

**A Report of Sudden Infant Death Syndrome Support Services
Among California Maternal, Child and Adolescent Health
Local Health Jurisdictions**

Presented by

Guey-Shiang Tsay, RN, MSN and Carrie Florez, BSW

**Maternal, Child and Adolescent Health
Center for Family Health
California Department of Public Health**

July 2008

Acknowledgements

We thank all the participants from the Maternal, Child and Adolescent Health Local Health Jurisdictions for their contributions to the survey.

**We also thank the following individuals
for their assistance and input for this survey.**

**Northern California Regional SIDS Council
Southern California Regional SIDS Council**

California SIDS Program

**Gwen Edelstein, RN, PNP, MPA
Cheryl McBride, RN**

Kathleen Nettesheim-Engel, RN, BS, MPH

**Maternal, Child and Adolescent Health
Center for Family Health
California Department of Public Health**

**Karen Ramstrom, DO, MSPH
Eugene Takahashi, PhD, MPH**

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A Report of Sudden Infant Death Syndrome Support Services Among California Maternal, Child and Adolescent Health Local Health Jurisdictions

Introduction

When an infant dies suddenly and unexpectedly, the shock, grief, and unimaginable loss is something only a parent who has experienced such a tragedy could describe. Due to the sudden and unexpected death of the infant, without any obvious cause, an investigation of the location where the death occurred and an autopsy are usually performed to aid in the final determination of the cause of death. For the parents of the infant, dealing with such a tragic and stressful life event is very difficult and the availability of resources to help work through their loss can be beneficial.

Sudden Infant Death Syndrome (SIDS) and the need for providing grief and bereavement support services to the family, including the caregiver, have been recognized in California through various legislation. Currently, each of the 61 Maternal, Child and Adolescent Health (MCAH) Local Health Jurisdictions (LHJs) receives a specific annual allocation for locally identified SIDS activities and/or interventions. Among a number of suggestions provided to LHJs on how best to use the local SIDS allocation, providing grief and bereavement support services to families and/or childcare providers is encouraged.

Background

During the meeting of the Northern California Regional SIDS Council (Council) in January 2007, a concern was raised regarding varying policies/procedures among LHJs in the provision of Public Health Nurse/Social Worker (PHN/SW) support services for presumed SIDS/Sudden Unexpected Infant Death (SUID) cases. Council members expressed their concern with challenges the LHJs encounter in meeting the time frame noted in the legislation for grief and bereavement support services. The Council agreed to draft a survey, and once approved by the State, to be sent to all LHJ SIDS Coordinators to gather information about the policies/procedures in the provision of PHN/SW support services when a presumed SIDS/SUID case occurs.

In addition to asking about issues of policies/procedures in the provision of grief and bereavement support services for presumed SIDS/SUID cases, the survey also included questions about:

- grief support services and follow up when a presumed SIDS/SUID case occurs in a child care setting;
- who has responsibility in the Coroner's office for notifying the LHJ of presumed SIDS/SUID cases;

- whether Coroner's offices have policies for the referral of presumed SIDS/SUID cases; and
- who at the LHJs has responsibility for receiving referrals from the Coroner's office.

The Council Public Health Nurses (PHNs) suggested additional questions to identify who has responsibility for making and accepting the presumed SIDS/SUID referrals which may determine if and where a communication breakdown was occurring. The PHNs also stressed concern about the possibility that a non-parent caregiver may not be receiving needed grief support.

Methods

A self-administered questionnaire survey of SIDS Support Services was sent via email to 61 California LHJ SIDS Coordinators with a copy to MCAH Directors (see Appendix A) on June 5, 2007. It was requested that completed surveys be returned via email or fax by Tuesday, June 12, 2007.

Follow-up for those LHJs not returning the survey was done via email and telephone. As of August 2, 2007, 59 of the 61 LHJs had returned completed surveys. Napa and San Benito did not return the survey.

The California SIDS Program received and compiled the survey responses to the 14 questions. The original surveys and related documentation were then given to the California MCAH Program. Each survey was reviewed and analyzed by the California MCAH SIDS Nurse Consultant and SIDS Research Scientist.

The findings were analyzed by combining all California LHJs (CA LHJs) and comparing Urban/Rural designation of the LHJs (Urban LHJs/Rural LHJs), based on the definition from the State of California, Rural Health Policy Council (see Appendix B). The Rural Health Policy Council defined a Rural LHJ as having a population of less than 250 persons per square mile and does not contain an incorporated area with a population greater than 50,000. All other LHJs are considered to be Urban. Based on this definition, there were 30 of 31 Urban LHJs and 29 of 30 Rural LHJs who responded to the survey.

It is important to note the survey responses may not be comprehensive depending on the understanding of the questions by the survey respondent. Some questions on the survey allowed for free response answers, which were summarized for easier interpretation. Other questions could have more than a single response, which results in percentages not adding to 100 percent. Responses not related to a specific question were noted where appropriate.

Results

The survey had a 97 % response rate, with 59 of the 61 LHJs completing the survey. For those 59 surveys submitted, 57 (97%) were completed by local SIDS Coordinators, PHNs, MCAH Directors, MCAH Coordinators, Senior PHNs, Supervising PHNs, PHN Managers, and Deputy Directors; and the remaining two surveys were completed by a Public Health Epidemiologist and a Perinatal Investigator.

