



## Child and Youth Mortality Review Committee

Te Rōpū Arotake Auau Mate o te Hunga Tamariki, Taiohi

# Fifth Report to the Minister of Health Reporting mortality 2002–2008

## Chapter 5 Systems Improvement

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## 5 Systems Improvement

### 5.1 Introduction

The data collected by the local child and youth mortality review groups since 2002 shows that the need for systems improvement within health and other sectors is a common factor that cuts across all causes of death. Appropriate recommendations for systems are difficult to develop because the layers of contributing factors are often incredibly complex. However, the CYMRC recognises that systems issues must be tackled, despite the complexity and challenges associated with initiating change.

This is the first CYMRC annual report to include a section devoted entirely to systems improvement. The CYMRC expects to continue presenting this section in future reports because systems improvement is fundamental to the prevention of deaths across all of the Mortality Review Committees. The evidence for this section is based on the qualitative narratives that accompany each local death review. The resulting recommendations from local reviews were systematically analysed in order to identify common themes associated with system improvement.

This chapter does not seek to assign blame to any individuals or organisations. Rather, the focus is on how systems can be improved so that children and young people in New Zealand receive the best care possible.

Kohn et al define a system as 'a set of interdependent elements interacting to achieve a common aim. The elements may be both human and non-human' (2000: 52). Non-human elements include equipment and technologies developed to support a system. This definition is useful for our purposes because it suggests there are many actors in a system, so the responsibility to address any potential failures in a system must be shared by all of the actors involved. In some cases it was clear that problems arose because a well-connected system did not exist.

#### 5.1.1 Improving the mortality review system

Over the last seven years much of the work of CYMRC has focused on setting up a system for mortality review<sup>52</sup> that will collect data and process it into information that highlights how, where and why risks of death cluster.

If the information gained from mortality review is to make a difference, it needs to influence other systems that work at individual, community and national levels. Mortality review can be a valuable tool for continuous quality improvement, supporting others to better assess risks and deliver interventions that reduce risk.

CYMRC has work planned to develop methods of analysis that make it easier to look at themes that contribute to death from many different causes (eg, alcohol may contribute to death from transport injury, assault and drowning). The Committee is continuing to build the national network of local child and youth mortality review groups (LCYMRCs) and develop better arrangements to work with advisors and researchers, all of which are systems that increase the influence of, and the value gained from, the process.

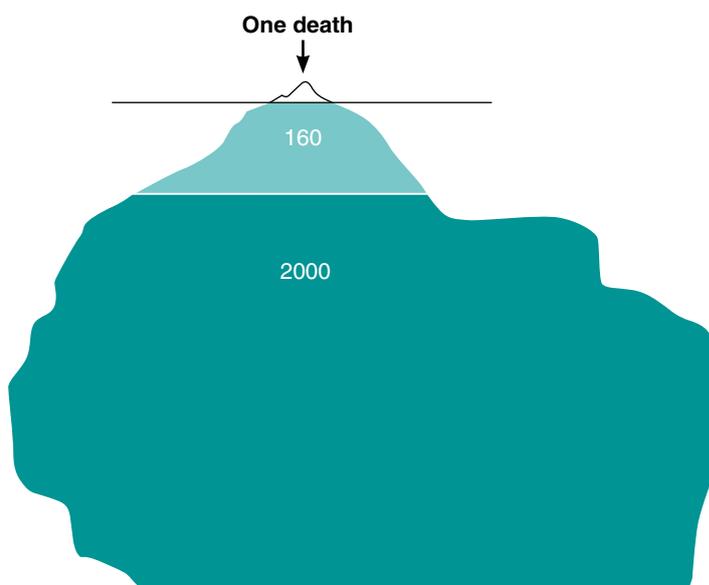
While accurate, routinely-collected mortality data is presented in this report, similar data reflecting the burden of morbidity from injury is not routinely available. At times the mortality data might indicate a small number of deaths, but neglects to show that a major burden of (potentially avoidable) morbidity occurred as well.

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52 The CYMRC Mortality Review Process is described in Appendices A and B.

