draft report as incomplete, inaccurate, and biased and said that it should be extensively revised before submission to the Congress. (See app. X.) The Foundation provided several general comments on the draft report and specific comments on various segments of the report.

We have carefully analyzed the Foundation's comments and found many of them to be incorrect or misleading; some are partially correct and others reflect valid concerns. Our views on the Foundation's specific comments that we believe warrant a response are included in appendix XI. The text of our report has been modified where appropriate to reflect what we believed to be valid concerns or comments of the Foundation.

The Foundation's general disagreements with our draft report centered around its belief that we

--failed to address all of the controversial issues concerning the SIDS program and suppressed information pertinent to the issues discussed in the report;

--sided with the "Feds" in discussing disagreements between HHS and the Foundation;

--practiced excessive fraternization with HHS officials while conducting our review;

--failed to apply cost-effectiveness measures to the Federal SIDS efforts; and

--failed to discuss why voluntary groups, such as the Foundation, believe they have been "frozen out" of programs, the initiation of which they influenced.

These are charges which are without foundation in fact. They are also charges which, in our opinion, should be viewed in the context of the controversy that has surrounded the SIDS program for several years.

The Foundation has been dissatisfied with various aspects of HHS' program management and with activities at the project level. It believes that its views concerning several individual aspects of program and project management have not been given sufficient credence by responsible SIDS program

officials. It has frequently voiced its concerns to program and project officials, and to top management of HHS and congressional representatives. In addition, although the Foundation and the Guild have the same overall goals, they have differing philosophies concerning what is best for SIDS victims' families, and this has resulted in friction between the two groups. Our responses to the five general charges made by the Foundation follow.

Failure to address all issues pertinent to the SIDS program

The Foundation said that we failed to address each of the issues which it believes are important concerning SIDS program management and cited several instances where it believes we suppressed information which would place HHS and the projects in a position to be criticized.

We developed our scope for this review to respond to questions posed by the congressional Committees in their February 1980 letter requesting the review. Where appropriate, we obtained and reported on the views of the individual parties, including the voluntary organizations, concerning issues related to those questions. Throughout our review, Foundation officials continually brought allegations to our attention which they believed pertinent to our review efforts. We did not attempt to follow up or report on all of these allegations because we were focusing our efforts on those issues of greatest concern to the Committees. Our experience in dealing with Foundation representatives throughout our review indicated to us that the Foundation desired a reinforcement of its views concerning the SIDS program. Because our views on the SIDS program differ from the Foundation's on some issues, the Foundation's criticism of our report is not surprising.

Our draft report contained all the information we believed pertinent to respond to the specific questions posed by the Committees and their offices. In August 1980, we provided an extensive briefing on our findings to Committee representatives. Also, we met with both HHS and Foundation officials to discuss our findings. We made no attempt during any of these discussions or in our draft report to suppress information pertinent to the Committees' questions.

Siding with HHS

We pursued the specific questions raised by the Committees and based our conclusions on an objective analysis of the information we obtained. Furthermore, our findings substantiated several of the problems identified by the Foundation. For example, one of the Foundation's main concerns has been the lack of clarity on the role of voluntary groups, and our findings and report confirm this is a problem that HHS needs to address. HHS agrees and plans to develop additional guidance in this area.

Excessive fraternization

In conducting this review, we met with, and examined documentation provided by, a wide range of officials involved in SIDS activities. Throughout the review, our purpose in dealing with these persons was to gather information and increase our understanding concerning issues pertinent to the Committees' questions. During this process, we attempted to question the many parties involved in SIDS and apprise them of our review objectives and our progress toward completing the work. Our participation at the meeting referred to by the Foundation (see p. 102) was an effort to summarize, to a group of individuals interested in SIDS (including representatives of the voluntary organizations), our plans for and progress in responding to the Committees' concerns. Our presentation at the meeting followed one given by a representative from the Senate Subcommittee on Child and Human Development. Also, we interviewed several representatives from the Foundation and Guild, including one person who the Foundation's executive director specifically asked us to contact.

Cost effectiveness

The Foundation stated that the report fails to apply measures of cost effectiveness to Federal SIDS efforts and states that we (1) "blithely" accepted HHS' estimate of $5.5 million to extend SIDS services nationwide, (2) did not take into account excellent SIDS programs in Alaska, Hawaii, and Oregon that operate without any Federal funds, and (3) ignored that the Foundation carries out the same activities as called for in an HHS contract for a national SIDS information clearinghouse.

The Foundation's statements are inaccurate and misleading. Chapter 3 of the report discusses the award of excessive funds to SIDS grantees and the need for HHS to reevaluate its funding of grantees. Our report contains no statement on the appropriateness of HHS' estimate of $5.5 million, which was made in 1978. Because of the lack of funding criteria, which is discussed in chapter 3 of our report, we did not draw conclusions on the appropriateness of HHS' estimate. As we stated, however, SIDS funding is not currently sufficient to enable HHS to extend services nationwide under the way the program is now structured and operated. Also, in a letter dated December 20, 1977, to a staff member of the House Subcommittee on Health and the Environment, one of the Foundation's vice presidents suggested an increase in the SIDS program authorization level to $8 million.

We did not evaluate SIDS programs in Alaska, Hawaii, and Oregon and are, therefore, not in a position to draw conclusions regarding the SIDS programs in those States. However, information available from HHS or provided by the Foundation showed that:

--A children's hospital in Hawaii applied for a Federal SIDS grant in 1980, and HHS awarded a $50,000 grant to the hospital for statewide SIDS services in Hawaii in that year. The hospital's grant application cited the desire to extend SIDS services statewide as one reason for needing Federal funds.

--In April 1980, the president of the Foundation's Alaska chapter stated: "Things have basically worked well for several years here in Anchorage. However, the rest of Alaska hasn't had a system whereby the appropriate people were always notified and getting help to SIDS parents has been delayed, and at times totally omitted, due to the lack of an organized system." The president pointed out that the Maternal and Child Health Coordinator for the Alaska Department of Health has been involved in the development of a SIDS management system for the State. In fiscal year 1980, HHS awarded $1,000 in Maternal and Child Health program funds to Alaska for SIDS activities.

--Following a visit to Oregon in 1978, one of the Foundation's vice presidents stated that Oregon probably still has one of the best basic SIDS management programs in the country. On the other hand, two problems he cited were the lack of training for

public health nurses and few followup visits to families. He stated that the State could organize a "superb" program for a relatively small amount of funds, such as a project grant. A university in Oregon applied for Federal SIDS funds in 1979 and 1980. The applicant was approved but not funded in 1979 and was not approved for a grant in 1980 because of deficiencies in its grant application.

The Foundation stated that it carries out the same SIDS clearinghouse activities as those for which HHS has awarded a contract to another firm. The SIDS program director believes, however, that a number of differences exist.

In Senate Report 96-102, dated April 20, 1979, the Senate Committee on Labor and Human Resources stated that "* * * although there has been great improvement in public understanding of SIDS, there were many persons who still needed to be reached." The Committee further stated that its intent was to have the contract mechanism used to engage public and private entities (including for-profit organizations) in performing SIDS clearinghouse activities. Also, in July 1979, the Foundation said that it concurred in the need for a national SIDS information clearinghouse.

We did not discuss SIDS clearinghouse activities in detail because, as requested by the Committees, we focused on whether HHS' July 1980 contract for clearinghouse activities met the requirements of Public Law 96-142 rather than on the similarities and differences between the Foundation's clearinghouse activities and those HHS has contracted for.

In addition, other factors complicate the issue of the Foundation's potential for formal involvement in HHS' clearinghouse activities. These include:

--Problems HHS previously had with the Foundation's performance on the mobilization contract and the continuing disagreements over the program between HHS and Foundation personnel. These problems appear to have made it difficult for HHS and the Foundation to develop a close working relationship on clearinghouse activities.

--The Guild also maintains information on SIDS and responds to public inquiries. The Guild has complained that HHS has frequently favored the Foundation over the Guild. Thus, if HHS were to rely solely on the Foundation to conduct clearinghouse activities, the Guild could perceive this as favoritism by HHS.

Role of voluntary groups

The Foundation stated that the voluntary agencies feel they have been "frozen out" by HHS relative to SIDS program philosophy determinations. Further, it stated that the most successful federally funded projects were those where volunteers and professional staff worked together, such as in New Mexico, Ohio, Washington, Long Island, and Massachusetts. It said that services suffered in those areas, such as Nebraska, California, and Missouri, where continuing conflict existed between professionals and volunteers.

We agree with the Foundation on the desirability of cooperative efforts between volunteers and project and HHS staffs and that good cooperation can enhance program performance. The SIDS project at Long Island (Stony Brook) is discussed in our report. However, we did not evaluate SIDS projects in New Mexico, Ohio, Washington, or Massachusetts, and therefore cannot comment on their programs or their relationships with volunteers.

Also, while HHS and voluntary group officials recognize that conflicts between paid professionals and volunteers exist both at the HHS level and at several projects, we could not conclude that these conflicts were entirely the fault of HHS or the projects; nor could we conclude that these conflicts directly caused problems relating to the quality of services. For example, although considerable conflict exists between the Maryland project staff and several Guild representatives, we could not conclude that the SIDS services provided in Maryland were not satisfactory because of this conflict.

Similarly, in Nebraska, conflict existed between the Foundation and the Nebraska Health Department, which is the SIDS program grantee. However, the State health department contracted with the Visiting Nurses Association for the day-to-day operation of project activities, including service delivery and educational efforts, and a Foundation representative told us that she had no problems with the performance of the Visiting Nurses Association.

From the information we obtained, it does not appear that HHS or SIDS projects have frozen voluntary groups out of program activities. However, controversy exists between the voluntary groups and HHS and those groups and some projects. We believe this controversy and conflicts among the involved groups stem from, or have been accentuated by:

--Lack of clarity in, or dissatisfaction with, the roles of the voluntary organizations in the management and operation of the SIDS program.

--Disagreements between voluntary group members and HHS or project staff concerning both program philosophy and management.

--Poor working relationships between the involved parties.

HHS' clarification of the role of voluntary groups in the management and operation of the SIDS program, as we have recommended, should help resolve, at least in part, the first problem. The latter two problems, however, are more difficult to resolve.

Guild

The Guild, like the Foundation, pointed out that it had been carrying out SIDS-related activities prior to the establishment of the Federal SIDS program and expressed concern about its role now that Federal SIDS projects are performing many of the activities it performed. Also, the Guild raised several general concerns about the Federal SIDS program and identified several specific concerns about the matters discussed in our draft report.

The need for clarification of the voluntary groups' role in the development and operation of SIDS projects has already been discussed in our report. We do not believe it is appropriate for us to respond to the Guild's comments on problems it has with the SIDS program in general, rather this should be done by HHS. Our response to the Guild's comments on matters discussed in our draft report follows.

Identification of SIDS cases

The Guild questioned whether the high autopsy rate for SIDS victims is due to project activities or to increased awareness by coroners. Also, the Guild expressed concern about the inability of some projects to review death certificates and thereby identify SIDS cases that may be misclassified.