Highlights of the survey results include:

- Staff turnover in some LHJs and Coroner's offices impacts the consistency of the policies/procedures and grief/bereavement support services within the LHJs.
- Over half of the LHJs do not know if their Coroner's office has a written procedure for referring SIDS and other SUIDs.
- More than half of the LHJs reported receiving notification of a possible SIDS death 24 hours or more after the autopsy.
- More than half of the LHJs are notified by the Coroner's office of all SUIDs.
- The majority of LHJs offer grief/bereavement services to families with a possible/pending SIDS diagnosis. Over half also provide services to families whose infant may have died from other unexpected causes (i.e. undetermined, accidental suffocation).
- Most LHJs provide grief support when there is a sudden unexpected death of an infant, not only to those noted in legislation as having "custody and control", but also for grandparents and the caregiver at the time of the death.
- The majority of LHJs reported initiating contact with the family, childcare provider, and/or foster parents within 3 working days of receiving notification of a possible SIDS death.
- Most LHJs provide continued grief/bereavement services after the initial contact. However, as a result of limited funding, some LHJs rely on community based SIDS support groups to provide continued grief/bereavement support services.
- LHJs are using multiple ways to contact those who experience an infant death.

Findings from each question on the survey are reported in the remaining pages of this document. The survey question, frequency of overall responses and frequency of responses by Urban/Rural designation of LHJs, and summary of free responses are included for each question. Frequency of responses for all CA LHJs combined is based on a sample size of 59, the total number of LHJs that completed the survey. Frequency of responses from the Urban LHJs are based on a sample size of 30, the total number of Urban LHJs completing the survey while frequency of responses from the Rural LHJs are based on a sample size of 29, the total number of Rural LHJs completing the survey. For the purpose of this report, "health department" and LHJ refer to the same organization.

Survey Findings

Question 1

*How are you notified by your coroner's office of a sudden unexpected infant death?
(Check all that apply)*

Coroner's offices notify LHJs of a SUID by the following: 83% of LHJs are notified by *telephone*; 36% by *fax*; 7% by *email*; and 8% of LHJs are notified by *other* ways. *Other* ways LHJs are notified include staff from the Coroner's office walking over to the health department and notifying in person, sending a letter, and the SIDS Coordinator calling the Coroner's office. LHJs with infrequent SUIDs may not know the means of notification by their Coroner's office.

Urban LHJs are notified by *phone* (73%) and *fax* (60%) while Rural LHJs are notified primarily by *phone* (93%). Rural LHJs also reported being notified more often in *other* ways (14%), including notification in person or sending letters, than being notified by *fax* (10%) or by *email* (3%).

Table 1 – Frequency of Notification Method by Coroner's Office of a Sudden Unexpected Infant Death

	<i>Responses*</i>			
	<i>Phone</i>	<i>Fax</i>	<i>Email</i>	<i>Other (please list)</i>
CA LHJs (n=59)	83% (n = 49)	36% (n = 21)	7% (n = 4)	8% (n = 5)
Urban LHJs (n=30)	73% (n = 22)	60% (n = 18)	10% (n = 3)	3% (n = 1)
Rural LHJs (n=29)	93% (n = 27)	10% (n = 3)	3% (n = 1)	14% (n = 4)

* Total responses may exceed 100% in each category of CA LHJs, Urban LHJs and Rural LHJs due to the possibility of multiple responses being selected for this question.

Question 2

*Who in your coroner's office notifies the health department about a possible SIDS death?
(Check all that apply)*

Survey results show that *Clerk/Office Staff*, *Coroner Investigator*, *Coroner*, and *Sheriff/Deputy* almost equally notify LHJs of possible SIDS deaths. A small percentage, 8%, reported being notified by *others* including the medical examiner/pathologist and also receiving notification from Vital Statistics. One LHJ reported the SIDS Coordinator initiates the contact with the Coroner's office.

A distinction was noted among Rural versus Urban LHJs. Rural LHJs are more often notified by the *Coroner* (45%) and *Sheriff/Deputy* (41%) while Urban LHJs are more often notified by *Clerk/Office Staff* (40%) and *Coroner Investigator* (40%).

Table 2 – Frequency of Notification Sources from the Coroner's Office of a Possible SIDS Death

	<i>Responses*</i>				
	<i>Clerk/ Office Staff</i>	<i>Coroner Investigator</i>	<i>Coroner</i>	<i>Sheriff/Deputy</i>	<i>Other (please list)</i>
CA LHJs (n=59)	32% (n = 19)	34% (n = 20)	31% (n = 18)	32% (n = 19)	8% (n = 5)
Urban LHJs (n=30)	40% (n = 12)	40% (n = 12)	17% (n = 5)	23% (n = 7)	13% (n = 4)
Rural LHJs (n=29)	24% (n = 7)	28% (n = 8)	45% (n = 13)	41% (n = 12)	3% (n = 1)

* Total responses may exceed 100% in each category of CA LHJs, Urban LHJs and Rural LHJs due to the possibility of multiple responses being selected for this question.

