Abstract
This paper discusses key service and support issues faced by families who have experienced a sudden unexplained death of an infant (SUDI), the majority of which are from sudden infant death syndrome (SIDS), within an environment of increasing social inequality and poor service coordination. The issues include: changes in the social and economic environments of SUDI families; the forensic focus of the professional response to a SUDI; inadequate training, audit and interagency coordination of key service agencies; and poor data collection for review and for tracking trends. The paper also discusses strategies developed by the Māori SIDS Prevention Programme (MSPP) team to address these issues. These include the development, in consultation with key players, of an integrated and holistic national SUDI death scene protocol with regional teams that facilitate the coordination of services at the local level. In addition, a child mortality review process is advocated. These issues and proposed strategies potentially have relevance to families facing other difficulties that require the support and/or involvement of a number of government and other agencies.

INTRODUCTION
This paper uses the case of sudden infant death syndrome (SIDS) to examine public sector service issues arising for New Zealand families within an environment of increasing social inequality and poor service coordination. The impact of economic and social inequalities,
and the fragmentation of government services, have been very evident amongst families experiencing the sudden and unexpected death of an infant (SUDI), the majority of which are due to SIDS. In recent years, as social disadvantage has become a more prominent feature in SIDS cases, these issues have been particularly challenging.

Since the introduction of new right economic and social policies in New Zealand in the 1980s, there has been growing concern expressed about increases in poverty, poverty-related disease, poor housing conditions and other such problems (e.g. Gunby 1996, Stephens et al. 2000, Baker et al. in press). Indeed, the long-standing social, economic and health gaps between Māori and non-Māori showed no decline over the decade from 1988 to 1998 and, in some cases, widened (Te Puni Kōkiri 2000). In the concomitant drive to improve efficiencies and increase accountability in the public sector, government agencies became more competitive, budgets were tightened and roles made more specific (Shirley 1990). By the mid-1990s, however, there was increasing public criticism about public sector fragmentation, dis-coordination, boundary keeping and cost shifting (Angus 1999).

These issues have particular relevance to families in which an infant has died of SIDS. In New Zealand SIDS occurs most commonly amongst the socially deprived, low birth-weight infants of young, smoking, Māori mothers (Mitchell and Scragg 1994). Māori SIDS Prevention Programme workers have found that such families face multiple social and economic problems and are often already involved with social and other agencies. Although a number of interagency initiatives like Strengthening Families and Family Start (Angus 1999) have recently been established to address some of the above problems, they do not service families of SIDS infants and there is no mechanism in place to review how services collectively impact on these families, how they might be better coordinated or what gaps remain.

The aim of this paper is to discuss key service and support issues faced by SIDS families, as ascertained through the work of the Māori SIDS Prevention Programme (MSPP), and to describe the strategies developed by the MSPP team to address these issues. While some of the issues raised and the strategies promoted are specific to SIDS and SUDI, the larger issues have relevance to families facing other difficulties that require the support and/or involvement of government and other agencies. The recognition and servicing of gaps in these services for SIDS families may contribute to the Labour Government’s stated priority of closing the long-standing social, economic and health gaps between Māori and non-Māori (Bidois 2000).

The paper begins with a background section on SIDS in New Zealand and the work of the MSPP team. Next, the issues that have been identified through the MSPP team’s close work with SIDS families and with the agencies involved with these families are presented,
alongside a range of strategies initiated by the team to address these issues. Lastly, the wider implications of these issues and strategies are discussed.

BACKGROUND

In the mid-1980s the SIDS rate in New Zealand was higher than that in most other developed countries (Mitchell et al. 1989). The New Zealand Cot Death Study, conducted between 1987 and 1990, identified four modifiable risk factors: prone infant sleeping, maternal smoking, not breastfeeding and infant bed-sharing (Mitchell et al. 1992), although the latter was later found to be most significant if combined with maternal smoking (Scragg et al. 1993). Other identified risk factors, which were not deemed to be modifiable were: low socio-economic status, young maternal school-leaving age, young motherhood, unmarried motherhood, non-attendance at antenatal classes, little or late antenatal care, greater number of previous pregnancies, low infant birth weight, prematurity, Māori ethnicity, male sex and admission to neonatal intensive care (Mitchell et al. 1992).