We recognize that both the Guild and the Foundation were heavily involved in SIDS activities prior to the establishment of the Federal SIDS program and that encouraging coroners and medical examiners to perform autopsies on infants who die suddenly and unexpectedly was and is one of their major efforts. Our review focused on the recent activities of projects. We did not conduct a detailed evaluation of SIDS activities prior to the establishment of the Federal SIDS program. Therefore, we did not comment on the extent to which all elements of the SIDS four-point management system existed prior to the establishment of the projects or what services would have existed if the projects had not been established.

Our statement that SIDS projects helped to encourage autopsies was based on our observation that several SIDS projects pay for autopsy-related expenses for SIDS victims, and project staffs contact medical examiners and coroners to make them aware of (1) the importance of doing autopsies on suspected SIDS cases and (2) any State requirements that might apply. We did not intend to imply that the projects were solely responsible for encouraging autopsies. We clarified our report on this issue.

We agree with the Guild's concern about the inability of some projects to review death certificates to help identify SIDS cases that may be misclassified. We clarified our report to indicate that the scope of our review did not include a review of infant death certificates to determine whether all SIDS deaths were properly identified. HHS has contracted for a study of death investigation systems which should provide information on this issue. Pending completion of this study, HHS may be able to help projects unable to review death certificates develop procedures for someone to do this on their behalf within the parameters of State confidentiality restrictions.

Counseling SIDS victims' families

The Guild expressed concern about (1) the varying extent to which projects directly provide or pay for counseling and (2) what it believes to be an insufficient use of parent groups by projects to help provide counseling. In discussing its first concern, the Guild referred to appendix I of our report, which shows the SIDS projects' budgets for fiscal year 1979.

As the note in the appendix indicates, it is not possible to determine the total amount of projects' budgets that are used for counseling because this information is not specifically identified in the budget. For example, the salary of the Dallas project's coordinator is shown in the personnel category of the project's budget, but the coordinator spends some of her time counseling SIDS victims' families. Thus, projects frequently spend more of their funds for counseling than their budgets show, but the amount is not specifically identified or readily determinable.

Projects use parents of SIDS victims or parent groups to help provide counseling and appear to be giving the families the opportunity to contact or be contacted by another SIDS parent or a parent group. If a family does not want to take advantage of this opportunity, however, it appears that there is little the project can do in view of HHS' and other confidentiality requirements. We agree with the Guild that the projects should attempt to maximize the use of parent groups. The additional guidance HHS said it would develop in response to our recommendations on the use of community groups in the operation of projects should help clarify the role of parent groups in helping projects provide counseling services.

Parent interviews

The Guild expressed concern because (1) we allowed projects to screen the parents we selected for interview, (2) some parents could not be located for an interview, and (3) some parents said they were contacted too late or had other problems with the services they received.

Because we did not want to contact any families who were known to be still experiencing trauma from their infant's death, we decided to give project staff the opportunity to screen the list of families we selected for interview. If projects had asked us to delete some families from our initial selection to ensure that we contacted only those families

that would comment favorably, it would appear, judging from the results of our parent interviews, that their efforts were not successful. For example, although one project asked us not to contact some families, two of the families we did interview from this project expressed a problem with the services they received.

Our reasons for not contacting any parents in Nebraska and for contacting parents only in Los Angeles for the California project are discussed on page 113 in our response to the Foundation's specific comments. Some of the parents we interviewed told us that they believed that counseling was offered too late after their infants' deaths to be very helpful. We are not suggesting what is or is not the most appropriate time to counsel parents. As stated in chapter 3, however, the problems cited by some of the parents we interviewed demonstrate the need for, and the importance of, projects' evaluating their own activities.

Self-evaluation

The Guild stated that projects should not evaluate their own performance because of the lack of objectivity. We believe that the Guild has misinterpreted the purpose of self-evaluation, which is to provide feedback to management on its operations to enable it to take corrective action when necessary. Self-evaluation is not intended to substitute for an independent review by an objective third party. We agree with the Guild that the projects need to be periodically evaluated by an outside organization, and in our report we recommend that HHS staff the SIDS Program Office sufficiently to enable it to do this.

APPROVED BUDGETS BY COST CATEGORY FOR 37 SIDS PROJECTS FUNDED IN FISCAL YEAR 1979

Project location	Personnel	Consultant and contractual	Counseling (note a)	Education and training (note a)	Autopsy related (note a)	Indirect costs	Other	Total
Alabama, Mobile	$ 36,866	$ -	$ 700	$ 1,000	$ 6,500	$11,060	$ 4,121	$60,247
Arkansas, Little Rock	19,227	6,590	-	-	17,834	1,845	4,737	50,233
California, Berkeley	95,019	9,000	-	-	-	32,516	29,916	166,451
Colorado, Denver	39,210	2,477	-	6,129	-	804	9,639	58,259
Connecticut, Hartford	37,770	-	1,500	-	-	14,179	3,828	57,277
Florida, Tallahassee	85,448	6,904	-	20,000	-	-	24,650	137,002
Georgia, Atlanta	29,410	-	-	2,500	10,500	3,297	4,293	50,000
Idaho, Boise	2,500	3,500	-	-	6,000	-	3,000	15,000
Illinois, Springfield	26,096	7,523	1,193	-	-	10,419	3,214	48,445
Illinois, Maywood	80,517	-	-	-	-	59,802	8,309	148,628
Iowa, Des Moines	30,691	600	-	688	-	10,742	7,000	49,721
Kentucky, Frankfort	12,051	-	17,000	15,300	-	5,000	5,326	54,677
Maryland, Baltimore	88,651	-	350	3,260	-	7,960	7,239	107,460
Massachusetts, Boston	46,599	32,420	10,600	2,500	1,800	51,585	9,250	154,754
Michigan, Grosse Point	40,527	63,657	-	-	-	-	7,400	111,584
Minnesota, Minneapolis	35,470	17,136	5,700	2,200	10,000	-	44,700	115,206
Missouri, St. Louis	58,312	9,125	-	1,500	-	-	16,562	85,499
Nebraska, Lincoln	34,588	16,154	-	6,000	-	-	-	56,742
New Hampshire Concord	18,207	910	1,834	1,456	-	3,828	3,111	29,346
New Jersey, Trenton	46,464	-	9,000	10,644	-	11,151	6,200	83,459
New Mexico, Albuquerque	39,816	4,500	-	425	3,000	11,711	12,376	71,828
New York, New York	87,888	9,075	-	1,500	-	8,928	18,064	125,455
New York, Albany	66,492	1,000	-	-	-	35,444	7,300	110,236

APPENDIX I

Project location	Personnel	Consultant and contractual	Counseling (note a)	Education and training (note a)	Autopsy related (note a)	Indirect costs	Other	Total
New York, Rochester	$ 46,426	$ -	$ -	$ 2,782	$ -	13,446	9,593	72,247
North Carolina, Raleigh	43,361	2,000	-	-	-	10,505	19,000	74,866
Ohio, Columbus	37,075	2,490	-	3,654	1,000	9,120	2,540	55,879
Oklahoma, Oklahoma City	40,809	4,000	11,000	2,500	-	10,035	6,656	75,000
Pennsylvania, Philadelphia	106,932	6,100	5,400	12,805	4,500	16,584	22,890	175,211
Rhode Island, Providence	21,568	-	6,000	2,000	-	-	2,065	31,633
South Dakota, Pierre	23,300	-	-	-	3,200	5,987	8,109	40,596
Texas, Dallas	30,988	-	2,800	4,140	13,800	9,071	5,800	66,599
Texas, Houston	66,936	35,780	-	-	-	-	997	103,713
Texas, San Antonio	8,361	-	2,000	5,450	3,148	2,503	3,551	25,013
Utah, Salt Lake City	69,339	-	-	2,092	4,500	971	4,840	81,742
Vermont, Burlington	6,202	-	-	5,000	3,000	1,732	3,000	18,934
Washington, Seattle	37,907	-	26,490	-	900	11,311	6,026	82,634
Wisconsin, Madison	45,800	-	4,000	3,000	6,000	7,920	11,514	78,234
Total	$1,642,823	$240,941	$105,567	$118,525	$95,682	$379,456	$346,816	$2,929,810

a/Represents only specifically identifiable amounts in budget submissions. Undeterminable amounts of budgeted costs in the personnel, consultants and contractual, and other categories are also directly related.

APPENDIX I

APPENDIX II

FAMILY NOTIFICATION FROM DATE OF INFANT DEATH

Project name	Sample of cases from SIDS project files	Number of cases not notified	Family notification from date of death: Within 48 hours	Between 48 hours and 7 days	More than 7 days	Unknown
University of Maryland School of Medicine	30	0	8	15	7	0
St. Louis Regional Maternal and Child Health Council, Inc.	30	0	2	5	1	22
Nebraska State Health Department	29	0	15	3	1	10
Loyola University Stritch School of Medicine	30	0	21	6	0	3
Medical and Health Research Association of New York City, Inc.	30	0	7	14	6	3
State University of New York at Stony Brook	24	0	21	2	1	0
University of Texas Health Science Center at Dallas, Southwestern Medical School	30	1	18	4	6	1
Harris County Health Department, Houston, Texas	30	4	3	4	19	0
California Department of Public Health Services	72	0	19	4	13	36
Illinois Department of Health	30	0	15	3	10	2
Florida Department of Health and Rehabilitative Services	30	0	0	0	1	29
Total	365	5	129	60	65	106

TIMELINESS OF COUNSELING OF SIDS FAMILIES

Project name	Total sampled	Data not available to determine if counseling occurred	Number of cases where families were counseled					Not counseled	Reasons for not counseling		
			Counseling occurred	Within 14 days	Between 15 and 28 days	More than 28 days	Date unknown		Could not locate family	Family refused	Other or unknown
University of Maryland School of Medicine	30	0	20	8	6	4	2	10	2	8	0
St. Louis Regional Maternal and Child Health Council, Inc.	30	6	20	6	7	3	4	4	1	3	0
Nebraska State Health Department	29	0	26	21	1	3	1	3	1	2	0
Loyola University Stritch School of Medicine	30	1	20	10	6	1	3	9	6	1	2
Medical and Health Research Association of New York City, Inc.	30	1	28	25	2	1	0	1	1	0	0
State University of New York at Stony Brook	24	0	24	23	1	0	0	0	0	0	0
University of Texas Health Science Center of Dallas, Southwestern Medical School	30	8	15	5	5	4	1	7	3	0	4
Harris County Health Department, Houston, Texas	30	0	19	15	2	2	0	11	4	5	2
California Department of Health Services	72	2	52	6	14	8	24	18	10	7	1
Illinois Department of Public Health	30	5	17	4	4	4	5	8	0	3	5
Florida Department of Health and Rehabilitative Services	30	0	20	12	4	2	2	10	7	1	2
Total	365	23	261	135	52	32	42	81	35	30	16

APPENDIX III

United States Senate

WASHINGTON, D.C. 20510

February 22, 1980

Honorable Elmer B. Staats
Comptroller General of the United States
General Accounting Office
441 G Street, N.W.
Washington, D.C. 20548

Dear Elmer,

We are writing to request a GAO audit of the Sudden Infant Death Syndrome Counseling and Information Project program authorized by part B of title XI of the Public Health Service Act.

The authorization of appropriations for this program will be due for reauthorization in fiscal year 1982 and the two authorizing committees will be developing legislative proposals in early 1981 to extend those authorizations.