Question 3

Does your coroner's office notify your health department of all sudden, unexpected infant deaths?

Two-thirds, 66%, of the LHJs are notified of all SUIDs. The results show the Urban LHJs are more likely to be notified (57%) than to not be notified (43%) of all SUIDs. A significant difference is seen for Rural LHJs with 76% likely to be notified versus 21% not being notified. Rural LHJs are more likely to be notified than Urban LHJs of all SUIDs, 76% and 57% respectively.

Table 3 – Frequency of Notification by Coroner's Office to LHJ of all Sudden Unexpected Infant Deaths

	<i>Responses</i>		
	<i>Yes</i>	<i>No (please explain)</i>	<i>No Response</i>
CA LHJs (n=59)	66% (n = 39)	32% (n = 19)	2% (n = 1)
Urban LHJs (n=30)	57% (n = 17)	43% (n = 13)	0% (n = 0)
Rural LHJs (n=29)	76% (n = 22)	21% (n = 6)	3% (n = 1)

Question 4

Does your coroner's office have a written procedure for referring SIDS and other sudden unexpected infant deaths to the health department?

More than half (56%) of the LHJs do not know if their Coroner's office has a written procedure for referring SIDS and other SUIDs to the LHJ. Thirty-one percent of the LHJs reported their Coroner's offices do have a written procedure while 12% of the LHJs reported their Coroner's offices do not have a written procedure.

Six of the seven LHJs who responded their Coroner's office does not have written procedures for referring SIDS and other SUIDs to the LHJs, reported various reasons for not having such a procedure. The reasons included having a written procedure for only SIDS deaths or for only suspected SIDS deaths; beginning the process of developing a written policy; being open to a written policy if approved by their county Council office, and needing to clarify the steps of a written policy due to previous inconsistencies. One LHJ reported not having a written procedure; however, the coroner reviews all deaths and makes sure the LHJ is notified.

Urban LHJs and Rural LHJs reported percentages for Coroner's Offices either having a written procedure (30% vs. 31%), not having a written procedure (13% vs. 10%), or not knowing if their Coroner's office has a written procedure (53% vs. 59%) for referring SIDS and other SUIDs to the LHJs.

Table 4 – Frequency of Coroner's Office Having a Written Procedure for Referring SIDS and Other Sudden Unexpected Infant Deaths to the LHJs

	<i>Responses</i>			
	<i>Yes</i>	<i>Don't Know</i>	<i>No (please explain)</i>	<i>No Response</i>
CA LHJs (n=59)	31% (n = 18)	56% (n = 33)	12% (n = 7)	2% (n = 1)
Urban LHJs (n=30)	30% (n = 9)	53% (n = 16)	13% (n = 4)	3% (n = 1)
Rural LHJs (n=29)	31% (n = 9)	59% (n = 17)	10% (n = 3)	0% (n = 0)

Question 5

How soon after the autopsy do you receive notification of a possible SIDS death?

Thirty-one percent of the LHJs are notified after the autopsy of a possible SIDS death within *24 hours*; 34% are notified *within 24-48 hours*; and 12% are notified within *3-7 days*. Three percent reported receiving notification after *more than one week* of the autopsy and 10% of the LHJs are notified within *weeks to months* after the autopsy of a possible SIDS death. Ten percent of the LHJs did not respond to this question.

Reasons for receiving notification within weeks to months or not responding to the question included the autopsy report taking 3-4 weeks to months to be completed; the time frame for notification depends on the doctor doing the autopsy; a death may not be known until the child death review team (CDRT) meetings, depending on the deputy who was handling the case; if staff are on vacation, notification is delayed; and one LHJ reported being unsure of how soon notification would be received, not having a death in many years. Three of the LHJs reported being notified before the autopsy is completed.

The results showed that Rural LHJs have a slightly higher percentage than Urban LHJs (34% vs. 27%) for receiving notification of a possible SIDS death after autopsy *within 24 hours*. However, Urban LHJs are more often notified within *24-48 hours* (50%) than Rural LHJs (17%). Seventeen percent of Urban LHJs receive notification within *3-7 days* compared to 7% of Rural LHJs. More Rural LHJs reported receiving notification *more than one week* or *weeks to months* than Urban LHJs. Seventeen percent of Rural LHJs and 3% of Urban LHJs did not respond to this question.

Overall, three-fourths of Urban LHJs receive notification of a possible SIDS death within 48 hours compared to half of Rural LHJs. Almost one-fourth of Rural LHJs receive notification of a possible SIDS death after one week or more following the autopsy.

Table 5 – Frequency of Timeframe in Receiving Notification of a Possible SIDS Death Following the Autopsy

	<i>Responses</i>					
	<i>Within 24 Hours</i>	<i>24-48 Hours</i>	<i>3-7 Days</i>	<i>More Than 1 Week</i>	<i>Weeks to Months (explain)</i>	<i>No Response</i>
CA LHJs (n=59)	31% (n = 18)	34% (n = 20)	12% (n = 7)	3% (n = 2)	10% (n = 6)	10% (n = 6)
Urban LHJs (n=30)	27% (n = 8)	50% (n = 15)	17% (n = 5)	0% (n = 0)	3% (n = 1)	3% (n = 1)
Rural LHJs (n=29)	34% (n = 10)	17% (n = 5)	7% (n = 2)	7% (n = 2)	17% (n = 5)	17% (n = 5)

Question 6

Who at your health department receives SIDS/other infant death referrals from the Coroner's office?