For every one death among children aged 0 to 14 in the Netherlands during 1991–95 (home and leisure accidents) there were:

- 160 hospital admissions
- 2,000 accident and emergency department visits



Source: UNICEF Innocenti Research Centre 2001.

Each condition has a different “Pyramid of Injury” (Trotter, Russell, Langley, and Casey 2005) that describes the burden of morbidity associated with each death. In Chapters 3 and 5, the lack of information about morbidity, particularly the frequency of permanent disability injury, was highlighted. Ideally, injury severity scoring information should be available; currently no ACC or health system routinely publishes this information. Such scores are vital to help plan injury prevention priorities. Without these scores priorities may be distorted because the main sources of information counted are deaths, hospital costs and case numbers which may have little bearing on morbidity or severity of injury. In the future it would be hoped that a national injury system could be informed by both mortality and morbidity data and such information become routinely available.<sup>53</sup>

It is therefore recommended that New Zealand develop better injury systems that link and collect data, perform surveillance, and report. Such systems can support the development of effective injury prevention and safety promotion by providing a basis for the formation, implementation and evaluation of evidence-based injury prevention strategies (MacKay et al 2006; European AdRisk 2007; National Trauma Registry Consortium (Australia and New Zealand) 2008). It is important that the special requirements of infants, children and young people are not lost within a system designed for adults. The cost of single cases of traumatic brain injury in childhood can be extremely high, up to \$20,000,000.<sup>54</sup> Small changes in case numbers can therefore have major implications.

Local review groups have identified some types of deaths where the responsibility for implementing system improvements lies with different government agencies depending on where the death occurs. This is not to suggest it is not clear who was at fault; rather, it means that it is not clear who should take responsibility and a leadership role in creating improvements. Types of death that stand out in this regard are driveway deaths,<sup>55</sup> farm transport deaths and off

53 The NZ Injury Prevention Secretariat and Statistics NZ are currently funding the Injury Prevention Research Unit at the University of Otago to develop a robust injury disability indicator that is informed by both mortality and morbidity data.

54 Jan White, ACC CEO, in speech to Health Select Committee on 19/8/2009.

55 “Driveway deaths” also occur in private and public car parks, garage forecourts and at the junction of driveway and road, impacting on which agency reviews the case.

road recreational vehicle deaths. New Zealand has the highest reported number of driveway deaths in the world (Beasley 2009). New Zealand also has a very high rate of farm transport deaths in relation to other countries.

Deaths related to roads are reviewed by the Ministry of Transport. Workplace-related deaths are reviewed by the Department of Labour. Recreational off road vehicle deaths get various reviews but may not fall to any one lead organisation. One organisation, ACC, is liable for the costs that arise from deaths or injury in any of these settings. So children and young people on farms, off-road in all terrain vehicles or in driveways may die with no organisation maintaining a systematic overview of the whole picture for this class of death. A systems-focused, collective strategy to reduce these types of deaths has the potential to make a difference, but this requires organisational leadership.

### **Implementing change**

Systems that deliver health, education and welfare are complex with some elements of care being for everyone (ie, universal) while other parts are targeted. Interventions to reduce risk can occur at many levels. Simply telling people to do things differently has limited benefit. *The Child Safety Good Practice Guide* (MacKay et al 2006) highlights a variety of interventions that can be used to complement each other.

1. Environmental modification (eg, pool fences, car seats, and road designs).
2. Product modification (eg, air bags in cars, hands free cell phones, blister pack medication, and safe hot water temperatures).
3. Legislation, regulation and enforcement (eg, legal limits for alcohol while driving and cycle helmet laws).
4. Promoting the use of safety devices (eg, smoke detectors and car seats).
5. Supportive home visits to families of young children (eg, Whānau Ora, Plunket, and Family Start).
6. Community-based interventions (eg, cost adjustment and mentoring programmes).
7. Education and skills development (eg, media work, motivation and support).