Between 1989 and 1992, a national cot death campaign disseminated information widely about the modifiable risk factors. During this time, New Zealand’s national SIDS rate halved. However, the Māori SIDS rate, which was more than twice that of the general population at the beginning of the campaign, saw a much smaller decline. By 1993 the Māori SIDS rate was six times that of non-Māori (Ministry of Health 1996). Thus the demography of SIDS infants shifted, with the majority of cases now Māori. With the subsequent 1995 redefinition of Māori ethnicity, the proportion of Māori SIDS cases further increased (Tipene-Leach et al. in press).

The MSSP was funded by Government in 1994 to address SIDS in the Māori community. It was developed into a national programme with five regional coordinators and a network of local workers. The development and work of this team have been documented elsewhere (Tipene-Leach et al. 2000). In brief, it has been involved in:

- the dissemination of SIDS information in the Māori community;
- the training of Māori community health workers in SIDS prevention;
- the support of Māori and other SIDS families;
- the development of a national infant mortality register which records all SIDS deaths;
- the development of infant death scene protocols; and
- the development of regional SUDI teams to respond to sudden and unexpected infant deaths.

The particular areas of concern discussed in this paper first arose as Māori SIDS regional coordinators moved to develop a systematic response to the plight of the mostly Māori SIDS families. The same problems were highlighted as one of the national team worked closely with workers from the different agencies involved in these deaths.
When a baby dies suddenly and unexpectedly in New Zealand, a process involving a number of agencies is begun under the authority of a coroner, with the Police as agent. This is mandated by the 1988 Coroners Act. The person who finds a baby unexpectedly dead may attempt resuscitation and should call the ambulance or a doctor. Following medical confirmation of death, the Police are called and usually it is the task of the nearest squad car to respond.

The police officers attending the death scene must firstly determine whether a homicide investigation is required. If not, they are required to collect information that will inform the coroner as to cause of death, and to arrange for the baby to be removed for compulsory post mortem examination. All this is done at a time when family members are still reeling from the shock of their baby’s death. Victim Support and/or SIDS support groups are called by the Police to provide or to arrange ongoing emotional and other support for the family. The Police death scene report (P47) and the pathologist’s post mortem report are the primary information forwarded to the coroner who will determine the cause of death.

As a result of their close involvement with SIDS families and other SIDS workers, the MSPP national and regional coordinators gained an intimate knowledge of both the SIDS parents’ personal, social and economic situation and the difficulties they experienced during the investigative process following their baby’s death. In addition, they became aware of the difficulties and contradictions for acute response staff, such as police officers and community workers. At quarterly intervals the regional coordinators met with the national team, at which time SIDS cases, prevention strategies and general trends were discussed. Data from the infant mortality register helped to create a full picture for the purpose of effective strategic planning. Through these debriefing and strategic planning sessions, the team identified a number of problematic issues regarding SIDS, pertaining also to other SUDI deaths.

**ISSUES**

The key issues identified by the team concerned: the social and economic environments of SIDS/SUDI families; the forensic focus of the professional response to a SUDI; the lack of systematic training for those dealing with SUDI families; the lack of health and social service audit processes; the poor coordination of the wide range of agencies involved with these families; and poor data collection for review and tracking trends.

**The Social and Economic Environments of SIDS/SUDI Families**

The 1991 national cot death prevention campaign’s work in educating the public about modifiable risk factors succeeded in reducing SIDS rates in New Zealand, largely because
of the shift from prone to back sleeping position for infants. Social disadvantage, however, is known to modify the protective effect of the infant back sleeping position (Mitchell and Tipene-Leach 1996). The bigger part of SIDS risk for Māori is related to maternal smoking, young motherhood and low infant birth weight (Mitchell and Scragg 1994), all markers of social disadvantage. The MSPP regional coordinators have found through their “hands on” work that many Māori SIDS families are coping with a number of difficult social and economic problems at the time of their infant’s death. These problems have included poor housing, unemployment, poverty, single parenthood, domestic violence, and involvement with the Child, Youth and Family Service or the criminal justice system.

