



Standards for Social Work



CALIFORNIA
SIDS
PROGRAM

SUDDEN INFANT
DEATH SYNDROME

CALIFORNIA DEPARTMENT
OF HEALTH SERVICES MCH

Sudden Infant Death Syndrome



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Introduction

A death from Sudden Infant Death Syndrome (SIDS) is a devastating experience for every family member and caregiver. The question of “What did I do?” or “What could I have done?” occurs and reoccurs for parents, siblings, and extended family members. Social workers may become involved when an infant is brought into the hospital emergency department, making home visits, or facilitating support groups. Other individuals touched by an infant’s death may also be contacted by the social worker: baby sitters, foster family members and community or agency staff.

Because of social work’s orientation to systems’ theory, social workers are able to evaluate the impact of the infant’s death from many viewpoints. Social workers take into account the extended social network and adhere to ethical guidelines that protect the individual’s dignity and right to self determination. The social worker also strives to protect the confidentiality of the client.

The following standards are to be used as guidelines for social workers who interact with individuals who are involved with SIDS. These standards do not cover everything that the social worker may encounter, but will help define issues, identify involved agency and community personnel, and facilitate appropriate interventions.

STANDARD 1. THE SOCIAL WORKER'S KNOWLEDGE AND SKILLS

- A. The social worker who provides services to SIDS families and caregivers shall have a baccalaureate and/or graduate degree from an accredited social work program.***

Interpretation

Social workers are trained professionals who provide highly complex services to individuals, and to the community. This is particularly true of social workers who work with SIDS families and caregivers. Roles social workers play in supporting SIDS families and caregivers include: advocate, diagnostician, evaluator, consultant and therapist. The particular role will vary with the setting in which services are provided, thus the academic background and advanced training required will vary with the setting. Complex and difficult situations require highly trained and experienced social workers, preferably with a master's of social work degree. If psychotherapy is included in the social worker's scope of work, clinical licensure is required. In addition to academic credentials, social workers who work with SIDS families and caregivers should understand the special needs of this population. Regardless of the service setting, all social workers should strive to become and remain competent in SIDS content, grief counseling, and family systems theory by critically examining current literature on these topics. In addition, social workers should have skill in working with multicultural clients.

B. The social worker who provides services to SIDS families and caregivers shall possess the knowledge, skills, and experience necessary to provide competent care to these clients.

Interpretation

The social worker should accept responsibility for services to SIDS families and caregivers only on the basis of existing competence. First and foremost, the social worker should know the statistics, epidemiology, typical history, and current proposed etiologies of SIDS. The social worker should have an understanding of the grief process and the ability to distinguish between normal and potentially problematic responses. The social worker should have knowledge of cultural differences in manifestations of grief.

It is said that one SIDS death affects 100 other individuals. These individuals include the parents, siblings, other relatives, friends, co-workers, childcare providers, and professionals who interact with the SIDS family. The social worker should know how to help all individuals affected by a SIDS death.

Social workers who work with SIDS families and caregivers should know the resources available to the bereaved. Since the SIDS death may precipitate a crisis situation, the social worker should be familiar with models of crisis intervention and twenty-four hour crisis intervention resources. Familiarity with grief support resources is particularly important. Social workers should specifically know how to access SIDS peer contacts or peer support groups.

SIDS cases may be complicated by other problems within the family such as illnesses, lack of extended family, poverty, drug or alcohol abuse, mental illness, and disrupted relationships. Social workers should understand family systems theory and be prepared to provide services to the entire family. The social worker must also be able to work collaboratively with community agencies to coordinate services given to SIDS families and caregivers.

STANDARD 2. THE SOCIAL WORKER'S ETHICAL RESPONSIBILITIES

A. The social worker who provides services to SIDS families and caregivers shall adhere to the principles of ethical standards as defined by professional social work organizations.

Interpretation

Social workers are responsible for maintaining high standards of professional conduct. Social workers are accountable for the services they provide to consumers, government, professional organizations, and to the community.

Given the unique vulnerability of SIDS families and caregivers, the social worker may be faced with ethical dilemmas that require difficult decisions. Professional social work organizations provide standards to guide ethical decision making. While the basic principles are similar among all codes of ethics, specialty areas within the profession often have their own standards of practice. It is important, therefore, that the social worker be a member of the professional organization that most closely represents their area of practice.