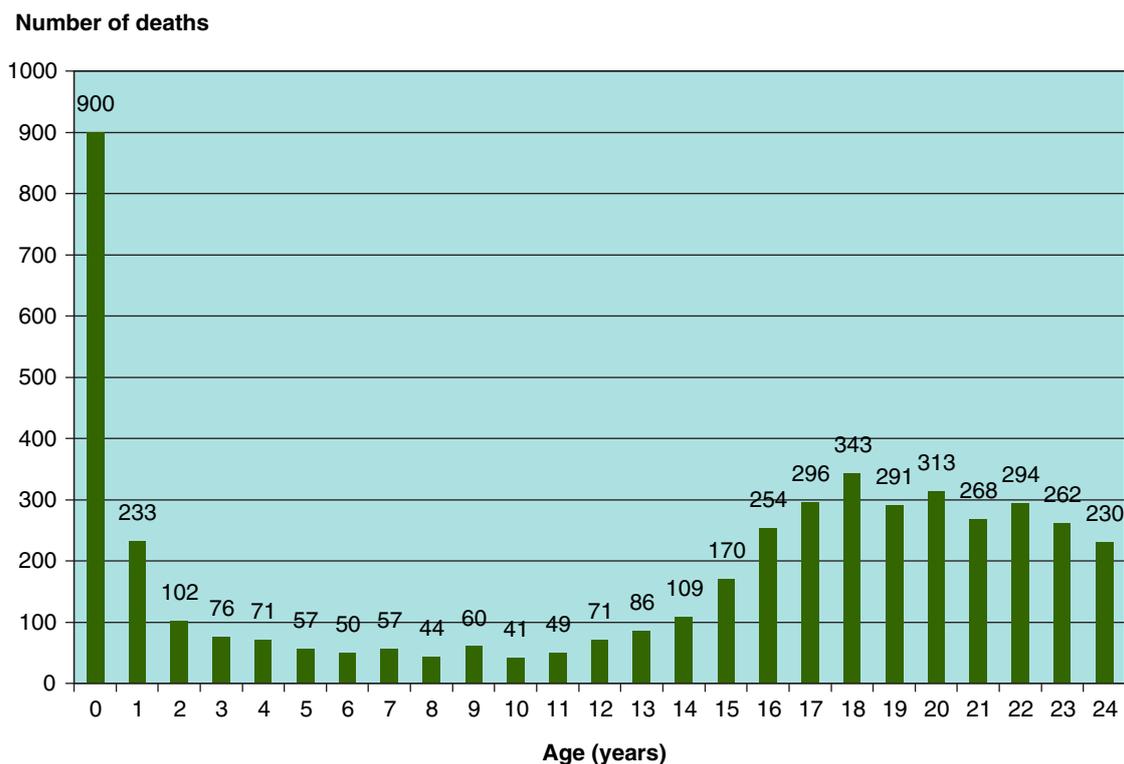
### **5.1.2 Improving care from health and social services**

A significant proportion of the recommendations recorded in the Mortality Review Database relate to two main age groups: birth to five years and adolescence. For birth to five years the emerging themes showed that the quality improvement focus needs to be on strengthening communication and information sharing between all providers in the infant and maternal care continuum.

For late adolescence there is an identified need to create more efficient transitions from child and youth to adult services, better mental health services, a strengthening of communication between general and specialist providers, and a strengthening of communication between health services, social services and the education system.

The themes for birth to five years and late adolescence run parallel with the profile of the two peaks in deaths that occur across the child and youth age span of 28 days to 24 years, as shown in Figure 5.1. Strategies that seek to reduce deaths in these age groups will also reduce rates of morbidity and serious injury causing lifelong impairment.

**Figure 5.1** Total number of deaths, by age, 2002–2008 combined



*Note: The deaths in the 0 age group do not include any deaths in the first 28 days of life. Deaths in the first 28 days of life are reported by the Perinatal and Maternal Mortality Review Committee (PMMRC).*

In both these age groups there is huge potential for quality improvement that strengthens the links between disciplines, organisations and sectors to reduce mortality and morbidity. Good links require an awareness of other services, an understanding of mutual needs and a commitment to continuous development and monitoring.