An informal review by the MSPP team, of cases occurring over a six-month period in 1999 in three regions, confirmed that many families were dealing with a multitude of difficult issues, with little in the way of support or social resources. A few resisted the involvement of any outsiders in their lives, including that of the MSPP team’s regional coordinators and their designated workers, because of their past negative experiences of involvement with government agencies.

Regional coordinators have consistently reported that when faced with families of high need it is not enough to simply deal with the immediate implications of the death of the baby, since these families need ongoing broad-based social and economic support. In addition, other children in the family have needs that are often overlooked. The death of an infant often has profoundly negative consequences on families already under-resourced and struggling with a myriad of difficult issues. This is made more difficult when services are fragmented, insensitive or unresponsive to their situation.

The Forensic Focus of the Professional Response to a SUDI

One of the major issues for families, regarding the professional response to a sudden and unexpected death of an infant, is its forensic focus. While coronial investigation is necessarily a central feature of the response to infant deaths, the manner in which this is carried out and the absence of attention paid to the family’s needs leave many feeling vulnerable. A SIDS diagnosis is one of exclusion, including exclusion of criminal misconduct. While coping with the trauma of their baby’s death, family members must also deal with this.

As the professional response stands in August 2000, the forensic nature of the investigation is not balanced by a medical and a professional social support for the families, or the inclusion of any mechanisms to ensure culturally appropriate processes. There is no systematic examination of the baby at the death scene, other than to confirm
Parents’ questions regarding medical aspects of their baby’s death often go unanswered. There is no designated forum to discuss the necessity of an autopsy, a highly sensitive issue for Māori (Dansey 1992). In addition, parents have no opportunity to present the baby’s previous health history, or to obtain information about the wider implications of this death, particularly for future babies.

Voluntary organisations, such as SIDS Family New Zealand, an organisation of parents who have experienced a SIDS death themselves, have traditionally played the key role in supporting family members through their grief and loss. While this group has historically provided invaluable support for SIDS families, the membership is primarily Pākeha and, with the shift in SIDS demography, its appropriateness to deal with Māori families is at issue. Moreover, volunteers are ill equipped to deal with the difficult social and economic issues with which many SIDS families now present. The need for a professional response to a SIDS family’s personal, social and cultural needs is clear. Families are currently not offered government-funded professional counselling, despite a recommendation for this from the international SIDS research community (Mitchell and Tipene-Leach 1996) and there is no system in place to assess families’ social and economic needs to determine whether other support services should be provided.

Because of the forensic emphasis of the investigation, the lack of a medical presence at the death scene and the positioning of social support in the voluntary sector, grieving parents are located in a relatively powerless position. The investigative focus of the primary professionals and the lack of a strong advocate exaggerate the power imbalance. This can exacerbate the trauma experienced by the family and may prolong grief resolution. These issues are of particular concern when the baby is from a deprived family and more so where there is a previous history of involvement with social agencies or the criminal justice system.

The lack of a comprehensive medical and social presence in the investigation also means that the information gathered for record, and used by the coroner to determine the cause of death, is restricted to the Police and the pathologists’ reports. Anecdotal reports indicate that police officers have been directed back to the family to get information that, in the absence of consistent protocols, was not collected at the initial visit. In addition, the coroner does not routinely receive the baby’s medical history, its antenatal, birth and postnatal records, or a medical perspective on the infant at the death scene. Nor is it usual for the coroner to be provided with information about the social environment in which the infant lived. The omission of medical and social data limits knowledge about the presence of known risk factors for SIDS, and complicates the satisfactory establishment of the cause of a sudden and unexpected infant death.
The lack of systematic training for those dealing with SUDI families, the lack of health and social service audit processes, and poor coordination of the wide range of agencies involved with these families are also important issues. Following an infant death a number of professionals become involved, including doctors, ambulance officers, police officers, the pathologist, the coroner, Victim Support, SIDS parent support and the MSPP regional coordinators. Also, there may be other agencies already involved with the family for other purposes.