This program has been authorized since fiscal year 1975, and we believe it is appropriate that a general program review and audit be undertaken at this time. Among the specific questions we suggest the General Accounting Office study are:

1. What general policies govern the awarding of SIDS counseling and information project grants?

   a. Does that policy require one program in every state and territory?

   b. How many grants are awarded state agencies; how many grants are awarded to nonprofit voluntary groups; and what factors are considered in deciding whether a program should be directed by a state agency or a nonprofit voluntary group?

2. Are voluntary groups with a demonstrated interest in SIDS involved in each SIDS project? What is the extent of that involvement?

APPENDIX IV

3. What mechanisms are utilized in awarding grants to ensure the programs can effectively carry out their responsibilities, are representative of and responsive to the needs of SIDS parents in the community, and are reviewed on a competitive basis? What role in that process is played by the advisory committee named by H.S.A. to review SIDS grant applications? What is the composition of that advisory committee? To what extent does it involve SIDS parents and other individuals with a professional interest in SIDS?

4. Has contract letting for SIDS programs been conducted in accordance with H.E.W. guidelines, and what provisions in those guidelines ensure protection of the public interest? Are the contracts awarded on a competitive basis? Are the requests for proposals adequately publicized?

5. Does the performance of the current contractee (Lawrence Johnson and Associates) meet H.E.W. standards normally applicable to contracts of this kind and adequately meet the contract terms?

6. How does this contract performance compare with the performance of the previous contractee, the National SIDS Foundation?

7. Is the contract for the clearinghouse activity consistent with the requirements of section 1121(a)(2)(B) of the Public Health Service Act as added by P.L. 96-142?

8. Has H.E.W. designated an administrative unit to carry out the SIDS program as required by section 1121(a)(1) of the Public Health Service Act as amended by P.L. 96-142? Has that unit been assigned such professional and clerical staff and consultants as well as management and supporting staff as are necessary for it to carry out its functions effectively, as required by law? Are there effective working relationships between the SIDS Administrative Unit in the Health Services Administration and those responsible for developing the SIDS research program at the National Institute of Child Health and Human Development that ensure appropriate coordination of clearinghouse and research activities?

In order for the results of your review to be taken into consideration by the authorizing committees when the statutory

APPENDIX IV

authorities for the SIDS program are reviewed in the 97th Congress, we would appreciate an informal report by August 1, 1980, and a final report, including recommendations for program improvement and any legislative recommendation that may be suggested by your review, by November 15, 1980.

With every good wish,

Cordially,

Alan Cranston
Chairman
Subcommittee on Child
and Human Development
Committee on Labor and
Human Resources

Warren G. Magnuson
Chairman
Committee on
Appropriations

Henry A. Waxman
Chairman
Subcommittee on Health
and the Environment
Committee on
Interstate and
Foreign Commerce

cc: Dr. Julius B. Richmond

APPENDIX V

DEPARTMENT OF HEALTH & HUMAN SERVICES

Office of Inspector General

Washington, D.C. 20201

13 NOV 1980

Mr. Gregory J. Ahart
Director, Human Resources
Division
United States General
Accounting Office
Washington, D.C. 20548

Dear Mr. Ahart:

The Secretary asked that I respond to your request for our comments on your draft report entitled, "The Sudden Infant Death Syndrome Program Helps Families But Needs Improvement." The enclosed comments represent the tentative position of the Department and are subject to reevaluation when the final version of this report is received.

We appreciate the opportunity to comment on this draft report before its publication.

Sincerely yours,

Richard B. Lowe III
Inspector General (Designate)

Enclosure

COMMENTS OF THE DEPARTMENT OF HEALTH AND HUMAN SERVICES ON THE GENERAL ACCOUNTING OFFICE'S DRAFT REPORT ENTITLED "THE SUDDEN INFANT DEATH SYNDROME PROGRAM HELPS FAMILIES BUT NEEDS IMPROVEMENT"

GAO RECOMMENDATION

We recommend that the Secretary of HHS develop a standard SIDS grant application format in which grant applicants are required to submit specific, measurable objectives for those aspects of operations critical to an effective program. In this regard, HHS should also issue guidance to applicants on the types of objectives appropriate for new and continuing projects and assure that projects evaluate their own performance as required.

DEPARTMENT COMMENT

We agree that further guidance to applicants should be prepared. Specific program objectives and performance criteria will be developed in FY 1981 and will be implemented in FY 1982. However, we will not develop a standard sudden infant death syndrome (SIDS) grant application format as guidance provided in OMB Circular A-102: Uniform Requirements for Grants to State and Local Governments, precludes this.

GAO RECOMMENDATION

We recommend that the Secretary of HHS establish criteria for funding SIDS grantees considering such factors as the number of SIDS cases in their service areas and the need for Federal funding in those areas.

DEPARTMENT COMMENT

We concur that the criteria for funding should be revised to reflect multiple factors affecting the incidence of SIDS. We will develop such criteria in FY 1981 to be implemented in FY 1982.

GAO RECOMMENDATION

We recommend that the Secretary of HHS issue guidelines on projects' appropriate use of community groups, including volunteers. These guidelines should include a clear statement of:

(a) the types of activities appropriate for community groups,

(b) the circumstances under which the groups can be used, and

(c) projects' responsibilities for ensuring appropriate use of the groups.

DEPARTMENT COMMENT

We concur. The Department is in the process of developing guidance to include these requirements which will be implemented in FY 1982.

GAO RECOMMENDATION

We recommend that the Secretary of HHS issue additional guidance to projects concerning case management and epidemiological data they are to collect and submit; periodically evaluate this data, and ensure that only data which are needed and used are collected.

DEPARTMENT COMMENT

We concur. In order to issue additional guidance, we will develop a data system to capture the appropriate information. We will coordinate these activities with the National Institute of Child Health and Human Development, NIH, and the National Center for Health Statistics, OASH. This data system will be developed in FY 1981 to be implemented in FY 1982.

GAO RECOMMENDATION

We recommend that the Secretary of HHS develop standards for measuring SIDS projects' performance and evaluate project performance against those standards.

DEPARTMENT COMMENT

We concur. Performance standards for measuring and evaluating SIDS projects will be developed in FY 1981 to be implemented in FY 1982.

GAO RECOMMENDATION

We recommend that the Secretary of HHS enforce requirements that grantees promptly report to HHS when they will not be spending all of the funds they were awarded and assure that future grant awards are offset with unexpended fund balances.

DEPARTMENT COMMENT

We concur. PHS policy will be enforced by treating estimated or actual unobligated balances remaining at the end of a budget period in the following ways:

1) as an offset (deduction) from the continuation award, if there is one,

2) as a carryover for use in a subsequent budget period, as additional funding authorized for purposes requested and justified in the continuation year application, and

3) as a refund to the Government.

APPENDIX V

GAO RECOMMENDATION

We recommend that the Secretary of HHS issue instructions--such as those applicable to the SIDS grant program--which prohibit panels reviewing contract technical proposals from including persons who might have reason to be biased, or might have the appearance of being biased against any competitor.

DEPARTMENT COMMENT

We concur. On October 10, 1980, the Department issued a Transmittal 80-06, a revision to the Procurement Manual, Section 3-3.5005 (b) (14), which stipulates program responsibility in procurement planning concerning conflict of interest. We will consider expanding this in the near future to include bias as a factor for consideration in evaluating technical proposals.

GAO RECOMMENDATION

We recommend that the Secretary of HHS assure that the scope of work statement in each contract provides adequate specificity regarding HHS' requirements and expectations.

DEPARTMENT COMMENT

We concur. The HSA will continue to adhere to the departmental procurement regulations 3-3.5102 which requires specificity in scope of work in contracts.

GAO RECOMMENDATION

We recommend that the Secretary of HHS assure that the SIDS Program Office is appropriately staffed on a continuing basis to permit it to periodically evaluate grantees' performance and compliance with program requirements.

DEPARTMENT COMMENT

We concur. Six staff years are authorized for SIDS program activities, including evaluation of grantee performance and compliance with program requirements.

APPENDIX VI

Sudden Infant Death Syndrome Regional Center
School of Social Welfare
Health Sciences Center
State University of New York at Stony Brook
Long Island, NY 11794
telephone: (516) 246-2582

November 12, 1980

Gregory J. Ahart, Director
United States General Accounting Office
Washington, D.C. 20548

Dear Mr. Ahart:

I am writing in response to the draft report on the Department of Health & Human Services Sudden Infant Death Syndrome Program prepared by your office and forwarded to me for comment. I appreciate the opportunity to respond to the report, which on the whole represents a thorough examination of the strengths and weaknesses of the SIDS Program.

There are, however, some critical points which we believe need further amplification in relation to the comments in the report on the Stony Brook Program. We were, of course, delighted to note that the reviewers recognized that the Stony Brook Project was "almost always meeting the HHS objectives for the SIDS four-point case management program (p. 15)", while the other projects experienced "variation" in this regard. Our ability to achieve this high level of performance with respect to the four points (identification, certification, notification, information and counseling), as well as in our community education and training activities, is the result of the level of resources available to the program and the manner in which we display and organize these resources. Thus, we were dismayed to see on page 48 the statement that the Stony Brook Project received "almost as much, $110,000 to serve an estimated 59 families. California received about $164,700 to serve an estimated 758 families". The report goes on to state that HHS needs to re-evaluate funding levels ... with respect to the number of estimated SIDS cases. This may be quite appropriate, but we believe it is an oversimplification of the problem because it fails to recognize the relationship of funding levels to measures of program quality and effectiveness, such as achieving the four-point case management program. The principal variable in this regard is the extent to which project engages in the most costly aspect

JEAN SCULLY, MSW, CSW
Director

Vivian Kessler
Assistant
Community Education & Training

JAMES P. DEEGAN, MSW, CSW
Counselor Coordinator

APPENDIX VI

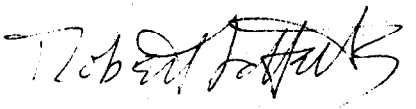
of the program, i.e., the counseling component. In addition, one needs to recognize that there are certain administrative costs involved regardless of the size of the program. Therefore, we would suggest that the report, on page 48, should include program effectiveness as a principal criteria for the re-evaluation of funding levels.

On page 54 the report calls attention to the need for HHS to establish more specific measurable objectives. We agree with this recommendation. However, the commentary on the Stony Brook Program on pp. 53-54 is misleading since it implies that our statement of goals is so vague that their attainment could not be measured. This fails to recognize that we have operationalized our five qualitative goals (quoted on p. 54) in an extensive evaluation system that we employ in the absence of HHS quantatitative guidelines. In fairness to the Stony Brook Project we believe this should be noted in the report, and I am attaching the evaluation documents used in 1979 and 1980 for your information. In addition, the goals quoted on page 54 do not include the complete goal statement included in our 1979 application. Naturally, if a specific project's material is used as an example, that material should be presented in full. This is not to say we disagree with the main point being made in the report. The manner of presentation, however, can easily be misunderstood without noting the points made above.

I hope that my explanations, comments and enclosures are helpful.

Let me again say that I appreciate the opportunity to respond to the draft report.

Sincerely yours,



Robert B. Lefferts, Ph.D.
Project Director

RBL:sm
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APPENDIX VII

Maryland SIDS Information and Counseling Project

University of Maryland
School of Medicine
Medical School Teaching Facility
10 South Pine Street, Suite 400
Baltimore, Maryland 21201

November 7, 1980

Mr. Gregory Ahart
U.S. Government Accounting Office
Human Resources Division
Washington, D.C. 20548

Dear Mr. Ahart:

We are in receipt of a copy of your draft report on the Department of Health and Human Services' Sudden Infant Death Syndrome Information and Counseling Program, and we appreciate the opportunity for review and comment. There are two statements made related to our Project, The Maryland SIDS Information and Counseling Project, for which we request reconsideration.