It is vital that appropriate life-saving responses are triggered when a child or young person is at risk from any cause. Working with the benefit of hindsight, many of the death reviews have shown that the child or young person was showing signs of risk but an appropriate system response was not triggered. The reasons for this include no one recognising the needs, no system in place to seek or initiate action, and the child or young person not being linked to systems that could help. It was also noted that, at times, misconceptions about privacy laws prevented the sharing of information.

### 5.1.3 Life course transitions

In the first five years of life and after 14 years, the peaks in mortality coincide with periods of rapid transition in the life course (as shown in Figure 5.1). These transitions are linked to developmental stages and, therefore, make all children and adolescents potentially vulnerable. It is important to consider how this pattern may also relate to system problems and the need to improve existing systems or create new systems that precede or coincide with times of vulnerability and peak mortality.

Gaps in care have been noted in many reviews, often having been identified when information is sought on care history and it becomes clear that crucial players in the continuum did not know who the others were and, consequently, were unable to connect and pass on any concerns.

In the first years of life there is high vulnerability due to physiological and developmental immaturity and parents need guidance and support. According to the CYMRC data, 47.4% of post-neonatal deaths in New Zealand are due to SUDI (as shown in Chapter 1 and Appendix C, at <http://www.cymrc.health.govt.nz>, *Fifth Report to the Minister of Health: Reporting mortality 2002–2008*). Meanwhile, 35.1% of deaths of children aged 1–4 years are due to unintentional injury (as shown in Appendix D, Figure E.2, at <http://www.cymrc.health.govt.nz>, *Fifth Report to the Minister of Health: Reporting mortality 2002–2008*). Both of these causes of death are considered preventable.

Although the primary cause of death for the infant age group changes after the first year, there are common themes related to system issues. The post-natal care continuum relies on links between the lead maternity care provider covering the ante-natal, birth and follow up care through to 4-to-6-weeks. At this stage, the responsibility is transferred to a Well Child provider and GP until the child starts school, with the GP remaining the pivotal health contact.

The quality of care in the first year of life is dependent on this three-way care continuum functioning well. Gaps in this system can break the chain of care. The continuum links may not be established or maintained, leading to crucial interventions being missed that can have life-threatening consequences for the most vulnerable infants. The recommendation that DHBs monitor the proportion of infants who have a named GP at age four weeks (Chapter 1) is a potential quality indicator for health care coverage.

After 14 there are increased challenges and risks associated with the developing independence of the young person. As stated in Chapter 3, this stage of life is marked by young people spending more time away from their family and whānau, exposed to more dangers and taking greater risks, which are a natural part of this stage of development. These challenges and risks require greater involvement from parents at a time when parental involvement is often declining fast.

In the health care system there are many age-related transitions that occur at this time of life, and these transitions will determine future pathways for the patient through the health system. Children who have been with paediatric services are frequently transferred to adult services around the age of 15, although it is important to note that there is a variable level of flexibility to allow provision of developmentally appropriate care to fit the needs of the individual young person.<sup>56</sup> In mental health and alcohol and other drug services, the age for transfer to adult services is deliberately set in the Ministry of Health National Service Framework as falling between the 18th and 20th birthdays.<sup>57</sup> The intention of this was to allow opportunity for the developmental needs of the young person to be considered so the best transfer to suit the individual within this two-year period could be planned; however, well-developed mechanisms to make this happen do not exist in every DHB.

Other government agencies shift young people to adult services at varying ages. Child, Youth and Family discharge clients at 17 years of age.<sup>58</sup> For education, the care responsibilities are linked to the legal requirement for children to be enrolled in school up to the age of 16 years. Those with special needs may continue to have educational support through to 21 years. The Independent Youth Benefit is available in specific circumstances for those between 16 and 18 years of age, but eligibility for most benefits begins at age 18. Justice deems a young person an adult at 17 years.

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56 *The New Zealand Health and Disability Sector Standards (Children and Young People) Audit Workbook* (Standards New Zealand 2004) supports the goal of developmentally appropriate care in developmentally appropriate settings.