The agencies seldom, if ever, come together to debrief or assess their process as a whole. The investigative process is built on an assumption that the key players are adequately trained and working collectively in the best interests of the community. There are, however, no provisions for interagency collaboration on training or support, or for measuring the professional and cultural performance of those involved in such work. For example, young police officers involved are often inexperienced, with little training in how to deal with the emotionally charged environment in which they must question parents and arrange for their baby to be taken away for autopsy.

There is also poor collaboration between those agencies involved in the investigative side of the process (e.g. Police, pathologists and coroners) and others involved more in a family support role (e.g. ambulance officers, voluntary support personnel and the local doctor). There is no single person in the multi-disciplinary infant death environment who formally overviews the service management of the family. There is no formal service audit, no debriefing of workers and no review as to whether processes have been culturally, or otherwise, appropriate.

This means that, at a time when they are experiencing considerable grief, families are dealing with a range of strangers, most of whom are not communicating directly with each other and few, if any, of whom have an overall picture of their case. In addition, many of those with whom they come into contact are not trained in dealing with the specific nature of a SUDI death and have no process to monitor the cultural safety of their practice. Since there is no formal audit process and no readily accessible forum for families to voice concerns, the only agency with which complaints might be lodged is the Health and Disability Commissioner. Few SUDI families, however, would be equipped to follow this avenue by themselves.
Poor Data Collection for Review and Tracking Trends

The information provided to the coroner by the Police is obtained by the officers who first attend the scene. These officers have very little specific training in what to look for at the scene of a sudden unexpected infant death and they do not have a prescriptive list of information to gather (Police Training Directorate 1997). In addition, there is no requirement for a medical death scene investigation, or a medical or social history of the infant. Since the diagnosis of SIDS is complex, thorough and accurate data are essential for the coronial investigation to make an informed finding as to cause of death (Byard and Krous 1999). Furthermore, coroners have historically worked quite independently and, although the Department for Courts has held responsibility for the collation of their work, a database that aggregates information for review and strategic planning purposes has not yet been compiled. There are, however, recent indications of change on this point with the establishment of the Coroner’s Council in 1998 and the Law Commission’s recent review of the 1988 Coroner’s Act (Law Commission 2000).

Finally, there is currently no mandatory requirement under the 1993 Health and Disability Services Act for infant mortality review and, therefore, there is neither a national nor a regional overview of infant deaths in New Zealand. Such information would be useful to establish best-practice guidelines, to inform service development, to identify possible trends and to inform further prevention strategies. A formal review of infant deaths would also provide families with the knowledge that their infant’s death has been taken seriously and learned from.

STRATEGIES

The MSPP team has put together three main strategies for dealing with the issues discussed above. Firstly, it has developed a national SUDI death scene protocol; secondly, it has designed a blueprint for a regional SUDI team to coordinate inter-agency response; and thirdly, it has joined others in advocating for mandatory infant mortality review.

Development of a National SUDI Death Scene Protocol

The development of a SUDI death scene protocol, which standardised both the service response and the collection of information, became the MSPP’s priority strategy for improving the investigation and support of SIDS and SUDI families. It was important that this protocol both standardise current practice and rectify the identified gaps and inadequacies. Iyasu et al. (1996) identified several advantages to having a standardised protocol, including that:
it assisted the pathologist and the medical examiner or coroner in ruling in or ruling out natural causes of death, child abuse or neglect, or injury;
• it helped identify public health threats, such as those related to consumer products or unsafe health practices;
• it could provide parents and caregivers with information about grief counselling, support groups and healthy infant-care practices; and
• it provided information on SUDIs and SIDS to epidemiologists and agencies with an interest in the welfare of children.

These advantages are all highly pertinent in New Zealand.