Page 23, Paragraph 2 states..."As another example, the Maryland Medical Examiner's Office would not permit the project to contact SIDS victims' families for 6 of the 30 cases we reviewed until special laboratory studies were completed. These studies were completed 12 to 30 days after death. Maryland project staff told us that in April, 1980, they took action to correct the problem..."

There are implications from this statement which definitely need clarification. Since it began, our Project has maintained an on-going, congenial, and profitable relationship with the Office of the Chief Medical Examiner (OCME) in Maryland. In the 6 cited cases, it was the opinion of the pathologist that a diagnosis of SIDS could not be made from the initial gross examination, and the case was put in a "pending further study" status, which certainly was his/her right and responsibility. From the Project's point of view, one advantage in the rationale for placing the case in "pending" status is to prevent making a diagnosis of SIDS and later having to revise it when laboratory data becomes available. In cases where there has been a revised diagnosis, the parents are obviously subjected to additional trauma. Laboratory studies which you designate as "special" are done routinely on all cases when there is an indication that, in fact, the diagnosis may be something other than SIDS. In addition, the last sentence in the statement implies that the Project did nothing about the situation until April, 1980. In

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fact, there has been continuing open dialogue with the OCME on a case-by-case basis as to whether counseling services should be offered to the family based on the needs of families experiencing sudden death, rather than on SIDS as a definitive diagnosis. It was in April, 1980, that a policy was established to formalize that procedure routinely for "pending" cases, and to incorporate a letter from the pathologist to the family in cases where counseling is indicated.

2. Page 60, Paragraph 2 states..."Although the Maryland project had evaluated some aspects of its operations, it had not evaluated the timeliness with which the 4-point program was being implemented...".

The vagueness of this statement, almost by innuendo, accuses the Project of inadequate performance, but does not clarify which "critical aspects" are included in its failure to evaluate "timeliness." We believe there should be clarification of what is meant by your statement.

Thank you for the opportunity to review the draft report. We would be uncomfortable to have these statements about our Project's functioning remain as they presently appear.

Sincerely,

Stanford B. Friedman, M.D.
Project Director

SBF:mg

Sudden Infant Death Syndrome Regional Center
LOYOLA UNIVERSITY MEDICAL CENTER
2160 South First Avenue, Maywood Illinois 60153 312 531-3420

November 17, 1980

Mr. Gregory J. Ahart, Director
Human Resources Divion
United States General Accounting Office
Washington, D.C. 20548

Dear Mr. Ahart:

I am responding to your request for our reaction to the draft of the proposed report on the DHHS Sudden Infant Death Syndrome Information and Counseling program. I and the rest of the staff have reviewed the draft critically, and, in general, feel that it is a fair, equitable evaluation of the situation. The draft is general in orientation and does not specifically identify our Center. However, we feel that the evaluations, as presented, are fundamentally accurate.

One minor question might be raised in terms of the conclusion that linking SIDS services with the Maternal and Child Health Program would present certain advantages. We feel that unless great care is taken for special identification of the non-government sponsored SIDS Centers, these areas might suffer.

I would like to congratulate you on the fair and even approach that you and your staff evidenced. Frankly, I was rather apprehensive when informed that SIDS parents would be contacted for their evaluation --not that I feared the results, but I was apprehensive that harm might be done to these parents. In actual practice the situation was handled well; the questionnaire was short and direct, and a psychologist directed the questioning. I thought that this was more than adequate handling of a difficult situation.

My conclusions are that the proposed report is a fair and equitable one, and this Regional Center, for one, has no specific objections to anything in the draft.

Sincerely,

Julius Goldberg, Ph.D.,Dr.P.H.
Project Director
SIDS Regional Center

JG/es

APPENDIX IX

2956 Eric Lane
Dallas, Tx. 75234

Mr. Gregory J. Ahart
Director
U.S. General Accounting Office
Washington, D.C. 20548

Dear Mr. Ahart:

After serious review of the draft report on the Department of Health and Human Services Sudden Infant Deaht Syndrome Information and Counseling Program, I am responding to you with some of the major problems I can identify. I am distressed that this report must be made so quickly, and that I have so little time to respond, However, I will briefly address the points in the report that I think need further consideration. As President of the International Council of Guilds for Infant Survival and a SIDS parent, I have always had clear expectations of the role of the SIDS Projects. I understood why the projects were created in the beginning, but believe that like so many other government programs, these projects have become a "white elephant." I think we really need to address the issue as to why these projects were formed, what they were set up to accomplish, their ability to accomplish these goals, their efficiency in accomplishing these goals, and the question as to whether they are the actual factor in these accomplishments. Then we must decide if we,in fact,need these projects at all.

Overall, I see that counseling is a major objective. These projects were set up to provide counseling to SIDS parents. The chart in your report indicates that many projects either do not offer counseling or do not pay for it. I do not beleive that the projects that do not pay for counseling are utilizing the parent groups for this purpose, although that is the primary purpose of those parent groups' existence. I do see a host of reasons why counseling was not performed. Something is seriously amiss if this continues.

I noted that the bulk of the Federal funds are used for staff salaries, and relatively little funds are identified specifically for use in counseling. In California, you state that the coroner's office provides no direct services to SIDS families, and that the local health department provides counseling services and report them to the SIDS project. Why,then is this project funded? In another project, staff members, who have never experienced the trauma of a SIDS death personally, determine not ot offer counseling to the bereaved family because it is too late. Too late??? How can this be justified?

Funding itself is a major problem. Funding is totally inconsistent with the incidence of SIDS in a defined area, clearly a waste of tax dollars. Alternate funding is recommended, but the Federal funds continue to support the programs. No alternate source will be sought until the funds are withdrawn by the Federal government. Efficiency is not governed, nor are actual accomplishments, and neither issue is addressed once a project has funding. Performance is not required in order to be funded, nor is performance guaranteed in the guidelines. Why must we support such an illogically managed program.

The report itself is not reliable in addition to all the other problems. Officials of the project had the opportunity to screen parents that were to be reviewed. Obviously, this is controlled data. Some parents were simply not availble to be interviewed. What happened to them? Are there actually parents benefitting from this project? Or is this a "white elephant" to drain the program of funds that could be better utilized in some other area? Under no circumstances should any project be allowed to evaluate their own effectiveness, or whom should be interviewed for this report.

The projects were set up to assist families, to improve responsiveness and ability of professional and community agencies to the SIDS problem, to increase awareness of SIDS, and to evaluate the effectiveness of the SIDS program. Parents, the suggested benefactors of the program, reported that some nurses were too late to be of much help, were not knowledgeable about SIDS, and were not sensitive to the parents' grief. The projects are clearly not functioning in the roles they were established if this is the case. I must also consider the fact that the project screened the parents that you interviewed, thus allowing you to interview only parents that would favor their services. This is controlled data, and therefore, I cannot rely on its accuracy. I must comment that from the various parents I have spoken with in the years I have been working with SIDS, I have come across very few that believe that the projects are serving the purpose for which they were intended. Granted, the projects are funded, and those funds allow the projects to accomplish more than a voluntary organization without such massive funds at their disposal. However, a voluntary organization is primarily interested in the services to the families and I believe that such organizations would be more effective in this role if these funds were also available to their organizations.

The point that now comes to my mind is the process of the grant awards. Sole source procurement is clearly wasteful and inefficient. Had these grants been available to individual volunteer organizations rather than Federal projects, I believe that the results would have been measurably more effective. The awarding on a sole source basis in some cases has hindered the program, and the requirements to HHS a hindrance in others. In both cases, the parents, the proposed benefactors of the program, are the recipients of ineffective good intentions. I know that management performance must be standardized so that all projects, if they are to continue, have the same functions and performance standards. These standards must be accountable to the benefactors. (A representative from NFSIDS once again guarantees a biased view of the project's effectiveness if a member of that organization is a paid staff member, or even a volunteer that has the possibility of some gain by favorable reporting. I do not understand how you can possibly find credibility in any such report, yet you have in this very report.) Under no circumstances should the grantee evaluate the perfomance of their own grant. In a case such as this, there exists no objectivity whatsoever.

I think you should seriously consider the functions of the projects. Death certificate review is not being carried out for lack of a means to implement this function. Confidentiality restrictions, among other reasons, is reason enough that a project has no more access to the names of SIDSfamilies than a voluntary effort. Questionable cases are not going to be found in the SIDS records. Clearly if the cause of death is asphyxiation, the death certificate will never reach the SIDS project. Notification of the cause of death in 24 hours is not being adhered to. (This should be the responsibility of the coroner who performed the autopsy and is better qualified to respond the any questions the family might pose.) Counseling is insufficient in

the projects that you reviewed. The identification of the SIDS infants is pronounced as effective because 95% are being autopsied. Thats great, but is this really due to a Federally funded project, or to increased awareness on the part of the coroners? This must be seriously considered in order to provide a reasonable evaluation of these projects.

For more than 15 years the International Guild for Infant Survival has existed, long before the SIDS porjects, to assist families in providing information, counseling, and various other support means when they experience a SIDS death. The Guild has educated both professionals and non-professionals about the seriousness of SIDS. We have diligently sought a means to have SIDS reported as the cause of death on the death certificate, and we have succeeded. We have worked with families, and community agencies to assure that suspected SIDS cases are autopsied. We have done all this on a voluntary effort. When we needed funds, we solicited them for that specific purpose. We pay no staff, yet we offer the same services that these projects were set up to offer. We had hoped that the funding from the Federal government would assure these services to families, and that possibly quality could be guaranteed in all areas. Unfortunately, this is not the case.

We have 33 white elephants, and I personally do not wish to see any more. Perhaps your recommendation of absorbing the administration of these projects into MCH would provide more consistent services and better management. Perhaps it will only increase the problems that already exist. More appropriately, I think the projects should more fully utilize the voluntary groups in their areas to provide these services. Further, I would recommend that in order to justify the tremendous salaries in each project, that each project be required to provide a qualified counselor to adequately service that area. A project that does not have a counselor should not be considered for funding, and certainly not at the costs currently projected. The personnel costs of the projects are totally outrageous and unjustified. This money could be better spent in researching the cause and prevention of SIDS.

Your recommendations are appropriate under the circumstances in all but a few exceptions: 1. For obvious reasons, projects should not be allowed to evaluate their own performance. 2. The role of the voluntary groups must be considered and utilized fully as part of this program. This is an essential ingredient that cannot be overlooked. 3. A review panel must be totally objective.

In conclusion, I wish to state that I personally beleive the projects are ineffective. However, they do serve some purposes. I would strongly recommend that the funds be decreased if counseling is not provided within the staff. Performance standards must be met, and must be the same in each project. Voluntary groups must be utilized fully. The purpose of the voluntary group should not be to control the project at all, but to promote the services of the project. If a project cannot provide records of its accomplishments in meeting its objectives established in the beginning, then funding should be withdrawn. If the project does not fully comply to the standards for which it was established, then it is a ehite elephant, and should be eliminated as a burden to the SIDS program. Unbiased evaluation is essential to efficiency, and we who have worked with SIDS for results are interested in efficiency. If a project cannot justify its cost with its effectiveness, then funds should be withdrawn. SIDS cannot afford to spend all its funds in helping people after the fact, but must make provisions to allocate more funds for research instead.