Two-thirds of LHJs reported that the *SIDS Coordinator* (66%) receives SIDS/other infant death referrals from the Coroner's office, followed by the *MCAH Director/Coordinator* (25%) and the *Supervising PHN* (25%), then the *Office Clerk* (19%). Twenty-nine percent of LHJs also reported *other* staff receiving the referrals, including the Public Health Epidemiologist, Nursing Directors, Health Officers, Nurse of the Day, PHNs, Deputy Directors, Deputy Director of Personal Health Care Services, and the Triage Supervisor. Five of the 17 LHJs reported *other* staff who receive the referrals are received by one person who holds the job of SIDS Coordinator, MCAH Director and Supervising PHN.

Seventy percent of Urban LHJs reported the referral is received by the *SIDS Coordinator* compared to 62% in Rural LHJs. More referrals are received by the *MCAH Director/Coordinator* or *Supervising PHN* in Rural LHJs than in the Urban LHJs. However, more referrals are received by the *Office Clerk* in Urban LHJs (27%) than in Rural LHJs (10%). More Rural LHJs reported various *other* staff receiving SIDS/other infant death referrals from the Coroner's office (38%) compared to Urban LHJs (20%).

Table 6 – Frequency by Staff who Receive SIDS/Other Infant Death Referrals from the Coroner's Office

	<i>Responses*</i>				
	<i>SIDS Coordinator</i>	<i>MCAH Director/Coordinator</i>	<i>Supervising PHN</i>	<i>Office Clerk</i>	<i>Other (please list)</i>
CA LHJs (n=59)	66% (n = 39)	25% (n = 15)	25% (n = 15)	19% (n = 11)	29% (n= 17)
Urban LHJs (n=30)	70% (n = 21)	17% (n = 5)	20% (n = 6)	27% (n = 8)	20% (n = 6)
Rural LHJs (n=29)	62% (n = 18)	34% (n = 10)	31% (n = 9)	10% (n = 3)	38% (n =11)

* Total responses may exceed 100% in each category of CA LHJs, Urban LHJs and Rural LHJs due to the possibility of multiple responses being selected for this question.

Question 7

Does your health department offer grief/bereavement services to families with a possible/pending SIDS diagnosis?

The survey results showed the majority of LHJs (86%) offer grief/bereavement services to families with a possible/pending SIDS diagnosis. Twelve percent reported they do not directly offer grief/bereavement services, with most of them stating they refer families to County Behavioral Health or connect families to community agencies, family counseling or the faith community. One LHJ stated they refer parents to a SIDS parent volunteer and the crisis line.

Of those LHJs who responded they do not provide grief/bereavement support, one reported that limited funding does not allow for extended grief/bereavement support. Other LHJs did not state why they do not provide grief/bereavement services.

Urban LHJs reported a higher percentage (93%) offering grief/bereavement services than Rural LHJs (79%). Rural LHJs had a higher percentage (17%) of not offering grief/bereavement services than Urban LHJs (7%).

Table 7 – Frequency of LHJs Offering Grief/Bereavement Services to Families with a Possible/Pending SIDS Diagnosis

	Responses		
	Yes	No <i>(If no, please explain your policy for follow up.)</i>	No Response
CA LHJs (n=59)	86% (n = 51)	12% (n = 7)	2% (n = 1)
Urban LHJs (n=30)	93% (n = 28)	7% (n = 2)	0% (n = 0)
Rural LHJs (n=29)	79% (n = 23)	17% (n = 5)	3% (n = 1)

Question 8

How soon after receiving notice of a possible SIDS death does your health department initiate contact with the family, childcare provider, and/or foster parents?

The majority of LHJs (88%) reported initiating contact with the family, childcare provider, and/or foster parents within *3 working days* of receiving notification of a possible SIDS death. Ten percent of LHJs reported initiating contact within *3-5 working days* followed by 2% of LHJs who reported initiating contact within *5-7 working days*. All LHJs reported initiating contact within one week.

Ninety-seven percent of Urban LHJs reported initiating contact with the family, childcare provider, and/or foster parents within *3 working days* compared to 79% of Rural LHJs. Seventeen percent of Rural LHJs reported initiating contact within *3-5 working days* compared to 3% of Urban LHJs. All Urban LHJs and the majority of Rural LHJs reported initiating contact within 5 days of receiving notification.

Table 8 – Frequency of Time to Initiate Contact after Receiving Notice of a Possible SIDS Death

	<i>Responses</i>			
	<i>Within 3 Working Days</i>	<i>3-5 Working Days</i>	<i>5-7 Working Days</i>	<i>7+ Working Days</i>
CA LHJs (n=59)	88% (n = 52)	10% (n = 6)	2% (n = 1)	0% (n = 0)
Urban LHJs (n=30)	97% (n = 29)	3% (n = 1)	0% (n = 0)	0% (n = 0)
Rural LHJs (n=29)	79% (n = 23)	17% (n = 5)	3% (n = 1)	0% (n = 0)

Question 9

How does your health department contact those who experience an infant death? (Check all that apply)

Almost all (98%) of LHJs reported they contact those who experience an infant death through a *face to face visit*, *telephone call* (86%), *mailing information* (56%), *dropping off SIDS information* (51%), and through *group visits* (8%). Two LHJs also reported contacting those who experience an infant death through *other* ways including email and one LHJ reported their PHN decides the type of contact.

