



California Sudden Infant Death Syndrome Program

SIDS Public Health Professionals

Frequently Asked Questions

What is meant by the *designated agent* of the local health officer?

The legislation defines this person as an appropriately trained public health professional. They can be a public health or social worker. The mandate states that this individual must be knowledgeable about the incidence of SIDS, the care and support of persons who have experienced a death of this nature and who has basic grief counseling skills.

Who are SIDS Coordinators? Does every county have one?

SIDS Coordinators are identified as the designated public health professional within each local health jurisdiction with training and knowledge about SIDS. This individual is a public health nurse or social worker who represents their city or county health department in matters related to SIDS. They serve as the liaison between the California Department of Public Health (CDPH) SIDS Program and the California SIDS Program and among other SIDS Coordinators. Their assignment to this position is determined at the local level. Certain jurisdictions have named two individuals to share this role and these professionals are identified as SIDS Co-Coordiators.

Who has the legal responsibility to contact the family, childcare provider, and/or foster parent upon being informed by the coroner of any case in which Sudden Infant Death Syndrome (SIDS) is the provisional cause of death?

The health officer of the city or county local health jurisdiction or his/her designated agent as per SB 362 California Health and Safety Code 123740 is required within three (3) working days of receiving notice from the coroner or other reporting agency to contact the person or persons who had custody and control of the infant at the time of the death.

Does the legal mandate require that a home visit is made?

No. The legislation simply states that there must be **contact** within three (3) working days of being notified of a possible SIDS death. Contact can be a face-to-face visit, a group visit or a telephone call. However, a home visit is recommended whenever possible. Those who experience a sudden unexpected infant death find that a home visit gives them an opportunity to express their feelings, gain an in depth understanding of SIDS and ask questions. For many, the home visit is the foundation of their support.

At the time of the initial contact what services should be provided?

One or more of the following services should be provided when the initial contact is made: an assessment of the family, childcare provider, or both; crisis intervention and counseling; a referral to community service(s); and a follow-up assessment of the progress of the family, childcare provider or both.

If an infant dies while at the home of a childcare care provider does this person receive any support services?

Yes. The legislative mandate requires that the person, who had custody and control of the infant at the time of the death, including childcare providers and foster parents, must receive follow up. Within three (3) working days of being notified of the presumed SIDS death, the trained professional is required to provide information, support, referral and follow up services.

Who has responsibility for providing SIDS support services, the county where the family/childcare provider or other primary caretaker lives, or the county in which the death occurred?

The county where the family, childcare provider or other primary caretaker **resides** always has responsibility for providing SIDS support services. This same county professional would be responsible for notifying the physician of record and submitting the mandated reporting form. In those cases where the death occurs in one county and the family resides in another, the SIDS Coordinator/PHN where the death occurred upon notification should immediately make a referral to the SIDS Coordinator where the family resides. There may also be times when the SIDS Coordinators from both counties are actively involved. Here are a few examples: the family lives in one county (i.e.: Los Angeles) and the infant's death occurred at the home of childcare provider in another county. (i.e.: Ventura); the infant dies in foster care in one county and the biological parent resides in another county; or the parents of a SIDS infant are incarcerated in one county and the baby dies in the care of a grandparent (legal guardian) living in a different county. Any time more than one county provides support services ongoing dialogue is encouraged between those public health professionals involved with the case. To make a referral to another SIDS Coordinator, refer to the listing of local health departments on the Program's website, www.californiasids.com

How does the infant's health care provider get notified that a baby under their care has died?

The trained public health professional has the responsibility to consult with the infant's physician of record following the SIDS death. The name of the physician and other information is sometimes provided by the coroner's office when the case is referred for support services. If not, information about the primary care provider can be obtained at the time of the initial contact with the family or caregiver. The California SIDS Program has developed a *SIDS Informational Portfolio for Health Care Professionals Whose Patient Has Died of SIDS*, which should be given to the physician of record to advise them of the infant's death and inform them about SIDS. Refer to the Professional Resources section of the California SIDS Program website, www.californiasids.com for more details and/or to download this informational resource.

Who monitors local departments to ensure compliance with follow up for presumptive SIDS cases?