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I hope that my comments have enlightened you. I am very concerned about the effectiveness of the SIDS program, and hope that your report will have some effect on the projects. It is my concern that all families be guaranteed the best services for the money allocated. I do not believe that this has been done in the past, and I hope that your report can correct this problem.

If I can offer any further comments please feel free to call me at my home any evening. I do work full time (8-5) and in most cases am not available during those hours. My number, for your convenience is 214-243-1261. Please keep me informed as to the progress and results of your report to Congress.

Sincerely,

Nina Copp

Nina Copp
President
International Council of
Guilds for Infant Survival, Inc.

NC:kj

APPENDIX X

National Sudden Infant Death Syndrome Foundation
310 S. Michigan Ave. • Chicago, Ill. 60604 • (312) 663-0650

November 10, 1980

Gregory J. Ahart, Director
Human Services Division
U.S. General Accounting Office
Room 130
12420 Parklawn Drive
Rockville, Maryland 20857

Attention Bernard Ungar

Dear Sir,

I am authorized by the Board of Trustees of the National SIDS Foundation to provide you with our organization's reponse to the proposed draft report on the Sudden Infant Death Syndrome.

RECOMMENDATION

THE NATIONAL SIDS FOUNDATION VIEWS THE GAO DRAFT REPORT AS INCOMPLETE, INNACURATE AND BIASED, AND URGES THAT IT BE EXTENSIVELY REVISED BEFORE SUBMISSION TO THE CONGRESS.

Introduction

Acting at the behest of the National SIDS Foundation and the Americal Academy of Pediatrics, an audit of HHS's administration of the Sudden Infant Death Syndrome (SIDS) program by the General Accounting Office was requested on February 22, 1980, by Senators Warren Magnuson, Alan Cranston, and Representative Henry Waxman. The GAO spent over one-quarter of a million dollars and over six months to conduct the study. The result is disgraceful. Lack of leadership and sloppy administrative practices within HHS are condoned with the usual bureaucratic plea for more staff and money. The sole recommendation to Congress -- namely consolidation of the SIDS information and counseling program with the Maternal and Child Health Programs, authorized under Title V of the Social Security Act is made even though GAO roundly criticized administration of the Title V programs in its report (HRD-80-24) dated January 21, 1980.

Major voids exist in the GAO report. No historical perspective is provided to place HHS's SIDS program in the context of SIDS management in the United States. The reader of the report is left with the impression that management activities and education and counseling began with the federal legislation of 1974 and are concentrated solely within the confines of the Parklawn Building in Rockville, Maryland. The voluntary health organizations interested in SIDS are depicted as nagging cry-babies obstructing the noble mission of the federal bureaucrats.

Without exception, when disagreement is identified between the National SIDS Foundation and HHS, GAO sides with the "feds." Though the report mentions "philosophical differences," only the HHS side is presented. Would it not be helpful to devote a few sentences to describing the organization and activities of the National SIDS Foundation and the International Guilds for Infant Survival? Even if the arguments of the Foundation are not mentioned, might not the unbiased reader of the report gain some perspective with the knowledge that the four-point SIDS management program was propounded by the Foundation and that out of the 37 federally funded projects, 30 were directly organized with technical assistance from the Foundation and two by the Guild?

The most glaring shortcoming in the GAO report is the failure to apply any measures of cost-effectiveness to the federal SIDS efforts. The auditors blithely accept the HHS estimate that $5.5 million in federal funds would be required to extend services nationwide (page 90), without taking into account the excellent SIDS programs in such states as Alaska, Hawaii, and Oregon, that operate without any federal dollars. The report states (page 80) that HHS awarded a twelve-month contract for $114,998 to a for-profit corporation for the establishment and operation of a national clearinghouse for SIDS and related information. No mention, however, is made of the fact that the National SIDS Foundation carries out the same exact activities, hopefully in a more compassionate manner, without using any taxpayers dollars.

It seems apparent to us that the GAO auditors got lost amongst the trees and failed to find the forest. The work is shoddy! With all the resources available for this study, how is it possible that the GAO auditors were unable to interview any parents in the entire state of Nebraska, or gain a perspective of services provided in the state of California by only talking to parents in Los Angeles County (page 13)? We believe it is more than just coincidence that the California and Nebraska projects were the ones to which the National SIDS Foundation directed most if its criticism.

The appearance of fairness of the audit is also called into question by, what we view, as excessive fraternization between GAO and HHS staff. For example, it was unseemly for GAO to participate in an HHS-sponsored meeting in Minneapolis in June, 1980, while the audit was being conducted. Who audits the auditors?

We feel it necessary to make the seemingly harsh comments above, not because of any personal malice to individuals in either HHS or GAO. We are distressed, however, that GAO has missed a golden opportunity to address the larger issue of how program philosophy is determined in the Department of HHS. It is not just the National SIDS Foundation nor the Guilds for Infant Survival, but a number of voluntary health

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agencies that feel that they have been "frozen out" of programs they originally spawned. It was our hope that the GAO auditors would discern that the most successful federally funded projects, judged by the quality of their service and education programs, were those where committed volunteers and paid professional staff worked in concert towards common goals (ie. Mexico, Ohio, Washington, Long Island, Massachusetts). In those states where there was continuing conflict between volunteers and paid professionals, the services suffered (ie. Nebraska, California, Missouri). The same thesis holds true for program administration at the national level. It is not only for economic reasons that civil servants must learn to capitalize on the talents of committed volunteers. The Government belongs to us all!

DETAILED COMMENTS ON THE GAO DRAFT REPORT ARE AS FOLLOWS

Chapter 1, Introduction Page 2: A myopic picture is provided of SIDS activities in the United States as if the "creation" occurred with the establishment of the HHS program following the legislation in 1974. A brief background statement should include a description of the campaign of the National SIDS Foundation started in 1972 to "humanize" the handling of SIDS in the United States.

Page 9: The description of the voluntary organizations is totally inadequate. At the very least, there should be a description of where they operate and how they are organized. For example, all policies of the National SIDS Foundation are reviewed by its Medical Board consisting of the most distinguished scientists in the field of SIDS research and management.

Page 10: A disclaimer should be injected that an unbiased assessment of the grant review process could hardly be obtained by attendance at only one session after the audit commenced.

Page 13: The credibility of the entire study is brought into question by the fact that it was impossible to locate any parents in the state of Nebraska, and that parent interviews in the state of California were limited to Los Angeles County. Obviously, nothing can be done about these deficiencies now, but the GAO report would gain a little status if the agency "ate a little crow."

Chapter 2, page 14, Project Performance: The initial paragraph is confusing. GAO says that they cannot evaluate project's success because of the lack of HHS performance standards, yet they (properly) proceed to use the four-point management system as a performance standard.

Page 15: The assertion is made that SIDS projects are providing community groups with the opportunity to provide advice and consultation without any documentation, whatsoever. Who was asked? Who responded?

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GAO describes the methods by which they assessed compliance with the four-point management program. The methods for assessing the adequacy of community group input should be outlined or else no conclusion should be published.

Page 16: The statement is made that some of the voluntary groups insist on access to the names of SIDS victims' families regardless of whether the families give their permission. Which ones? It is a policy of the National SIDS Foundation that families not be visited by parent volunteers unless they have given their permission. The wording gives a deceptive picture of the policies of the Foundation. Incidently, Mr. Ungar of GAO was given this information in writing during the oral debriefing in Chicago, on September 18.

Page 20: Half of the detected deficiencies in documenting the cause of death (13 out of 26) occurred just in the state of California. Yet, GAO is most "diplomatic" about never mentioning that the California project is a disaster.

Page 26: GAO appears to accept alot of "finger pointing" as an excuse for poor project performance. Invariably, deficiencies are blamed on "others" ie. health departments, medical examiners, etc. What about just plain poor program performance?

Page 27: GAO is to be commended for trying, in some localities, to gain a measure of "consumer" satisfaction with project services. We judge the fact that when 19 our ot 82 families contacted were never even offered counseling services that the project performance should be judged to be poor. Why not just say so?

Page 31: Again, another calumny against the Guild and Foundation. How was the evidence for participation or lack of participation of Guild or Foundation representatives sought? Surely, there must be variability from project to project. Surely, the GAO auditors were able to identify the projects where good communication took place between the voluntary organizations and project staff, and the projects where the communications were poor. Because relationships between the voluntary organizations and the federally funded projects was a specific item of study, we deserve better than the blanket statement that appears at the top of page 31.

Page 32: Doesn't the fact that the California project depends solely on parent volunteers to provide all counseling in the San Diego region, suggest again, that there is something wrong with the California project?

Page 33: The statement at the top of page 33 is typical of the bias shown throughout the report against the National SIDS Foundation. Did the GAO simply accept the word of a project official in St. Louis, that the Kansas City Chapter of the Foundation discourages visits by

the local Health Department to families? Perhaps it is true, but was an official of the Kansas City Chapter given the opportunity to respond to the accusation?

Page 34: The statement by the SIDS program director, regarding appropriate involvement of voluntary groups as part of community councils should be framed as an example of "bureaucratic blather." She says that "she and a representative from BCHS-Division of Policy Development, plan to develop guidance in this area and expects to have it completed and issued by the end of 1981." Incredible!

Chapter 3, Grant Award and Administration, Page 35: GAO says that HHS followed its own policies and procedures to ensure that grants were awarded on a competitive and objective basis. They did not assess, however, whether or not HHS's policies and procedures are satisfactory to meet national needs. The report points out that the funds awarded to individual projects were not necessarily commensurate with either the number of SIDS cases in the area, or the adequacy of local resources. GAO should have pointed out that states like Mississippi and Tennessee, which have great needs and inadequate resources, don't have any Federal grants. Thus, while HHS had a review process to examine the merits of individual proposals, local need was factored in at only five out of a total 100 points. Again, GAO gets lost in the trees.

Page 39: GAO states that "The office prefers to work through State Health Departments for state-wide projects." That is obvious, but is the policy stated in any grant manual, and if so, under what authority? It is one thing to prefer a particular type of organization, but quite another to discourage other applicants, as HHS has done. GAO chooses to ignore the allegation of the NSIDSF that existing state-wide projects not connected to health departments who are threatened with having their funds withdrawn, and that only health departments have been encouraged to apply for future funds. Apparently, our complaint was not even investigated.

Page 41: While GAO states that "The award of two grants for Nebraska appears questionable" there is no examination of the circumstances of the two awards. Again, as occurs throughout this report, GAO suppresses all information that places HHS in an unfavorable light in awarding grants or contracts.

Page 46: Another "convenient" suppression of important information regarding Nebraska. Why doesn't GAO mention that the Regional Health Systems Agency of Nebraska recommend disapproval of the project submitted by the State Health Department? Thus, it was not only the local Foundation Chapter that protested. That HHS later overruled the recommendation of the Nebraska HSA seems irregular when they admit they don't have the staff or the time to adequately supervise existing programs. The obvious collusion between Nebraska Health Department

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officials and HHS is "swept under the rug."