Almost all Urban LHJs (97%) and all Rural LHJs contact those who experience an infant death through *face to face visits*. Urban LHJs are more likely than Rural LHJs to use various ways to contact those who have experienced an infant death, whereas, Rural LHJs primarily use *face to face visits* and *telephone calls*.

Overall, LHJs use a number of ways to contact those who experience an infant death.

Table 9 – Frequency of Ways LHJs Contact Those who Experience an Infant Death

	<i>Responses*</i>					
	<i>Face to Face Visit</i>	<i>Group Visit</i>	<i>Telephone Call</i>	<i>Drop off SIDS Information</i>	<i>Mail Information</i>	<i>Other (explain)</i>
CA LHJs (n=59)	98% (n = 58)	8% (n = 5)	86% (n = 51)	51% (n = 30)	56% (n = 33)	5% (n = 3)
Urban LHJs (n=30)	97% (n = 29)	13% (n = 4)	90% (n = 27)	57% (n = 17)	70% (n = 21)	7% (n = 2)
Rural LHJs (n=29)	100% (n = 29)	3% (n = 1)	83% (n = 24)	45% (n = 13)	38% (n = 11)	3% (n = 1)

* Total responses may exceed 100% in each category of CA LHJs, Urban LHJs and Rural LHJs due to the possibility of multiple responses being selected for this question.

Question 10

What is your health department's policy for grief/bereavement support services? (Check all that apply)

Ninety-five percent of the LHJs provide grief/bereavement support services for *possible SIDS deaths*, 69% for *confirmed SIDS deaths*, 59% for *other sudden unexpected infant deaths (i.e. undetermined, accidental suffocation)*, and 36% for *other types of infant deaths*. Of the 21 LHJs who stated providing services for *other types of infant deaths*, ten also provide grief/bereavement support services for stillbirths, terminal illness, congenital anomalies, fetal demise, cord accidents, prematurity, drowning, suicides, and miscarriages/preterm births.

All Urban LHJs and 90% of Rural LHJs reported providing grief/bereavement support services for *possible SIDS deaths*. Both Urban and Rural LHJs similarly reported providing support services for *confirmed SIDS deaths*. However, Urban LHJs had a higher percentage of providing support services for *other sudden unexpected infant deaths* and *other types of infant deaths* than Rural LHJs.

Overall, LHJs provide grief/bereavement support services for various causes of infant death, not just for possible and confirmed SIDS or other SUIDs.

Table 10 – Frequency of Various Infant Deaths which Receive Grief/Bereavement Support Services by LHJs

	Responses*				
	Confirmed SIDS Deaths	Possible SIDS Deaths	Other Sudden Unexpected Infant Deaths (i.e. undetermined, accidental suffocation)	Other Types of Infant Deaths (please explain)	No Response
CA LHJs (n=59)	69% (n = 41)	95% (n = 56)	59% (n = 35)	36% (n = 21)	3% (n = 2)
Urban LHJs (n=30)	67% (n = 20)	100% (n = 30)	63% (n = 19)	43% (n = 13)	0% (n = 0)
Rural LHJs (n=29)	72% (n = 21)	90% (n = 26)	55% (n = 16)	28% (n = 8)	7% (n = 2)

* Total responses may exceed 100% in each category of CA LHJs, Urban LHJs and Rural LHJs due to the possibility of multiple responses being selected for this question.

Question 11

Who does your health department provide with grief support when there is a sudden unexpected death of an infant? (Check all that apply)

When there is a SUID, 95% of the LHJs provide grief support to the *biological parents*, 81% to the *adoptive parents*, 73% to the *caregiver at time of death*, 71% to the *foster parents* and to *other family members*, 68% to the *grandparents* and to the *childcare/daycare provider*, and 22% to *others*. Several of the LHJs who reported providing grief support to *others* noted those persons included anyone who requests such services. One LHJ provides services to pediatricians and another provides services to medical providers. One LHJ marked all available choices except *others* noting they “listen and act in a supportive manner; however they are untrained in counseling.”

All Urban LHJs provide grief support to the *biological parents* followed by 83% *adoptive parents*, *foster parents*, *childcare/daycare provider*, and *other family members*. *Grandparents and caregiver at the time of death* are provided support by 77% of Urban LHJs.

Ninety percent of Rural LHJs provide grief support to the *biological parents* followed by *adoptive parents* (79%) and *caregiver at the time of death* (69%). Fifty-nine percent of Rural LHJs reported they provide grief support to *other family members*, *grandparents*, and *foster parents*. Only 52% of the Rural LHJs reported providing support to the *childcare/daycare provider* when there is a SUID.

Overall, LHJs provide grief support to not only the parents of a SUID, but also to many other people related to or involved with the infant.