In conjunction with a community paediatrician, the MSPP team developed a protocol depicting the sequence of the coronial investigation and various assigned roles as they usually occurred in the case of a sudden and unexpected death of an infant. Added to this protocol were facilities for medical, social and cultural support, appropriate data collection and a mortality review process.

Of central importance was the development of a process that balanced the strongly forensic focus with a medical death scene investigation. Paediatricians would collect necessary death scene information and could play an important mediator role between the family and the forensic nature of the Police role. They could also facilitate social support services. They would be a neutral person to whom the family could address questions on medical matters, the post mortem and other aspects of the forensic investigation. In addition, they could provide paediatric input to the pathologist, who in many cases may not have specialist paediatric knowledge.

Coroners, the Police, pathologists, paediatricians, Māori communities, SIDS families and others were then revisited to discuss the protocol. It was often the first time the professional response to SUDI had been presented as a whole picture, and certainly the first time the medical and social structures had been linked to the coronial process. It provoked considerable discussion.

Through the involvement of the key agencies in the development of the national protocol, there has been strong support for it. Although it has not yet been formally implemented nationally, the key agencies involved concur on the need to standardise and enhance the infant death scene process. Police at National Headquarters have indicated their support for the addition of a medical examination to the SUDI death scene investigation, and paediatricians are currently developing a standard medical examination. Pathologists have agreed to a minimum standard autopsy protocol and to working with a small team of pathologists reviewing all SIDS histology. Importantly, coroners are now supplying information on infant deaths directly to the MSPP infant mortality register.
At the same time, advocacy has proceeded for the development of SUDI training programmes for those agencies involved, particularly in the acute response phase. For example, a police training programme instituted in Queensland (Joyce and Graydon 1997) has been promoted as a model for use in this country. The programme trains a cadre of senior officers who nominate to become involved in liaising with and supporting each SUDI family.

Development of Regional SUDI Teams

The need for a coordinated response to a sudden and unexpected death of an infant led to further consultation and the development of a blueprint for a regional SUDI team, a pilot of which is planned for Auckland. The SUDI teams would comprise the local representatives of the relevant agencies involved in a SUDI, with special attention paid to balancing the forensic, medical, social and cultural strands of the professional response. The MSPP regional coordinators would be responsible for coordinating these agencies in the first instance. Those involved would work collaboratively using the national SUDI death scene protocol as the basis of their acute response and their ongoing work with the families, adapting it as necessary to local conditions and requirements.

The SUDI team’s involvement with the families would be coordinated through a family advocate, who would be chosen from and by SUDI team members. The family advocate would be responsible for coordinating and liaising with the others to meet the social and health needs of the family. The aim is to ensure good case management with a lead coordinator who works with the family to prioritise and address their needs. This would include assistance with immediate concerns, such as paying for a funeral, as well as the establishment of a range of long-term supports, such as grief counselling, budget advice, housing support and the provision of apnoea mattresses for future babies.

Advocacy for Child Mortality Review

A third strategy taken was to advocate, alongside others, for a mandatory infant mortality review. Post-neonatal mortality reviews had been operative in parts of New Zealand from the mid-1980s under the Area Health Boards, although there had not been a national committee to coordinate this information. With the restructuring of the health system in 1993 there was no designated body with responsibility for these reviews and they ceased to occur (Curtis 1994).

The MSPP began lobbying for their re-establishment, as its work showed that a systematic child mortality review was necessary for service audit and as a means of identifying possible preventable causes and general trends. A review process would provide an
imperative to ensure that the identified gaps and inconsistencies in the data collected following a death would be addressed.

In 1999 the team presented a submission supporting the Child Mortality Review Board Bill proposed by the National MP Bob Simcock. In June 2000 it organised a national meeting of coroners, paediatricians, pathologists, Police, Māori health providers and community representatives to discuss the topic. An outcome of the meeting was a report for the Government strongly endorsing the development of child mortality review. The Simcock Bill, however, became subsumed into the New Zealand Public Health and Disability Bill, which (as it stands in August 2000) enables the establishment of a Mortality Review Committee but neither makes it mandatory nor makes a specific commitment to child mortality review. The pilot Auckland SUDI team protocol, however, includes a comprehensive infant mortality review process.