Page 58: GAO calls for more site visits to projects even in the fact of the admission that HHS has not developed criteria for judging the quality of performance. Program officials say that they don't have enough travel money. The Foundation supplied written information to GAO (gained from the Senate Appropriations Committee) that in FY '76 - 18% and in FY '77 - 23% of the total amount of money going for grants and contracts was allocated for travel, consultants and conferences.

Chapter 4, Contracts, Page 61: GAO concludes that HSA "objectively and equitably" evaluated the five contract proposals. Would that GAO have "objectively and equitably" have evaluated the protests of the Foundation in regard to the contracts. Instead, they use a wide brush with white paint to exonerate the federal bureaucrats from any wrong doing. Even if the GAO did not find merit in any of the Foundation's arguments, might not the report seem more fair if some of them were at least cited?

Some examples:

Page 67: After only one year of performance on the contract, doesn't it seem remarkable that HSA staff suddenly became aware of "other" organizations with the apparent capabilities to perform the required services? Why are none of the names of these organizations with such potential not cited?

Page 68: The implication is given throughout that it was the Foundation that desired a sole-source contract. Yet, GAO was provided with written documentation that the Foundation urged that the contract be put out for competitive review. It was the director of the Bureau of Community Health Services (Dr. Martin), his deputy (Dr. Marshall), and the SIDS program director (Ms. Norris) who as late as November 1979, insisted that they wanted a sole-source contract.

Page 69: GAO states "The HSA official who was alleged to have told the Foundation that its contract would be extended was not authorized to make such a statement." A rather mild and questionable admonition for the Deputy Director of the Bureau of Community Health Services, Dr. John Marshall, who according to Mr. Ungar of GAO, admitted making the statement.

Page 71: A wording change is requested in line 17, to read "that the Foundation --- was not inclined to aggressively pursue its contract efforts solely through health departments."

Page 72: The dispute between Foundation and HSA officials about the department's insistance on a monolithic approach through state health departments is discussed. Absent from the GAO Audit, however, is the information that at a meeting on February 10, 1978, Dr. Edward

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Martin, Director of the Bureau of Community Health Services, supported the contention of the Foundation and ordered his subordinates to promote a more flexible approach in mobilization of community resources.

The GAO acknowledges on pages 70 & 71, that the terms of the contract were not "sufficiently specific" and in other instances, that HSA did not compel the Foundation to fully comply with the contract requirements. Yet, on page 72, they state that the Foundation reports did not contain all the information that HSA desired after stating that the information that HSA desired was never clarified. Catch-22!

Page 73: GAO states that Lawrence Johnson & Associates (LJA) were slowed in their conduct of the contract work because they couldn't share the Foundation's experiences as expressed in the final report. That's ridiculous! Though not delivered to HSA, all the information eventually contained in the final report was submitted to the Senate Subcommittee on Child and Human Development during the hearings on Renewal Legislation and appear in the Senate Report dated March 1, 1978.

Page 73: In discussing the Foundation's shortcomings in the contract work, GAO purposefully omits mentioning the written commendations prepared by the project officer, Dr. John Marshall, dated May 9, and July 28, 1978. I say, purposefully, because in the verbal debriefing, GAO assured the Foundation that HHS would be criticized for criticizing performance on one hand, and providing written commendations on the other. In the verbal debriefing, GAO also said that Dr. John Marshall admitted (not alleged) that he provided false reasons to the Foundation about why the contract was terminated. Again, more whitewash.

Page 77: Why were only four out to 19 states contacted by GAO to testify about LJA's performance on the contract?

Page 79: Concerning LJA's evaluation contract, isn't it strange that it took GAO to inform HSA officials about what was going on with one of its own contracts?

Page 80 - Information Clearinghouse: That GAO is not the slightest bit interested in assisting the Congress to detect waste and duplication in HHS is evidenced in the lack of any comment on how this expensive new clearinghouse duplicates the services that the National SIDS Foundation has provided to the public for the last 15 years. Clearly, HHS is bent on building its own empire with taxpayer dollars, even if the same services are available through a voluntary agency. GAO, the "Congressional watchdog," is asleep!

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Conclusion

For all the reasons cited above, the National SIDS Foundation finds the draft GAO report as incomplete, inaccurate and biased, and urges that it be extensively revised before submission to the Congress.

Sincerely,

Abraham B. Bergman, M.D.
Vice-President

ABB:kw

GAO'S RESPONSES TO SPECIFIC COMMENTS OF THE NATIONAL SIDS FOUNDATION

In addition to expressing several general concerns about our review and draft report, the Foundation made numerous comments regarding specific issues discussed in the report. These comments are cited below along with our responses.

COMMENT

"Lack of leadership and sloppy administrative practices within HHS are condoned with the usual bureaucratic plea for more staff and money."

RESPONSE

This statement is incorrect. Our report does not condone lack of leadership or sloppy administrative practices. It identifies several areas where improvement in management is needed. For example, we pointed out that in 1979, HHS did not adequately track grantees' use of previous years' funds and failed to apply unused funds to the next period's grant awards. (See p. 34.)

Also the report states that insufficient staffing has been a major problem impeding the ability of the SIDS Program Office to adequately monitor grantees. Inadequate HHS staffing for the SIDS program has also been a concern of the Foundation, as evidenced in correspondence it provided to us. Our report contains no recommendation for additional funds, although it points out that it does not appear that comprehensive SIDS programs can be extended nationwide under the current way the program is structured, managed, and funded.

COMMENT

"The sole recommendation to the Congress--namely consolidation of the SIDS information and counseling program with the Maternal and Child Health Programs, authorized under Title V of the Social Security Act is made even though GAO roundly criticized administration of the Title V programs in its report (HRD-80-24) dated January 21, 1980."

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RESPONSE

The Foundation is correct that our January 21, 1980, report to the Congress on pregnancy outcome (HRD-80-24) is critical of the Maternal and Child Health program. The report contained many recommendations to the Congress and HHS for improvement, and HHS initiated corrective action. One of the problems discussed in that report was the large number of related Federal programs in the Maternal and Child Health area, and we identified the SIDS program as a candidate for consolidation with the Maternal and Child Health program. For the reasons discussed in chapter 5 of this report on SIDS, we recommended that the Congress consolidate the SIDS and Maternal and Child Health programs.

The Foundation has expressed concern about such a consolidation for a number of reasons, including its belief that some Maternal and Child Health program directors would not effectively carry out SIDS programs and that statewide programs are not always appropriate. One of the Foundation's vice presidents, however, has stated that, eventually, it makes sense to put SIDS under other Maternal and Child Health programs.

We made our recommendation with the belief that, if the Congress decides to act on it, it would seek the views and advice of HHS, voluntary organizations, the States, and other interested organizations on the most appropriate manner and timing for such a consolidation. Putting the SIDS program into the Maternal and Child Health program, in our opinion, would not necessarily require only one project in each State, nor would it necessarily require that only State health departments provide services. States could choose how to organize SIDS management efforts and could rely on local health departments, voluntary groups, or others to provide services. Provision could also be made for HHS to take alternative actions if a State were unwilling or unable to carry out its responsibilities.

COMMENT

"Even if the arguments of the Foundation are not mentioned, might not the unbiased reader of the report gain some perspective with the knowledge that the four-point SIDS management program was propounded by the Foundation and that out of the 37 federally funded projects, 30 were directly organized with technical assistance from the Foundation and two by the Guild?"

RESPONSE

Our report did not identify the four-point SIDS management program as being proposed by the Foundation because (1) HHS had adopted it and made it part of its regulations and guidelines, and (2) we were evaluating projects in terms of HHS requirements. We did not intend to deny credit to the Foundation for developing the four-point program, and we clarified our report to reflect the Foundation's concern. (See p. 11.)

Because of the problems with the Foundation's progress reports and final report under its mobilization contract with HHS, which are discussed in chapter 4, we could not quantify or verify all of the Foundation's accomplishments under that contract within the time of our review. Also, our review did not include an evaluation of Foundation activities to mobilize community resources or carry out educational activities under other HHS contracts or grants or using its own or other resources. Therefore, we are not in a position to substantiate or refute the Foundation's statement that 30 federally funded SIDS projects were directly organized with its help. However, HHS staff credit the Foundation with many mobilization accomplishments as a result of the work it did under the contract and with other resources, and we noted that the Foundation conducted mobilization, educational, and promotional efforts in many areas.

COMMENT

"Major voids exist in the GAO report. No historical perspective is provided to place HHS's SIDS program in the context of SIDS management in the United States. The reader of the report is left with the impression that management activities and education and counseling began with the federal legislation of 1974 and are concentrated solely within the confines of the Parklawn Building in Rockville, Maryland. The voluntary health organizations interested in SIDS are depicted as nagging cry-babies obstructing the noble mission of the federal bureaucrats."

"Chapter 1, Introduction Page 2: A myopic picture is provided of SIDS activities in the United States as if the

GAO note: The page numbers in the comments refer to pages in our draft report and do not always correspond to the page numbers in the final report.

'creation' occurred with the establishment of the HHS program following the legislation in 1974. A brief background statement should include a description of the campaign of the National SIDS Foundation started in 1972 to 'humanize' the handling of SIDS in the United States.'"

"Page 9: The description of the voluntary organizations is totally inadequate. At the very least, there should be a description of where they operate and how they are organized. For example, all policies of the National SIDS Foundation are reviewed by its Medical Board consisting of the most distinguished scientists in the field of SIDS research and management."

RESPONSE

The Foundation's statement that no historical perspective of SIDS management is discussed in the report is incorrect. Chapter 1 of the report briefly describes the limited Federal SIDS activities before enactment of Public Law 93-270 and points out that the Foundation and the Guild conducted SIDS counseling, information, and education activities prior to enactment of this law. We do not describe details of SIDS management activities before establishment of the Federal SIDS program or details on the organization and activities of the voluntary organizations because an evaluation of these activities was not within the scope of our review. The Committees requesting our review asked us to look at issues involving the Federal SIDS program. We did not intend to deny credit to the Guild or Foundation for their many contributions in the SIDS field. We clarified our final report to indicate SIDS educational and promotional activities conducted by the Foundation under HHS contracts or grants. (See p. 2.)

COMMENT

"Page 10: A disclaimer should be injected that an unbiased assessment of the grant review process could hardly be obtained by attendance at only one session after the audit commenced."

RESPONSE

The Foundations's comment fails to consider the other work we performed--which is discussed in chapters 1 and 3 of our report--to assess the grant review process for the SIDS program. HHS convened two SIDS grant application

review panel sessions in 1980--a 2-1/2-day session in May and a 1-day session in July. We interviewed panel members during the May session and attended part of the July session to observe the proceedings. In addition, we interviewed persons who had served on previous panels and reviewed documents associated with the grant review process.

COMMENT

"Page 13: The credibility of the entire study is brought into question by the fact that it was impossible to locate any parents in the State of Nebraska, and that parent interviews in the State of California were limited to Los Angeles County. Obviously nothing can be done about these deficiencies now, but the GAO report would gain a little status if the agency 'ate a little crow.'"

RESPONSE

Contacting parents of SIDS victims was a very sensitive component of our review. We and the project staffs were concerned about the possible effects our interviews might have on the parents. To avoid contacting family members whose infants died recently, we agreed not to contact families whose infants died after December 31, 1979.