B. The social worker who provides services to SIDS families and caregivers shall give primacy to the client's interests and demonstrate respect for the integrity of clients.

Interpretation

The social worker's primary responsibility is to protect the welfare and to respect the integrity of their clients.

Giving primacy to the client's interests means that the social worker does not exploit the relationship with clients for personal gain. The social worker should be aware of personal values, beliefs, and attitudes toward the death of an infant, guarding against the intrusion of personal needs and issues into the care of the clients.

One way social workers demonstrate respect is by promoting autonomy and self determination. The social worker does so by providing accurate and complete information, apprising clients of their rights, and involving clients in the plan of care.

The ethical social worker does not use the unique position of power associated with the social worker-client relationship to influence clients in any way that is not in the client's best interests. It is important that social workers maintain therapeutic boundaries given the vulnerability of SIDS families and caregivers.

- C. *The social worker who provides services to SIDS families and caregivers shall provide high quality care with sensitivity to the client's socioeconomic status, ethnicity, religious beliefs, age, gender, or sexual preference.***

Interpretation

The ethical social worker does not engage in or condone any form of discrimination on the basis of socioeconomic status, ethnicity, religious beliefs, age, gender, or sexual preference. The social worker should not impose personal values, beliefs, or cultural practices upon the client.

The social worker should be aware of the family's culture, values, and beliefs regarding the death of an infant. It is also important to acknowledge cultural and gender norms for the expression of grief and associated preferences regarding rituals and practices surrounding death. The social worker should encourage the family or caregiver to use whatever cultural practices that are effective in coping with this loss. As appropriate, the social worker should collaborate with informal and community support systems. The social worker should recognize when intervention is needed and when to defer to pre-existing networks.

In the event that communication barriers impair the delivery of services, the social worker facilitates effective communication. This often means involving medically trained translators. Although it is convenient to use family members who are bilingual, adult family members should only be used under critical circumstances when no other source of translation services is available. Siblings or children should never be used as translators because of the sensitive and painful nature of the topic.

The social worker shall act as an advocate to protect the client from discriminatory practices. In addition, the social worker should provide culturally sensitive interventions.

D. The social worker who provides services to AIDS families and caregivers shall safeguard the privacy of clients by maintaining confidentiality of client information.

Interpretation

Social workers have a primary obligation to keep confidential the information that is obtained as a result of the social worker-client relationship. The social worker may reveal confidential information only with the informed consent of the client. This obligation to respect the privacy of the client holds for all circumstances except when doing so violates government mandated reporting laws or when a clear danger is posed to the client or others.

The social worker should inform the client that information will remain confidential and under what conditions the information may be disclosed. The client's verbal or written consent should be obtained prior to making referrals to other agencies, parent groups, or support services.

Although professional social work organizations have guidelines for protecting the privacy of clients, the social worker's first obligation is to adhere to the policy of the employing agency. In the absence of a policy, the social worker should facilitate the development of such policies. The policy should include guidelines on what information should be obtained, how it is recorded, who has access to records and under what circumstances, and plans for maintaining records.

STANDARD 3. THE SOCIAL WORKER'S INTERVENTIONS

- A. The social worker who provides services to SIDS families and caregivers shall assist the bereaved to cope with the death of the infant.***

Interpretation

Social workers provide services to the bereaved in a variety of settings including emergency departments, county health departments, social service departments, schools, community agencies, childcare or foster care homes, or in private practice. The services provided by the social worker depend upon the environment in which the contact occurs.

- 1. EMERGENCY DEPARTMENTS: The hospital social worker shall be notified of all presumed SIDS cases upon their arrival at the emergency department and support the bereaved as appropriate.*

Social work services shall be offered to families or caregivers of infants upon arrival to the emergency department with a presumed diagnosis of SIDS. These services should include, but are not limited to: psychosocial assessment, crisis intervention, counseling, information and referral. The social worker should approach the family in an open and non-judgmental manner to facilitate information gathering and supportive relationship building.

On arrival to an emergency department with the infant, caregivers should be provided with a private location to review the events surrounding the death. The social worker, in conjunction with the

physician and nursing staff, should create a supportive environment for the caregiver as the facts are related. Any discrepancies should be reviewed to eliminate the possibility of abuse or neglect.