WIDER POLICY IMPLICATIONS

In this paper we have stressed the need for the development and implementation of a comprehensive protocol for SUDI deaths that ensures a coordinated and sensitive process by a well trained team to support families through the trauma of the death of their baby and ensures sound data for audit and review. This is consistent with a recommendation made by the international SIDS research community in 1996 that there be a move away from biomedical research on SIDS pathology to determine causation, toward the development of death scene investigation protocols and a formal child mortality review process (Mitchell and Tipene-Leach 1996).

Since many SIDS families now come from situations of deprivation and are coping with a number of difficult social and economic issues at the time of their infants' deaths, it is particularly important that the forensic emphasis is balanced by a strong medical and social support presence and that services are well coordinated and responsive to their needs. Given that the majority of SIDS families are Māori, there is an added imperative from Treaty of Waitangi obligations and the Labour Government's stated commitment to close the gaps between Māori and non-Māori (Bidois 2000), to address these inadequacies in services and support and to ensure services are culturally appropriate.

Where there is already social agency involvement with a family, the death of an infant may provide an opportunity to ensure better coordination of services either through the SUDI response team or through linking the family with a programme that can perform that coordination role. If the family is not already receiving support, a SIDS death may provide an opportunity for families to be offered services they did not know they could access or, in the case of families reluctant to have outsiders involved in their lives, to develop the trust required to offer appropriate and acceptable support.
The death scene protocol has application beyond SUDI cases to other sudden deaths, such as suicide. In addition, it has application to other cases where families engage with a number of agencies and where poor coordination and collaboration are issues.

The need for better coordination of social and other services to families is a well recognised problem and one that led to the advent of Strengthening Families and Family Start (Angus 1999). The Strengthening Families programme, begun in 1996, is a collaborative initiative between the social welfare, health and education sectors that aims to provide integrated support for “at risk” families who access a range of social and other supports. The focus is on supporting the family to ensure better social, educational and health outcomes for the children. Local management groups comprising agency representatives convene, usually with family members, to devise a coordinated support strategy. This programme is still in its fledgling stage with not all regions yet having an independent coordinator.

The Family Start programme, begun in 1998 and sitting under the umbrella of Strengthening Families, is co-funded by the Health Funding Authority, Early Childhood Development and Child, Youth and Family. It aims to provide an integrated early childhood support service to families identified as “high risk” who agree to the service. Families can be enrolled from the third trimester of pregnancy until the baby is six months old and a family worker provides a home-based early intervention service until the child is five years old. The programme, which was initially based in three regions, expanded into 13 other sites over 1999/2000.

There are some functional similarities between the regional SUDI teams and these new interagency initiatives. As yet, however, having a SUDI does not qualify the family for entry to these latter programmes. The point of entry to the Strengthening Families programme is through “at-risk” children or young people, with the aim being to support the family to assist the child. In the event of SUDI the sad reality is that the child is dead and the programme does not become involved with these families unless they are already involved through another child.

Family Start appears to have particular relevance to the prevention of SIDS in that families exhibiting SIDS risk factors qualify for entry. In this case it is possible that a SIDS family may already be involved with the programme at the time of death. Where this is not the case, however, families do not qualify for entry to the programme, although they would certainly qualify during a subsequent pregnancy. As these programmes become more embedded at the local level and have more resources assigned to them, the interface between them and the SUDI teams may become clearer. Certainly the potential for bridge building is apparent.
Finally, the link between social deprivation and maternal smoking and the non-modifiable risk factors suggests that, in addition to education about risk factors and provision of a well coordinated service, there is a need to deal with the broader socio-economic and political issues that underlie social deprivation, particularly amongst Māori. While efforts to coordinate services for more effective servicing of at-risk families are important, they will only be effective in the longer term if families’ social and economic disadvantage are also addressed.

REFERENCES


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