The Nebraska project began serving SIDS victims' families in October 1979 and opened six SIDS cases occurring between then and December 31, 1979. Four of the families had moved or had telephone numbers that were not in service. The other two families were not counseled by the project--one was counseled by the family's physician, and the other was counseled by a mental health agency staff member.

We could not take a random sample of SIDS cases in California because of the project's lack of complete data. Therefore, we selected two counties--Los Angeles and Alameda--from which we would contact SIDS victims' families. Our initial efforts to contact families were delayed for several weeks until we could resolve the concerns of the project director relating to the State's confidentiality law and arrangements for any necessary counseling services for families after our contacts. After these problems were resolved, we contacted parents from Los Angeles. However, Alameda County officials refused to approve our parent contacts because they believed that our interviews would upset the parents. Representatives from the Committees requesting

our review were aware of these problems in California and advised us not to proceed without the voluntary cooperation of the parties involved.

COMMENT

"Chapter 2 , page 14, Project Performance: The initial paragraph is confusing. GAO says that they cannot evaluate project's success because of the lack of HHS performance standards, yet they (properly) proceed to use the four-point management system as a performance standard."

RESPONSE

In chapter 2 of our report, we used the SIDS four-point management program as criteria for evaluating one component of project performance. However, HHS had not established performance standards for determining whether the frequency with which projects met the criteria--the elements of the four-point program--was satisfactory. To illustrate, such a performance standard might be that projects operational for at least 3 years are expected to ensure that families are notified within 48 hours of the date of death in at least 95 percent of the cases in their service areas each year. We could not judge whether 10 of the 11 projects were accomplishing program objectives because of the lack of such performance standards.

COMMENT

"Page 15: The assertion is made that SIDS projects are providing community groups with the oportunity to provide advice and consultation without any documentation, whatsoever. Who was asked? Who responded?"

"GAO describes the methods by which they assessed compliance with the four-point management program. The methods for assessing the adequacy of community group input should be outlined or else no conclusion should be published."

"Page 31: Again, another calumny against the Guild and Foundation. How was the evidence for participation or lack of participation of Guild or Foundation representatives sought? Surely, there must be variability from project to project. Surely, the GAO auditors were able to identify the projects where good communication took place between the voluntary organizations and project staff, and the projects where the communications were poor. Because relationships

between the voluntary organizations and the federally funded projects was a specific item of study, we deserve better than the blanket statement that appears at the top of page 31."

RESPONSE

In our draft report we discussed our methodology for assessing community group involvement. In addition to interviewing community council members at each of the projects we visited, we reviewed minutes of council meetings and interviewed project staffs. Although the extent of voluntary group involvement in project activities varied among the projects, lack of communication between voluntary group members and project staffs did not appear to be the major barrier impeding cooperation among these groups. Uncertainty about or dissatisfaction with the roles of the voluntary organizations seemed to be a major problem.

We did not make any conclusions on the appropriateness of community group involvement because of HHS' lack of criteria in this area. However, we added information on community group involvement in project activities to our report in view of the Foundation's concern. (See p. 21.)

COMMENT

"Page 16: The statement is made that some of the voluntary groups insist on access to the names of SIDS victims' families regardless of whether the families give their permission. Which ones? It is a policy of the National SIDS Foundation that families not be visited by parent volunteers unless they have given their permission. The wording gives a deceptive picture of the policies of the Foundation. Incidently, * * * GAO was given this information in writing during the oral debriefing in Chicago, on September 18."

RESPONSE

Local Guilds in Dallas and Maryland and two Foundation chapters in Chicago believed that they should have the names of SIDS victims' families. By letter dated September 22, 1980, the Foundation sent us its January 1977 policy statement on release of parents' names. We did not refer to it in our draft report because we were discussing one SIDS project and two local Foundation chapters in relation to HHS' requirements, not those of the National SIDS Foundation. However, we did not intend to present a deceptive picture of the National SIDS Foundation and clarified our report to recognize the National Foundation's policy. (See p. 24.)

COMMENT

"Page 20: Half of the detected deficiencies in documenting the cause of death (13 out of 26) occurred just in the State of California. Yet, GAO is most 'diplomatic' about never mentioning that the California project is a disaster."

RESPONSE

Our report does not include discussions of all SIDS activities at each of the 11 projects we visited. Instead, we used our findings at various projects to illustrate the types of systemic problems we identified. Our report discusses several problems at the California project. One of the project's major problems was its lack of data on the extent to which all elements of the SIDS four-point management program were being implemented.

The California project did not collect data on autopsies or use of SIDS on death certificates from coroners or the health department until after the end of the year. Therefore, it could not monitor these activities in a timely manner. Also, the project did not have sufficient data on the notification and counseling elements of the four-point management program, as pointed out in our report.

We agree that the California project has had several problems in carrying out its responsibilities that need to be resolved. HHS and the project are aware of the need to take corrective actions, and some have already been initiated. The SIDS program director visited the project in December 1980 to discuss the problems further and to develop additional corrective actions.

COMMENT

"Page 26: GAO appears to accept alot of 'finger pointing' as an excuse for poor project performance. Invariably, deficiencies are blamed on 'others' ie. health departments, medical examiners, etc. What about just plain poor program performance?"

RESPONSE

The Foundation's statements are incorrect. For example, the draft report clearly stated that five projects did not have followup procedures to assure that counseling was provided. The report points out, however, that some of the

problems experienced by the projects are related to the degree of cooperation they receive from others, such as medical examiners, coroners, or health departments. For example, eight of the projects we visited assumed responsibility for notifying families of autopsy results, and medical examiners or coroners frequently failed to notify these projects of the autopsy results promptly. However, after the projects were informed, they generally notified the families within 48 hours after they learned about the autopsy results.

Our findings at the Maryland project provide another example. Some of the parents we contacted said that they were dissatisfied with the services they received after the death of their infants. In discussing these cases with the Maryland project staff, they told us that they did not have direct control over community health nurses who did much of the counseling for the project, but that they would discuss these problems with appropriate officials in the local health departments to resolve the problems.

COMMENT

"Page 27: GAO is to be commended for trying, in some localities, to gain a measure of 'consumer' satisfaction with project services. We judge the fact that when 19 out of 82 families contacted were never even offered counseling services that the project performance should be judged to be poor. Why not just say so?"

RESPONSE

Of the 18 1/ families who said that they did not receive or were not offered counseling, 15 said they were contacted by project representatives concerning their infants' deaths, and 3 said they were not contacted. Of the 15

--14 received a home visit and 1 received only a letter,

--12 said the information they received was helpful, and

--6 (2 from 1 project and 1 each from 4 projects) said they would have liked counseling (5 of these 6 received a home visit).

1/The draft report said 19 families; however, the correct number is 18 families.

Of the three families who said they were not contacted, two from one project said that they would have liked to have been contacted. One of these two families said that it initiated contact with the project and received a letter in response but no followup visit. Although the third family said it was not contacted, project staff and records indicated the family received a home visit.

We discussed the results of our review and our parent interviews with the project staffs, and they agreed to take corrective action.

COMMENT

"Page 32: Doesn't the fact that the California project depends solely on parent volunteers to provide all counseling in the San Diego region, suggest again, that there is something wrong with the California project?"

RESPONSE

In our view, the major problem in San Diego was not that the project relied on parent volunteers. Rather, the problems related to the fact that the Foundation chapter was not reaching all segments of the target population and the lack of specificity concerning the project's responsibilities when it relied on other groups to provide counseling. These problems are discussed in our report. Also, our report notes that the project recognized the problems in San Diego and initiated efforts to resolve them. We believe that projects that rely on other organizations to provide counseling need to ensure that these organizations effectively carry out their responsibilities.

COMMENT

"Page 33: The statement at the top of page 33 is typical of the bias shown throughout the report against the National SIDS Foundation. Did the GAO simply accept the word of a project official in St. Louis, that the Kansas City Chapter of the Foundation discourages visits by the local Health Department to families? Perhaps it is true, but was an official of the Kansas City Chapter given the opportunity to respond to the accusation?"

RESPONSE

We made several unsuccessful attempts to contact the Foundation member alleged to have discouraged the Kansas City health department from providing counseling services. We were informed that the Foundation's Kansas City chapter had become inactive in SIDS activities. A former member of the Foundation's Kansas City chapter told us that the chapter began to become less active starting around 1977, at least partly because of internal controversy, but she had no information on this allegation. The president of a new Foundation chapter that was forming in the Kansas City area told us that she was not familiar with the activities of the previous chapter members. In view of the Foundation's concern, we deleted discussion of the allegation in question from chapter 2 of our report.

COMMENT

"Chapter 3, Grant Award and Administration, Page 35: GAO says that HHS followed its own policies and procedures to ensure that grants were awarded on a competitive and objective basis. They did not assess, however, whether or not HHS's policies and procedures are satisfactory to meet national needs. The report points out that the funds awarded to individual projects were not necessarily commensurate with either the number of SIDS cases in the area, or the adequacy of local resources. GAO should have pointed out that states like Mississippi and Tennessee, which have great needs and inadequate resources, don't have any Federal grants. Thus, while HHS had a review process to examine the merits of individual proposals, local need was factored in at only five out of a total 100 points. Again, GAO gets lost in the trees."

RESPONSE

Chapter 5 of the report discusses problems encountered by HHS in meeting national needs under the SIDS program. For example, it points out that some States have not applied for a SIDS grant. Mississippi is one such State. An organization in Tennessee had a SIDS grant in fiscal years 1975 and 1976, but HHS disapproved its fiscal year 1977 grant application because of lack of progress in implementing a SIDS program. Another organization in Tennessee applied for a SIDS grant in 1979, but HHS disapproved the application because of deficiencies in it. HHS identified Mississippi as

a priority target area under its mobilization contracts with the Foundation and Johnson & Associates. Tennessee was identified as such an area in HHS' mobilization contract with Johnson & Associates.

The Foundation is correct that HHS' scoring system for the SIDS program used in 1980 allotted only five points to need. However, the Foundation identified this problem during the July 1980 grant application review panel session, and HHS and panel members took steps to resolve the problem. HHS funded all approved SIDS grant applications in 1980. Therefore, no adverse consequences resulted from the weight given to need in the scoring system that year. HHS used a different scoring system in previous years.

COMMENT

"Page 39: GAO states that 'The office prefers to work through State Health Departments for state-wide projects.' That is obvious, but is the policy stated in any grant manual, and if so, under what authority? It is one thing to prefer a particular type of organziation, but quite another to discourage other applicants, as HHS has done. GAO chooses to ignore the allegation of the NSIDSF that existing statewide projects not connected to health departments who are threatened with having their funds withdrawn, and that only health departments have been encouraged to apply for future funds. Apparently, our complaint was not even investigated."

RESPONSE

Our draft report states that HHS had not established a formal policy to limit SIDS grant eligibility to certain types of organizations. Public Law 96-142 authorizes HHS to make grants to public or nonprofit private entities for SIDS information and counseling activities. We did not ignore the Foundation's allegation that HHS had discouraged organizations which are not State health departments from applying for grants. In July 1980, we discussed this allegation with one of the Foundation's vice presidents. He could not provide a single example of a situation in which HHS discouraged an organization from applying for a grant.

COMMENT

"Page 41: While GAO states that 'The award of two grants for Nebraska appears questionable' there is no examination of the

circumstances of the two awards. Again, as occurs throughout this report, GAO suppresses all information that places HHS in an unfavorable light in awarding grants or contracts."