Health and Safety Code 123745 (SB 1068) specifies that "the State will monitor or contract with a person to monitor whether the health officer or his/her designated agent (SIDS Coordinator/PHN/other trained professional) is performing the duties required within the established time frames." The California Department of Public Health MCAH Division contracts with the California SIDS Program to monitor compliance by health department professionals who provide support services as well as coroner offices. The Program checks to determine if coroner cases are referred to the local health department within 24 hours of the presumptive SIDS diagnosis and whether support services were received within three (3) working days of being notified of the infant's death. The California Department of Public Health Epidemiology, Assessment and Program Development Unit has a similar system for monitoring the mandated autopsy and death scene protocols that are submitted to them by local coroners.

Is there a system in place to determine if local departments submit the mandated documents for SIDS cases?

Yes. Documentation is required by both the coroner's office and the local health department for all suspected SIDS cases. Coroners are required to submit a *Coroner Notification Card* and local health jurisdictions (SIDS Coordinators/PHNs) document their initial contact on the *Public Health Services Report Form*. These reporting documents are sent to the California SIDS Program where they are reviewed by a nursing professional. Each case is assigned a State file number and placed on an Epidemiology Log which is submitted to the California Department of Public Health (CDPH) on the 15th of each month. The CDPH Epidemiology, Assessment and Program Development Unit has a similar system for monitoring the mandated autopsy and death scene protocols. The Program and State confer regularly to determine if the appropriate documents have been submitted for each suspected SIDS case.

Is the *Public Health Services (PHS) Report Form* the only document that the SIDS professional needs to submit to the California SIDS Program?

The *Public Health Services Report Form* is the only form that is **required** to be submitted. However, for purposes of data collection by the CDPH it would be helpful if the following documents were also sent to the California SIDS Program: the contact or assessment page of the *Public Health Services Report Form*; a copy of the baby's birth certificate; and a copy of his/her death certificate. The *PHS Report Form* and *Contact Worksheet* along with a listing of definitions and instructions for completion can be found in the SIDS Coordinators section of the website under Protocols. The form, when submitted, must be an original which is signed and dated.

When should the *Public Health Services Report Form* and any other documents be sent to the California SIDS Program?

Within thirty (30) days of the date of the presumed SIDS death, the *PHS Report Form* documenting contact or attempted contact must be submitted. If the family, childcare provider or other person is to receive continued support services, upon closure of the case, any additional information should be submitted to the California SIDS Program for data abstraction purposes.

Is it still necessary to submit the *Public Health Services Report Form* when contact is not made or services are refused?

Yes. To document these situations and remain in compliance with the SIDS mandates, there is a section on the form related to the Primary Caretaker and Childcare Provider which states, "contact not established" and "reason." This section should be completed with any information you have obtained. Some reasons contact may not be established might include: "unable to locate family as they have moved, no forwarding address," "family resides in another county, case referred to the SIDS Coordinator there," or "contact not appropriate upon further investigation as cause of death not determined to be a presumed SIDS." This same documentation is required when services are refused. Examples might include: "family states they are leaving the area, do not want services," "planning funeral, not interested in PHN services. Might want follow up later," or "family discussed PHN home visit with attorney, was advised to decline services."

How is the mandated reporting of presumptive SIDS cases monitored?

The California SIDS Program nursing professional compiles a log of all *Public Health Services Report Forms* and *Coroner Notification Cards* for presumed SIDS cases by the 15th of each month. On a quarterly basis usually after the 15th of March, June, September and December, letters are sent to county coroners and/or SIDS Coordinators when there are missing documents. It is the responsibility of the SIDS Coordinator upon receipt of a compliance letter to ensure the mandated documents are submitted to the Program.

What are the roles and responsibilities of the SIDS Coordinator?

The roles and responsibilities of the SIDS Coordinator are defined by each of the local SIDS Programs. However, most SIDS Coordinators assume similar responsibilities. These may include but are not limited to:

- Serves as the designated professional for their local health department for matters related to SIDS.
- Acts as the liaison between the California Department of Public Health MCAH SIDS Program and the California SIDS Program.
- Accepts and coordinates referrals for all presumed SIDS cases and is responsible for ensuring mandated support services are provided and that documentation of the follow up is reported to the California SIDS Program.
- Coordinates the dissemination of *SIDS Informational Portfolios* for parents, childcare providers, foster parents, grandparents, and the infant's health care provider and ensures that all materials are updated as needed with the most current information.
- Shares updates from the CDPH MCAH Division and California SIDS Program as appropriate with other professionals involved in SIDS including dissemination of research articles, new/revised publications, policies/procedures, etc.
- Attends the Northern or Southern California Regional SIDS Council Meetings and/or educational offerings such as the Annual SIDS Conference and California SIDS Program trainings when approved by the local health jurisdiction.
- Collaborates with the local MCAH Director to identify existing activities, services, and interventions and areas of need to be addressed through the CDPH MCAH SIDS Program allocation.
- Assists in the development, production and/or distribution of SIDS educational materials and information to targeted populations.
- Provides trainings and materials to hospital staff, childcare providers, foster parents, emergency personnel, public health professionals, community based organizations, and others involved/affected by SIDS.
- Attends local health fairs, conferences, and other events to provide SIDS education and information.
- Collaborates with other programs and organizations to promote SIDS awareness and outreach such as CHDP, WIC, AFLP, BIH, CPSP, and Department of Social Services Community Care Licensing.
- May serve as the SIDS professional representative to the local Child Death Review Team and other related task force groups, boards, and/or councils.
- Works with the Coroner's office to develop, implement, and maintain a notification system for the referral of all presumed SIDS cases.
- Assists newly bereaved families to identify bereavement support services such as SIDS Parent Support Organizations, Compassionate Friends, HAND, SHARE, etc.
- Coordinates referrals for burial and interment services as needed for newly bereaved families with limited financial resources.
- May serve as a SIDS support group facilitator or co-facilitator with another SIDS professional and/or trained SIDS parent.
- Advises the California SIDS Program of local staffing changes, mailing/address updates, new email addressees, and other pertinent information included on the Program's website and data base listing.
- Shares innovative SIDS activities and/or projects with the California SIDS Program for purposes of appraising other SIDS Coordinators statewide.
- Maintains/updates the *SIDS Handbook for Public Health Professionals* utilizing it as a resource in undertaking assigned responsibilities and training agency staff.

What is the best way to prepare for a SIDS home visit?

The SIDS home visit requires the use of many nursing skills. Prior to the home visit it is necessary to have a good basic understanding of SIDS and the most current research. Good counseling skills, especially the ability to be an active listener and knowledge of the grieving process are also essential. The public health professional should be prepared with information about community resources such as local mental health and bereavement support services, burial and funeral assistance, and religious groups which may be needed by those impacted by the sudden loss. It is also necessary to assess one's own personal feelings and emotional state to ensure that this does not affect the delivery of bereavement support services.

There are a variety of avenues available to attain the skills and knowledge to prepare for the SIDS home visit. SIDS trainings and conferences and the California SIDS Program website (www.californiasids.com) provide up to date information about SIDS. *A Practical Guide to the SIDS Home Visit* is an excellent resource to prepare for the home visit and offers a wealth of information on all aspects of providing SIDS support services. Refer to the Professional Resources section of the Program's website for this guide. Seek technical assistance and guidance from other professionals such as your local SIDS Coordinator, other colleagues with years of experience and knowledge and/or the nursing professionals at the California SIDS Program. Because the sudden unexpected loss of an infant is such an emotional and tragic event and its' impact is so devastating, it is especially important that the professional take the time to be prepared for the SIDS home visit.

How does a professional receive training about SIDS and obtain the skills necessary to provide support services including grief/bereavement counseling?

The California SIDS Program provides training for public health professionals biannually. These all day educational offerings provide an in depth overview of SIDS including current research findings and the latest SIDS risk reduction recommendations. Other areas that are presented are the role of the coroner and the mandated autopsy/death scene investigation. There is a major emphasis on the grieving process, socio-cultural and individual differences in expressing grief including children, and how to recognize and assess normal versus abnormal reactions to grief. The emotional impact and coping with grief as the caregiver are also covered along with communication skills. As part of the training, parents and others impacted by a SIDS event share their experiences so that professionals can understand first hand the tragedy of SIDS and identify ways those affected by the sudden unexpected loss of an infant learn to cope.

The California SIDS Program also coordinates an Annual SIDS Conference each October and regular electronic updates are sent to SIDS Coordinators to keep them informed about the latest research and SIDS findings. An array of educational and informational resources is available on the Program's website and resources are updated as they become available. In addition, there are links to other state and national organizations/agencies with other sudden infant death and SIDS information. Other activities that will help prepare the SIDS professional to assist families include attending grief trainings and building rapport with local SIDS Parent Support Organizations and other health care professionals involved with SIDS.



Produced by the California SIDS Program under funding
by the California Department of Public Health
Maternal, Child and Adolescent Health Division

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