Table 11 – Frequency of Recipients who Receive Grief Support from LHJs when there is a Sudden Unexpected Infant Death

	<i>Responses*</i>			
	<i>Parents (Biological)</i>	<i>Parents (Adoptive)</i>	<i>Other Family Members</i>	<i>Grandparents</i>
CA LHJs (n=59)	95% (n= 56)	81% (n = 48)	71% (n = 42)	68% (n = 40)
Urban LHJs (n=30)	100% (n = 30)	83% (n = 25)	83% (n = 25)	77% (n = 23)
Rural LHJs (n=29)	90% (n = 26)	79% (n = 23)	59% (n = 17)	59% (n = 17)

	<i>Responses*</i>			
	<i>Childcare/Daycare Provider</i>	<i>Caregiver at Time of Death</i>	<i>Foster Parents</i>	<i>Others (please explain)</i>
CA LHJs (n=59)	68% (n = 40)	73% (n = 43)	71% (n = 42)	22% (n = 13)
Urban LHJs (n=30)	83% (n = 25)	77% (n = 23)	83% (n = 25)	30% (n = 9)
Rural LHJs (n=29)	52% (n = 15)	69% (n = 20)	59% (n = 17)	14% (n = 4)

* Total responses may exceed 100% in each category of CA LHJs, Urban LHJs and Rural LHJs due to the possibility of multiple responses being selected for this question.

Question 12

Does your health department continue to provide grief/bereavement services after the initial contact has been made?

The survey results showed 90% of LHJs continue to provide grief/bereavement services after the initial contact has been made. Among these LHJs, 21 continue providing grief/bereavement services on a case by case basis depending on the needs of the family; 4 LHJs usually provide 2 visits for grief/bereavement services; one LHJ offers bereavement services as needed but noted most families decline the services; a few of the LHJs noted the SIDS Coordinator encourages more than one visit; another keeps a case open if ongoing support is needed; the extent/length of involvement with the family is up to the PHN making the visit or it depends on the caseload of the PHN. One LHJ reported protocols are in place regarding contacting the family at specific times throughout the year following the death. Another LHJ reported they usually give the family a card and tell them to call if they need further assistance. Another reported if there is a need, the case can be opened to targeted case management. One LHJ reported the SIDS Coordinator/PHN is available to listen/refer to support group counseling because their county does not offer grief services.

Eight percent of LHJs do not continue to provide services after the initial contact has been made. Of the five LHJs that marked *no*, one noted as a result of limited funding, they rely on community based organizations to continue grief/bereavement services and another LHJ noted they leave their information with the family and encourage them to contact as needed. One LHJ did not respond to the question but noted they were unsure of continued grief/bereavement services because “no deaths have occurred yet”.

The results showed 93% of Urban LHJs and 86% of Rural LHJs continue to provide grief/bereavement services after the initial contact has been made. Ten percent of Urban LHJs and 7% of Rural LHJs do not continue to provide grief/bereavement services.

Table 12 – Frequency of LHJs Continuing to Provide Grief/Bereavement Services after the Initial Contact

	Responses		
	No	Yes (please explain)	No Response
CA LHJs (n=59)	8% (n = 5)	90% (n = 53)	2% (n = 1)
Urban LHJs (n=30)	10% (n = 3)	93% (n = 28)	0% (n= 0)
Rural LHJs (n=29)	7% (n = 2)	86% (n = 25)	3% (n = 1)

Question 13

Please share any comments about your health department's internal policies/procedures and grief/bereavement support services concerning sudden unexpected infant deaths.

More than half of the LHJs (59%, n=35) provided comments about their internal policies/procedures and grief/bereavement support services. The remaining LHJs (41%, n=24) did not respond. Seventy-three percent (n=22) of Urban LHJs and 45% (n=13) of Rural LHJs provided comments. Comments are summarized into two groups; one is internal policies/procedures and the other is grief/bereavement support services.

Fourteen LHJs shared comments related to their internal policies/procedures:

- Some LHJs reported their policies being under revision, while others noted they continue to follow protocols as required by the State even though the mandates have been suspended or they do not have their own guidelines.
- One LHJ noted that while they have not had a death in some time they would use the Practical Guide if needed.
- Four LHJs stated they have policies and/or procedures in place that work well. Relationships with the Coroner's office are good, families know they will receive an exact cause of death, and various agencies coordinate to discuss findings and answer any questions.
- Some LHJs reported not receiving referrals on a regular basis, others noted that funding and time is limited, and the need for LHJ specific information on infant deaths was noted.
- One LHJ said the survey alerted them for the need to have a written procedure to disseminate to staff.

Twenty-eight LHJs shared comments related to their grief/bereavement support services:

- Many LHJs reported providing initial grief/bereavement support services and then referring families to agencies within the community.
- Other LHJs noted the need for grief/bereavement support services for their residents, while smaller LHJs do not have resources because of so few deaths. Other comments included PHN's having limited time and resources and if families are difficult to find they may not receive services.
- The need for cultural specific information was noted, such as brochures in different languages.
- Some LHJs obtain support information from the national SIDS Foundation and also the California SIDS Program.
- A number of LHJs stated the high priority of grief/bereavement support services in their work, another having a very supportive director about offering grief/bereavement support to families, and another stated the desire to increase collaboration with the coroner's office.
- Some LHJs also noted the need for new staff to receive grief/bereavement training.
- While some LHJs reported the SIDS Coordinator being responsible for the role of multiple positions, it was noted they provide support to the PHN who provides grief support and outreach to families.