While medical staff examine the infant, the social worker should provide supportive counseling and facilitate the needs of the family. For example, the social worker should contact individuals outside of the hospital including family, friends or clergy, and arrange for interpretation services when indicated. The social worker serves as a liaison between family and medical personnel, facilitating communication of medical information to the family.

In this early phase of the grief process, the social worker should work with the emergency department personnel to allow the caregivers sufficient time to hold the infant and to maintain the infant in the emergency department until family or friends arrive. A memory packet, including pictures, foot or hand prints, and lock of hair can be prepared for the family and presented by the social worker. Care should be taken to offer mementoes that do not conflict with the cultural or religious practices of the family.

The social worker may discuss disposition of the baby's body, advising the family that immediate decisions are not necessary. Options for burial or cremation can be reviewed at this time or in future contacts during the first few days following the death. The family should be informed of resources in the community relating to SIDS. The family should be informed that professionals from the Public Health Department and the Coroner's Office will contact them. It is important that the family understand State mandates for an autopsy and the completion of a death scene investigation by the coroner.

The social worker who meets the family in the emergency department should make contact with the caregiver within a week of the SIDS event to provide support and to ensure that outside support services are in place.

2. *PUBLIC HEALTH DEPARTMENT: The social worker in the Public Health Department shall be notified of all presumed SIDS cases. They shall ensure compliance with mandated reporting requirements and support the bereaved as appropriate.*

Since the enactment of SIDS legislation in July, 1974, social workers have been involved in outreach to affected parents and caregivers. Public Health Departments have variously used social workers either as the coordinators of such services and/or as the direct service link to the parents, State and the larger SIDS community. The education and expertise of the social worker lends itself most appropriately to this service. With an understanding of family systems, grief processes, community resources and linkages, social workers are in a position to effectively and sensitively assess and assist their clients.

Social workers who coordinate SIDS services should be responsible for training and supervision of interdisciplinary staff who interact directly with SIDS families and caregivers. They should ensure that timely contact is made with the family or caregiver and that appropriate services are provided.

Public Health Department services shall be initiated within three days of notification of a presumed SIDS death. The social worker should offer condolences, discuss immediate concerns, assess knowledge regarding SIDS, and identify sources of support within the family through an initial telephone contact. If appropriate, information regarding peer support networks or crisis intervention

resources should be provided. Plans for a home visit should be made during the initial phone contact. During the home visit, the social worker should discuss SIDS literature, answer questions, conduct a grief assessment (i.e. suicide risk, areas of guilt, blame, grief responses), and evaluate strengths, risk factors, actual and potential problems. The family or caregiver should be encouraged to review and recreate events preceding, including, and following their baby's death. The social worker should reinforce family strengths and competencies in parenting, and in their response to their baby's death. Special attention should be given to the bereavement needs of children who are present in the environment.

In addition to supporting the family or care giver, the social worker is responsible for gathering information about the case and forwarding this data to the State.

- 3. FOSTER CARE SETTING: When a foster child dies of SIDS, the social worker shall immediately respond to meet the needs of the foster family and the biological family, insuring that the licensee has met their reporting mandates.*

The social worker shall make contact as soon as possible, in person, with the foster family to lend support and review the circumstances prior to the SIDS event. It must be clearly communicated to the foster parent that there is no blame. The social worker shall gather information for the case record and insure that the reporting responsibilities of the licensee have been met. It is important that the social worker collaborate with the local Public Health Department in both the investigative process and in providing service to the foster family.

The social worker should assess the capacity of the foster parent to continue fostering other children placed in their care, and to determine if they need temporary respite. The social worker should facilitate access to mental health intervention if the foster parent needs this service. The social worker should alert the other social workers with foster children placed in this home to assess how they are coping with the loss.

The social worker should contact the biological parents to discuss the SIDS event and to determine what support and referral services are appropriate. If there are siblings, attention should be given to their bereavement needs.

The death of a foster child has an impact on the entire fostering community. Therefore, SIDS training should be an integral part of preparing a foster care licensee. Social workers who work with foster care providers also should receive SIDS training to ensure that this community has appropriate education regarding SIDS.