RESPONSE

We did not conduct a detailed review of HHS' 1975 SIDS grant application review and grant award procedures and, therefore, did not evaluate all the circumstances surrounding HHS' award of two SIDS grants for Nebraska in 1975. However, in connection with our review of HHS files to obtain SIDS program funding information, we questioned the need for HHS to award grants to two Nebraska applicants having overlapping service areas. (See pp. 8 and 29.)

COMMENT

"Page 46: Another 'convenient' suppression of important information regarding Nebraska. Why doesn't GAO mention that the Regional Health Systems Agency of Nebraska recommend disapproval of the project submitted by the State Health Department? Thus, it was not only the local Foundation Chapter that protested. That HHS later overruled the recommendation of the Nebraska HSA seems irregular when they admit they don't have the staff or the time to adequately supervise existing programs. The obvious collusion between Nebraska Health Department officials and HHS is swept under the rug.'"

RESPONSE

In 1980, the Southeast Nebraska Health Systems Agency and the Health Planning Council of the Midlands disapproved the Nebraska project's SIDS grant application. The Southeast Nebraska Health Systems Agency disapproved the application essentially because (1) it generally opposed Federal categorical grant programs and questioned the need to have a separate program for SIDS, and (2) it believed that the State's mental health system could carry out SIDS activities. The Health Planning Council of the Midlands disapproved the application because it believed that (1) costs were unreasonable, (2) the project failed to meet the needs of any specific target population, and (3) the project failed to cooperate with volunteer groups.

The decision by the Health Planning Council of the Midlands conflicted with the findings and recommendations of

its project review committee, and the decision by the Southeast Nebraska Health Systems Agency conflicted with the findings and recommendations of its staff. In July 1980, HHS overruled the disapproval decisions of the two Health Systems Agencies and explained its reasons for doing this.

Also, by letter dated June 3, 1980, the Nebraska Health Planning and Development Agency refuted the arguments for disapproval cited by the Southeast Nebraska Health Systems Agency. In June 1980, an official of the Health Planning Council of the Midlands told us that his agency's conclusions on the unreasonableness of the Nebraska project's costs and the project's failure to meet the needs of a specific target population were based on statements made by Foundation representatives. He said that he did not have documentation to support these conclusions. In our view, the underlying cause of the problem in Nebraska is the continuing poor working relationship between the SIDS project director and Foundation representatives.

We did not include a discussion of the Nebraska Health Systems Agencies' actions in our report because we did not believe it relevant to the questions asked by the Committees requesting our review. Also, we have no evidence of collusion between HHS and the Nebraska health department.

COMMENT

"Page 58: GAO calls for more site visits to projects even in the face of the admission that HHS has not developed criteria for judging the quality of performance. Program officials say that they don't have enough travel money. The Foundation supplied written information to GAO (gained from the Senate Appropriations Committee) that in FY '76 - 18% and in FY '77 - 23% of the total amount of money going for grants and contracts was allocated for travel, consultants and conferences."

RESPONSE

HHS had criteria (regulations and guidelines) for evaluating projects' performance, but it did not have performance standards. Through site visits, HHS can determine whether projects are complying with program regulations and guidelines and help projects resolve problems. The information provided by the Foundation on SIDS program funding for fiscal years 1976 and 1977 did not include any more details than the percentages cited above. Our review did not include a

detailed evaluation of program expenditures in those years. The percentages cited by the Foundation appear to relate to funding for both grantees and for HHS, and are, therefore, misleading. According to HHS data, about $3,100 and $6,100 were used for travel by SIDS Program Office staff in 1979 and 1980, respectively.

COMMENT

"Chapter 4, Contracts, Page 61: GAO concludes that HSA 'objectively and equitably' evaluated the five contract proposals. Would that GAO have 'objectively and equitably' have evaluated the protests of the Foundation in regard to the contracts. Instead, they use a wide brush with white paint to exonerate the federal bureaucrats from any wrong doing. Even if the GAO did not find merit in any of the Foundation's arguments, might not the report seem more fair if some of them were at least cited?"

RESPONSE

Our report does not exonerate HHS from any wrongdoing relative to its contract award procedures. We addressed the Foundation's allegations that, in our opinion, were material to determining the outcome of the contract award process. We did not address those allegations that did not appear to make a difference relative to the contract award decision, nor did we evaluate all HHS' procurement practices.

COMMENT

"Page 68: The implication is given throughout that it was the Foundation that desired a sole-source contract. Yet, GAO was provided with written documentation that the Foundation urged that the contract be put out for competitive review. It was the director of the Bureau of Community Health Services * * *, his deputy * * *, and the SIDS program director * * * who as late as November 1979, insisted that they wanted a sole-source contract."

RESPONSE

Our report is critical of HHS for failing to seek competition; whether the Foundation desired a sole-source contract was immaterial. The documentation referred to by the Foundation is apparently its April 18, 1979, letter to BCHS in which the Foundation states that it had been willing to compete for the contract. In a July 7, 1978, letter to the

Director of BCHS discussing continuation of the Foundation's mobilization contract, one of the Foundation's vice presidents stated that he understood that future contract work probably would be subject to competitive bid. BCHS officials told us that they did not "insist" on a sole-source contract, but that they subsequently told the Foundation that they did not believe a competitive procurement was necessary.

COMMENT

"Page 69: GAO states 'The HSA official who was alleged to have told the Foundation that its contract would be extended was not authorized to make such a statement.' A rather mild and questionable admonition for the Deputy Director of the Bureau of Community Health Services * * *, who according to * * * GAO, admitted making the statement."

RESPONSE

We clarified our report to reflect the Foundation's concern. (See p. 48.)

COMMENT

"The GAO acknowledges on pages 70 & 71, that the terms of the contract were not 'sufficiently specific' and in other instances, that HSA did not compel the Foundation to fully comply with the contract requirements. Yet, on page 72, they state that the Foundation reports did not contain all the information that HSA desired after stating that the information that HSA desired was never clarified. Catch-22.'"

RESPONSE

Our report states that in some instances, the terms of the contract were not sufficiently specific. Although the contract did not sufficiently specify the level of contract activity, the contract specifically set forth documents to be submitted and the type of information the Foundation was to include in them. For example, HSA's February 1978 contract modification with the Foundation required the Foundation to submit (1) written notification of its plans to conduct contract activities in agreed upon States 10 days before the date a visit was scheduled and (2) a report of each visit to agreed upon States 21 days or less after the visit. Also, the contract specified the type of information to be included in the visit reports. The Foundation frequently did not submit the required notifications or reports of site visits.

Also, HSA's December 1976 contract with the Foundation identified the specific minimum types of information to be included in quarterly progress reports. For example, the progress reports were to contain a quantitative and qualitative description of the Foundation's progress, including accomplishments, activities, and techniques used. Also to be included was a report on the readiness or progress of the identified areas in organizing an effective SIDS program relative to each element of the four-point management program. However, the Foundation's progress reports did not always contain the required information.

BCHS and Foundation representatives seem to agree that HSA did not provide sufficient additional guidance to the Foundation during the first year of the contract on how the information was to be presented in progress reports, but agree that BCHS provided better guidance after the first year. In July 1978, BCHS told the Foundation that its progress reports were improving, but that further improvements were needed.

Our report does not state that HSA never clarified the information it wanted in progress reports. Thus, while the Foundation appeared to be uncertain of precisely how HSA wanted information to be presented in progress reports, the contract specified the minimum types of information that were to have been included.

COMMENT

"Page 72: The dispute between Foundation and HSA officials about the department's insistence on a monolithic approach through state health departments is discussed. Absent from the GAO Audit, however, is the information that at a meeting on February 10, 1978, * * * Director of the Bureau of Community Health Services, supported the contention of the Foundation and ordered his subordinates to promote a more flexible approach in mobilization of community resources."

RESPONSE

We did not attend the February 10, 1978, meeting and, therefore, do not know exactly what was said or done at that meeting. However, BCHS officials told us that the Foundation's statement is not accurate. BCHS' director told us that he did not order his subordinates to promote a more flexible approach in mobilizing community resources. He said that he did try to resolve a dispute between his staff and the Foundation.

COMMENT

"Page 73: GAO states that Lawrence Johnson & Associates (LJA) were slowed in their conduct of the contract work because they couldn't share the Foundation's experiences as expressed in the final report. That's ridiculous! Though not delivered to HSA, all the information eventually contained in the final report was submitted to the Senate Subcommittee on Child and Human Development during the hearings on Renewal Legislation and appear in the Senate Report dated March 1, 1978."

RESPONSE

Some of the information obtained by the Foundation under its mobilization contract was contained in the report of a March 1, 1978, hearing before the Senate Subcommitee on Child and Human Development on the Sudden Infant Death Syndrome Act Extension of 1978. Johnson & Associates representatives told us that they had this report, but it was not current and did not contain sufficient details on the specific mobilization activities undertaken or the organizations contacted. They said that their attempts to obtain additional information from the Foundation were unsuccessful, and that the lack of this information impeded their mobilization efforts. Also, the Foundation's statement that all the information in its final report appeared in the Senate report is incorrect. The Foundation's final report contained more details and more current information than its earlier report to the Senate Subcommittee. We modified our report to recognize the Foundation's comments. (See p. 50.)

COMMENT

"Page 73: In discussing the Foundation's shortcomings in the contract work, GAO purposefully omits mentioning the written commendations prepared by the project officer, * * * dated May 9, and July 28, 1978. I say, purposefully, because in the verbal debriefing, GAO assured the Foundation that HHS would be criticized for criticizing performance on one hand, and providing written commendations on the other. In the verbal debriefing, GAO also said that * * * [the project officer] admitted (not alleged) that he provided false reasons to the Foundation about why the contract was terminated. Again, more whitewash."

RESPONSE

Our report clearly states that HSA (1) never formally informed the Foundation of dissatisfaction with its performance regarding mobilization activities and (2) had said that the Foundation performed satisfactorily during the first year of the contract. The project officer's May 9, 1978, letter to the Foundation discussed one of the Foundation's projected work scopes, not its past performance. In the July 28, 1978, letter, BCHS' project officer stated that one of the Foundation's quarterly progress reports "* * * is satisfactory to meet minimum standards under our procurement rules." The project officer further stated that, while the report showed continued progress toward effective communication regarding the Foundation's activities, further improvements were necessary. In our view, the project officer's statements in this letter do not appear to be a commendation.

The Foundation's last comment is misleading. HHS' mobilization contract with the Foundation was not terminated. The contract period ended, and HHS awarded the subsequent contract competitively. By letter dated June 4, 1979, BCHS' project officer told the Foundation that he had previously given the Foundation incorrect information regarding the reasons its technical proposal for the competitive mobilization procurement was unacceptable. Further, the project officer said that, as far as he could recall, he gave the Foundation his own views rather than an official response. Regardless, the official's statements were not material to the outcome of the contract award.

COMMENT

"Page 77: Why were only four out to 19 States contacted by GAO to testify about LJA's performance on the contract?"

RESPONSE

The discussion of four States in our report refers only to those States where the representatives we contacted said that both the Foundation and Johnson & Associates were helpful. We contacted representatives from eight States and the District of Columbia to obtain their views on Johnson & Associates' mobilization efforts. Representatives from all of these States and the District said that Johnson & Associates' efforts were helpful.

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