57 The Ministry of Health National Services Framework sets the service specifications for Mental Health Services.

58 However Section 110 guardianship orders continue until the young person is 20 years of age.

All of these variations create fragmented care and gaps through which young people can go 'missing' in the system, increasing the chances of not getting the full level of support needed with, in some cases, lethal consequences. An important element of any transition is having someone who supports continuity of care across the transition, so not all services change at the same time. *The Child and Young People Audit Workbook* (Standards New Zealand 2004) has many comments around planning for successful transitions stressing the importance of it being a planned and graduated process.

#### 5.1.4 Identification of at-risk infants, children and young people

The mortality review process highlights how risk factors often cluster together in such a way that death results. Each chapter of this report highlights how this occurs for different conditions. Many recommendations made by the local child and youth mortality review groups make it clear that appropriate tools to identify risk are often not being used. This is a common factor across key agencies, including health services, education, welfare and police. Information gathered from the local child and youth mortality review process shows that some risks appear quite obvious, but reviews still indicate that too often such risks go unidentified or no agency takes the lead in initiating the appropriate action.

More widespread use of risk assessment tools needs to occur and more tools should be developed. Every time a tool is used it must lead naturally to an intervention. The sort of toolkit proposed for SUDI prevention is an example of a system that completes the loop from risk identification to intervention (see Chapter 1).

##### **Towards Wellbeing: A service response to young people in need by Dr Marie Connolly PhD, Chief Social Worker, Ministry of Social Development**

In 2000, Child, Youth and Family introduced a new set of initiatives to strengthen their services to young people at risk of suicide. They released a new set of tools that could be used at any time when a social worker is concerned about a young person's behaviour or presentation. The tools provide practitioners with a guide for recognising and assessing the needs and strengths of young people.

In addition to the tools, the "Towards Well-being" programme was established. Recognising the particular vulnerability of young people engaging with the service and the complexity of the work, the "Towards Well-being" programme was designed specifically to provide expert advice to social workers.

The clinical advisors, who are external to the statutory service, help the social worker pull together the young person's individual plan and assist in monitoring the plan's progress. They also offer advice and assist with the provision of services from external agencies. Social workers have reported a positive working relationship with the clinical advisors and benefit from the assistance as well as having another eye over their cases.

The tools and the "Towards Well-being" programme more generally have been effective in strengthening the professional safety net around young people at risk. An agreement between professionals also enables the clinicians to access information regarding a young person at risk by receiving alerts when the tools have been completed. This allows for a rapid response to the situation and supports the ongoing conversations that strengthen the young person's care.

The tools, the programme and, in particular, the high-level professional support has enhanced Child, Youth and Family practitioners' understanding and responsiveness to young people who are self-harming or at risk of suicide.

### 5.1.5 Lack of services

There are also deaths that have occurred when it was clear that the child or young person needed care but there were simply no care services available. This type of systems issue can stem from a combination of factors, such as agencies being unable to meet the presenting workload, services not provided in the area, services that are not targeted towards the specific needs of children and adolescents, or admission criteria that unintentionally create gaps.

Nationwide, some services are clearly better developed for adults than they are for older youth. These include mental health services, alcohol and drug programmes, and tobacco cessation programmes. This has been apparent in those reviews where the transition from child to adult services has missed developing risks and opportunities for intervention. Several local reviews highlighted the fact that children living in rural areas face greater challenges in accessing services.

It is vital that all services are planned and delivered with the patient journey (client journey) in mind. This requires a holistic perspective, and seeing things through the eyes of a child or young person. Within the health sector, someone should have an overview of all services for children and young people in a region. It is then possible to plan and purchase the services needed during patient journeys, rather than purchasing groups of services that may not be connected to one another, inevitably leaving gaps. Some DHBs have overcome this problem by appointing child and youth portfolio managers to support the development of a balanced portfolio of services to meet community needs.