Question 14

Please list any questions/concerns you have about the responsibilities of the coroner and/or local health department when a presumed SIDS death occurs.

Comments were provided by 37% (n=22) of the LHJs about their questions/concerns related to the responsibilities of the coroner and/or local health department when a presumed SIDS death occurs. The remaining LHJs (63%, n=37) did not respond. Forty-seven percent (n=14) of Urban LHJs and 28% (n=8) of Rural LHJs provided comments. Comments are summarized into two groups; one is responsibilities of the coroner and the other is responsibilities of the local health department/LHJ.

Concerns regarding the responsibilities of the coroner when a presumed SIDS death occurs:

- Two LHJs reporting infant death diagnosis occurring outside of their county and this increases the delay of the final diagnosis.
- One LHJ noted having concerns over death scene and autopsy protocols not being submitted to the State and about how to encourage submission of the protocols.
- A few LHJ's were concerned over how the cause of death is diagnosed. Concerns included the length of time it takes to receive the final diagnosis which is difficult for the family, who ultimately decides what the final diagnosis is and if there is any legal responsibility by the coroner to notify the parents of the final diagnosis.
- Other concerns included referrals of infant deaths not being forwarded to LHJs and the delay in receiving referrals when an infant dies over the weekend.
- One LHJ noted their concern over first responders transporting all babies when death is obvious at the location where the infant died.
- Another LHJ reported having difficulty doing home visits if the diagnosis is possible SIDS or Undetermined.
- One LHJ reported having good communication between the coroner and the LHJ.

Concerns regarding responsibilities of the LHJs when a presumed SIDS death occurs:

- The lack of funding for SIDS support grief counseling was noted. Hospitals provide limited support and one LHJ noted being able to provide support only through the MCAH program funding and is not able to provide any follow-up.
- Another LHJ reported limited low/no cost grief community based resources.
- Another concern raised was the availability of training for law enforcement personnel.
- One LHJ noted uncertainty with the process of sudden unexplained infant deaths because of the infrequency of infant deaths and the unavailability of a written protocol for how infant death cases get to the LHJ.
- One LHJ reported after having established a relationship with the CDRT and medical examiner, many issues have been resolved.
- Another LHJ suggested the results of this survey may be used as a tool for LHJs to initiate policy discussion.



APPENDIX A

CALIFORNIA SUDDEN INFANT DEATH SYNDROME PROGRAM

Survey of SIDS Support Services

PLEASE NOTE:

To return the survey via email: Type your responses directly into the shaded areas, save the document and then attach it to a new email addressed to gedelstein@californiasids.com.

To return the survey via fax: Print the survey (shaded areas will not print). Write in your responses, and then fax it to **916-851-5937**.

1. How are you notified by your coroner's office of a sudden unexpected infant death? (check all that apply)

Phone Fax Email Other (please list below)

2. Who in your Coroner's office notifies the health department about a possible SIDS death? (check all that apply)

Clerk/office staff Coroner Investigator Coroner
 Sheriff/Deputy Other (please list)

3. Does your coroner's office notify your health department of all sudden, unexpected infant deaths?

Yes No (If no, please explain)

4. Does your coroner's office have a written procedure for referring SIDS and other sudden unexpected infant deaths to the health department?

Yes Don't know No (If no, please explain)

5. How soon after the autopsy do you receive notification of a possible SIDS death?

Within 24 hours 24-48 hours 3-7 Days
 More than 1 week Weeks to months (please explain)

6. Who at your health department receives SIDS/other infant death referrals from the Coroner's office?

SIDS Coordinator MCAH Dir/Coordinator Sup. PHN
 Office clerk Other (please list)

7. Does your health department offer grief/bereavement services to families with a possible/pending SIDS diagnosis?

Yes No (If no, please describe your policy for follow up.)

8. How soon after receiving notice of a possible SIDS death does your health department initiate contact with the family, childcare provider, and/or foster parents?

Within 3 working days 3-5 working days
 5-7 working days 7+ working days

9. How does your health department contact those who experience an infant death? (check all that apply)

- | | | |
|--|---|--|
| <input type="checkbox"/> Face to face visit | <input type="checkbox"/> Group visit | <input type="checkbox"/> Telephone call |
| <input type="checkbox"/> Drop off SIDS information | <input type="checkbox"/> Mail information | <input type="checkbox"/> Other (explain) |
-
-

10. What is your health department's policy for grief/bereavement support services? (check all that apply).

Our health department provides services for:

- | | |
|---|---|
| <input type="checkbox"/> Confirmed SIDS deaths | <input type="checkbox"/> Possible SIDS deaths |
| <input type="checkbox"/> Other sudden unexpected infant deaths (i.e. undetermined, accidental, suffocation) | |
| <input type="checkbox"/> Other types of infant deaths (please explain) | |
-
-

11. Who does your health department provide with grief support when there is a sudden unexpected death of an infant? (check all that apply)

- | | | |
|---|---|---|
| <input type="checkbox"/> Parents (biological) | <input type="checkbox"/> Parents (adoptive) | |
| <input type="checkbox"/> Other family members | <input type="checkbox"/> Grandparents | <input type="checkbox"/> Childcare/daycare provider |
| <input type="checkbox"/> Caregiver at time of death | <input type="checkbox"/> Foster parents | <input type="checkbox"/> Others (please explain) |
-
-

12. Does your health department continue to provide grief/bereavement services after the *initial* contact has been made?