4. *DAYCARE SETTING: When a SIDS death occurs in a childcare setting, the social worker in the day care licensing organization shall contact the caregiver and facilitate access to support services.*

When a death occurs in a childcare setting, the daycare licensing organization is notified of the death. If the death is determined to be SIDS, the social worker shall contact the childcare provider to determine what services are needed and to assist the provider in obtaining those services. The daycare licensing social worker does not provide psychotherapy services, but should ensure that the caregiver is informed regarding the resources available for counseling or other services as needed.

If the final diagnosis is other than SIDS, the social worker shall investigate the death to determine if the daycare provider license should be revoked. The social worker collaborates with community agencies, such as the local Public Health Department, Child Protective Services and law enforcement, during the investigation period.

5. *PRIVATE PRACTICE: The social worker providing psychotherapy services to SIDS families and caregivers is engaged when the grief process impairs the quality of daily living. The social worker's role is to enhance the client's psychosocial functioning.*

Licensed clinical social workers may be engaged for psychotherapy either through private practice or through the auspices of a counseling/ social service agency.

Clients may seek or be referred for individual, couple, family or group counseling or psychotherapy at any point after the SIDS death. It is important to note that the impact of loss may have life-long effects, emerging as developmental passages and triggering past events. Therapeutic attention may have various foci, including but not limited to: normalizing the grief process; complicated, unresolved bereavement; relationship dysfunction; clinical depression; post traumatic stress disorder; or attachment difficulties.

The client's presenting complaint and condition reflects the individual client's relevant personal history, characterological, cultural, environmental and relationship situation. What makes the SIDS loss unique to each individual will inform and direct the therapeutic process. The therapist should endeavor to "start where the client is" and consider the client's goals for treatment. The diagnosis and treatment may be brief (six to twelve visits) focusing on symptom

relief, or long term (six months to three years) focusing on in-depth structural work.

The therapist should engage a client in a treatment agenda that is specific, measurable, achievable, relevant to the client, and that includes plans for termination of the relationship. The agenda should also be within the client's ability to reimburse.

While therapists may operate from a variety of theoretical orientations, basic clinical social work practice is based upon an understanding of psycho-social development, human behavior, psychopathology, interpersonal relationships, and stress theory.

B. The social worker who provides services to SIDS families and caregivers shall facilitate dissemination of SIDS information to clients and to the community.

Interpretation

The social worker who interacts with SIDS families and caregivers has an obligation to possess current, accurate information about SIDS and to ensure that this information is disseminated to clients and to the community. Accurate SIDS information is available from the National SIDS Resource Center, state SIDS Programs, SIDS parent organizations, and from libraries. Materials suitable for families and for the community are also available.

The social worker who interacts with a SIDS family or caregiver should evaluate their knowledge and understanding regarding SIDS. When appropriate, informational materials should be provided. In addition, social workers should provide consultation and education to other professionals who work with SIDS families and caregivers. They should ensure dissemination of SIDS information in a variety of ways, including lectures, organizing workshops, speaking at conferences, or writing journal or newspaper articles.

C. The social worker who provides services to SIDS families and caregivers shall conduct an evaluation of SIDS services.

Interpretation

The social worker should conduct a quality assurance evaluation of the appropriateness, adequacy, and effectiveness of the services provided to SIDS families and caregivers. The evaluation may be comprised of client surveys, outcome analysis, and determination of what services were provided. The evaluation should address the extent to which clients are able to access services, how well program goals and objectives are met, whether there are measurable outcomes, and client satisfaction with services. The results of the evaluation should be used to direct future services offered to SIDS families and caregivers.



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The National Association of Social Workers (NASW) is the largest organization of professional social workers in the world. As of June 1999, over 155,000 members participated in 55 chapters throughout the United States, Puerto Rico, the Virgin Islands, and the international community.

The association works to enhance the professional growth and development of its members, to create and maintain professional standards, and to advance sound social policies.

The Social Work Practice Committee of the National Association of Social Workers, California Chapter reviewed and approved in March 1995, the Standards for Social Work in Sudden Infant Death Syndrome. These standards are to be used as guidelines and serve as a model for social workers in California who interact with individuals involved with Sudden Infant Death Syndrome.



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