Initiatives like Strengthening Families are also a step towards greater collaboration and co-ordination of services that are tailored to meet the needs of individual families.<sup>59</sup>

Some reviews highlighted the needs of the increasing numbers of children and young people in New Zealand who do not have English as a first language. They may be at risk as the health system is challenged in finding ways of providing services in their language that are sensitive to their unique cultural needs. Professionals have a responsibility to recognise when interpreters are needed and to make sure they are available and provided.

### 5.1.6 Services should form a chain of care

The local review process has highlighted cases where a lack of engagement with services, particularly the health system, may be a sign of risk that can go unidentified. This can occur following referral between providers, while making the transition from child to adult services, or when transferring from a general to a specialised health care provider. Cases are documented where a child has been discharged from one service but has not had any follow-up to make sure that another service has picked up care, or that discharge instructions are being followed. These breaks in the chain of care also feature in a number of reports from the Health and Disability Commissioner. The Commissioner has drawn our attention to a number of cases that highlight issues with regard to care coordination where poor co-ordination of care has contributed to poor outcomes.<sup>60</sup>

It is important that health services view themselves as components in an unbroken chain of care. Every “discharge” or referral should be regarded as a transfer of care to another, with the last point of contact needing to remain responsible until the next one picks up the care

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59 ‘Strengthening Families is a cross-sectoral, whole-of-government initiative which uses a structured process of government agencies and community organisations working together to achieve better education, housing, health and social outcomes for families. Both government and non-government/community organisations participate in Strengthening Families.’ Source: <http://www.strengtheningfamilies.govt.nz>, accessed 9 September 2009.

60 Case information can be reviewed on the Commissioners’ website at [www.hdc.org.nz](http://www.hdc.org.nz). Specific case numbers are: 07HDC10316, 08HDC04311, 00HDC02720, 01HDC01802.

responsibility. In the context of transient involvement this principle remains important (eg, a patient seen for the first and only time). The local child and youth mortality review groups are ideally placed to identify and rectify breaks in the chain of care by taking action and initiating changes to systems using the organisational links of their group membership.

When a child or young person does not show up for an appointment, it should be viewed as a time of concern.<sup>61</sup> Failure to show up for an appointment might indicate signs of neglect in the home (ie, parents not encouraging care) or, in the case of mental health care, it might suggest the child is at high risk for self-harm. The local review process has shown that failure to show up for an appointment is particularly common prior to suicide (see Chapter 4). There are a number of examples that highlight the need to follow up when a person does not attend an appointment.<sup>62</sup> These examples also emphasise the need for follow up after discharge from care and illustrate the need for continued work on the goals outlined in the *New Zealand Suicide Prevention Action Plan 2008–2012* (Ministry of Health 2008a). Some services are now being designed with this principle in mind. The B4 School Check system now tracks referrals from source to agency to which they are referred with follow up to ensure the visit took place.<sup>63</sup>

The local reviews show that it is not uncommon to hear the story of a young person who was admitted to hospital several months prior to death with depression, poly-substance abuse and thoughts of suicide, then discharged to the care of a GP and community health service provider. The young person did not attend any appointments following discharge and later completed suicide. This raises the question of whether follow-up to ensure the young person received care would have prevented their death. It is also interesting to note that the discharge referrals in these types of cases often show no reference to the high risk of substance abuse despite the fact that the *New Zealand Suicide Prevention Action Plan 2008–2012* advocates for improved mental health and addiction services in Goal 2, Action 2.5.

Many of the adolescent suicides reviewed demonstrate the need for strong systems of communication between GPs, alcohol and drug services, community providers and mental health services. They also remind us that we must reach out to young people after they have been discharged from care and/or when they miss appointments.