- No Yes (please explain below)
-
-
-

13. Please share any comments about your health department's internal policies/procedures and grief/bereavement support services concerning sudden unexpected infant deaths.

14. Please list any questions/concerns you have about the responsibilities of the coroner and/or local health department when a presumed SIDS death occurs.

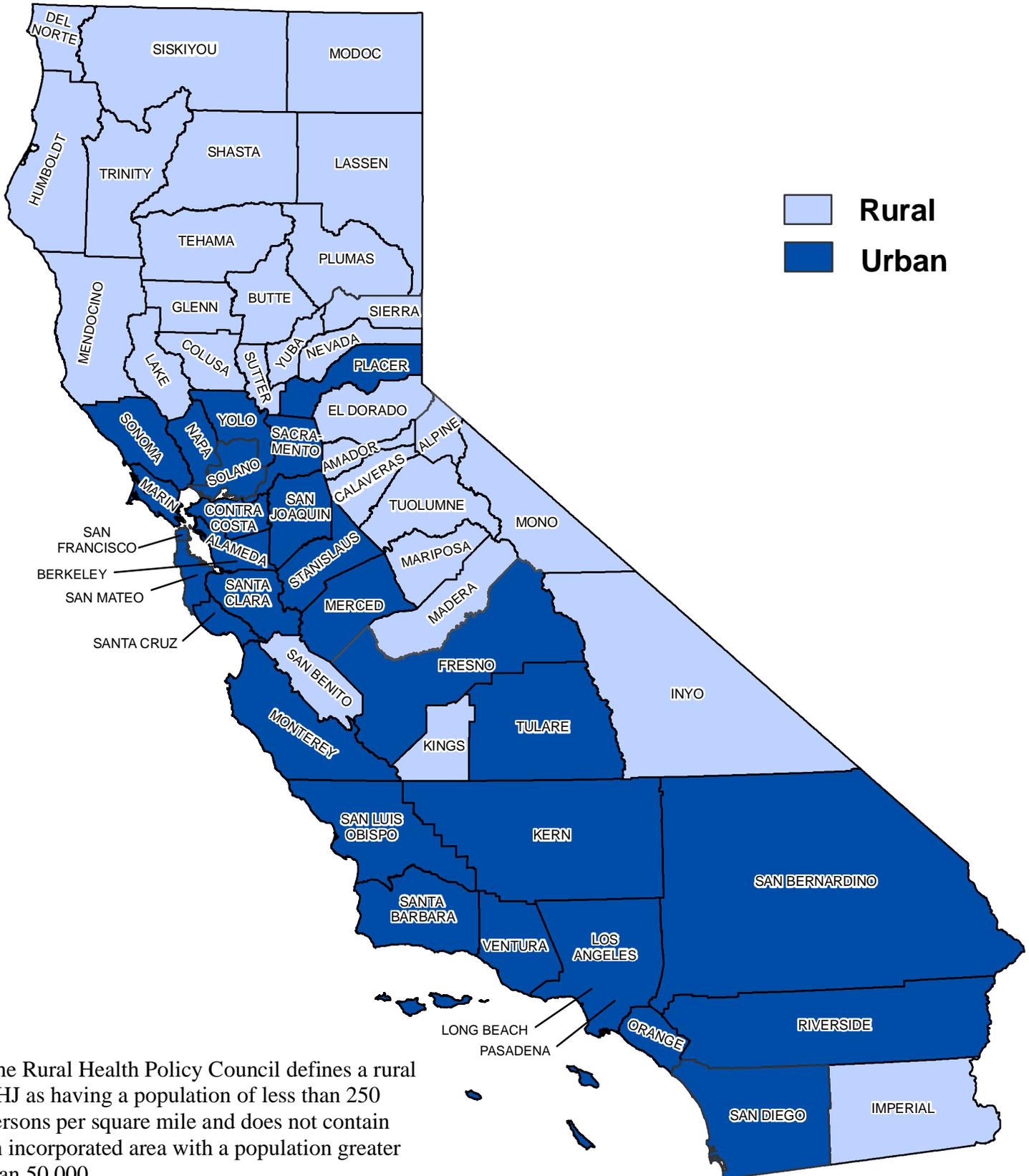
Completed by: _____ Title: _____

Health Department: _____ Date: _____

Thank you for taking the time to complete this survey. Your input will help us to identify how to best serve the needs of those experiencing a sudden unexpected death of an infant. Please fax or email this form to the California SIDS Program by the close of day Tuesday June 12, 2007.

APPENDIX B

California Local Health Jurisdictions (LHJ) by Urban and Rural Designation



The Rural Health Policy Council defines a rural LHJ as having a population of less than 250 persons per square mile and does not contain an incorporated area with a population greater than 50,000.