### 5.1.7 Risks of relocation

Another risk highlighted by local review was the dislocation of care that can happen if the child has recently moved. If a child has moved – particularly to another geographic region – records may not be transferred. As a result, new care providers will not know about previous conditions or the child may not yet have had time to develop an adequate support network. In one tragic death, the family had recently moved, fracturing established support networks and the child died of family violence before any new supports were in place. No neighbours knew the child, the

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61 In her 2006 Master's thesis, Kaye Hudson found that in the Capital & Coast DHB there was a growing number of patients who did not attend (DNA) their follow-up appointments in the outpatient department. Hudson argues: 'The assumption is often made when talking about DNA rates that the failure to attend outpatient appointments is the fault of the individual patient. As identified by previous studies undertaken both internationally and nationally, hospitals also contribute to non-attendance at outpatient clinics. In this study over 50% of the participants identified either hospital administration failures or hospital barriers as the reason for their non attendance.' *Capital and Coast District Health Board's Contribution Towards Patients' Non-attendance at Outpatient Clinics*, Department of Public Health, University of Otago, Wellington. URL: <http://www.uow.otago.ac.nz/academic/dph/Publicationsreports/Kaye%20Hudson%20abstract.doc>, accessed 9 July 2009.

62 As this section draws on actual cases, please note that careful attention has been given to make sure that all cases are not identifiable.

63 Personal communication with Dr Pat Tuohy, Chief Advisor – Child and Youth, Ministry of Health.

school did not know of the risks, social agencies had not caught up with the move, and the child died before health agencies were involved. No one agency was to blame but the 'system' had left a gap and the child was not protected – no one was 'watching over' the child.

A similar story is that of a young person who died by suicide shortly after the family relocated. The local child and youth mortality review group concluded from their investigation of this death that the deceased had not had time to establish a support network within available public services or through a network of peers.

These examples illustrate the additional level of vulnerability a person can face when they have recently relocated. Risks associated with lack of support need to be incorporated into the assessments done by the health sector, social service agencies and schools. It is important that each agency continues to offer care until there is certainty that another has picked up the role. It is too easy for services to "discharge" their duty of care without confidence another has picked it up, especially when they move to a new location.

### **5.1.8 Chronic illness**

These underlying systems issues apply to other types of deaths as well. Children and young people with chronic conditions can pose unique risks as they require "long-term support systems centred on the individual" (Standards New Zealand 2004).

The National Advisory Committee on Health and Disability 2007 report, *Meeting the Needs of People with Chronic Conditions*, stated:

The organisation and delivery of health services has traditionally developed within a cure-focused model concerned with turning acute episodes into survivable events.

Too often this "cure-focused model" of episodic care is transposed to chronic care with little consideration of the special needs of this group. Families with children with chronic conditions are often stretched to full capacity caring for their child and have no time to organise the services of the many agencies involved in care. Long-term complex care requires a team approach, with access to key workers, case managers and integrated care co-ordinators. Without good team work, care can be compromised, with increased risk of death. Risks arise from compromised clinical care, difficulty making the transition from one service to another, or failure to provide adequate support to families.

An extreme consequence of stress for families of children with chronic conditions is illustrated in the report into the death of Casey Albury (Werry 1998). Casey was a 'moderately to severely intellectually handicapped' young woman with autism who was killed by her mother in 1997. Casey's mother was found guilty of manslaughter, but it was widely understood that part of her distress was caused by 'a sense of injustice' because she felt that she should have been provided with more respite care from the state (Ibid: 5). While cases like this are mercifully rare, this case emphasises the importance of supporting families adequately.

### **5.1.9 Lack of information sharing**

Some local reviews indicated that risks had been identified but information was not shared in a timely manner and/or to the appropriate party in order to prevent the death. This lack of co-ordinated information sharing, both within the health sector and across government agencies, is common. There are many examples of cases where children and young people were known to government agencies but the agencies failed to share vital information with one another. At other times, agencies and health care professionals failed to take action when signs of risk were evident because no one organisation felt it was their role to take the lead in initiating the appropriate life-saving responses.

Lack of information sharing because of privacy concerns contributes to death in two main circumstances. The first is when a child is at risk of abuse or neglect but there are no actions taken to get additional support to the care givers. Although death directly from child abuse is relatively rare, neglect or poor parental supervision is a relatively common contributing factor in deaths.<sup>64</sup> The second circumstance is when clinical care is compromised because important information is not shared between health services and families, or between health services and community providers. This is especially important for the quality of care of young people at risk of suicide and self-harm.

A key step forward would be to reduce the barriers presented by concerns about breaching aspects of the Privacy Act and the rights of children and young people. The Children, Young Persons, and Their Families Act 1989 (the CYPF Act) and the Health Information Privacy Code 1994 (Office of the Privacy Commissioner 2008) contain clear guidelines on reporting concerns where risk of harm is a priority. Section 15 of the CYPF Act states that:

any person who believes that any child or young person has been, or is likely to be, harmed (whether physically, emotionally, or sexually), ill-treated, abused, neglected, or deprived may report the matter to a social worker or a member of the police.

Furthermore, section 16 of the CYPF Act states that:

no civil, criminal, or disciplinary proceedings shall lie against any person in respect of the disclosure or supply, or the manner of the disclosure or supply, by that person pursuant to section 15 of information concerning a child or young person (whether or not that information also concerns any other person), unless the information was disclosed or supplied in bad faith.

Similarly, Rule 11 of the Health Information Privacy Code 1994 (Office of the Privacy Commissioner 2008) states that a health agency that holds health information must not disclose the information unless the agency believes, on reasonable grounds, that the disclosure of the information is necessary to prevent or lessen a serious and imminent threat to (i) public health or public safety or (ii) the life or health of the individual concerned or another individual.

It is important to remember that the Privacy Code is written to give *protection* in the event of a legal or other challenge to disclosure of appropriate health information; it is not intended to prevent appropriate disclosure.

Fortunately, there are some very good examples of information sharing at the local level to ensure children and families get the best support. For instance, some DHBs are developing teams to identify families in need of extra support before the birth of an infant. When such a need is identified, a 'wraparound' care team is developed so that the needs of the family are supported before abuse or neglect can become established. Key players in this sort of work involve the health sector, Child, Youth and Family (CYF), the police, mental health services, the Family Violence Intervention Programme, Well Child providers and drug and alcohol services.

### **5.1.10 Improving care and support after the death of an infant, child or young person**

The death of a child or young person is a tragic event that most services do not encounter very often. A number of local groups have identified problems with the processes relating to "after death care." It seems the tragic and infrequent nature of child and youth death has led to systems not being well developed in some services. The CYMRC has therefore suggested that

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64 Further work is needed to define how often it contributes. The improved analysis planned for the CYMRC database should address this gap.

LCYMRGs perform work related to the development and refinement of a local care pathway. The issues that need to be addressed in guiding good practice may include:

1. using first responders (police, ambulance, or primary care) to trigger a chain of supportive care
2. supporting the family in understanding after death processes, the Coroner's role, and post mortems
3. an organised system that provides support for families, including those where death occurs without health system involvement and considers the needs of siblings and/or children of the deceased
4. access to appropriate post mortem examinations
5. access to palliative care
6. ensuring that key stakeholders are informed of the death (eg, general practitioners or the Ministry of Education Traumatic Incident team)
7. directing the family to services and information
8. healing care for the wider community
9. "switching off" care systems and automated recall systems within health and other services – all files, recall systems and registers being deactivated so that all those involved in care know the child has died.

Post mortem examinations can be a very important part of the after death pathway. For this reasons, the CYMRC was represented at the workshop on Perinatal Pathology organised by the PMMRC (see appendix A11 at <http://www.cymrc.health.govt.nz>). In addition to concerns about the sustainability of Perinatal Pathology Services, the CYMRC notes difficulties in accessing appropriate post mortem assessment in some parts of the country and concerns about the workforce provision. The development of a clinical network for perinatal and paediatric pathology is seen, therefore, as a high priority.

## 5.2 The CYMRC leading change at the local level

The systems issues outlined above that have been highlighted by local child and youth mortality review groups require both local and national action. Although many of the review groups are still in their establishment phase, the review process is already demonstrating that the CYMRC model of mortality review is a powerful tool for local change because it promotes inter-agency and cross-sector co-operation and collaboration. It is very easy to overlook the extent to which the LCYMRG develops a collegial environment that supports good practice and provides direct feedback on strengths, thereby reinforcing successful work.

Outside of the health sector, local changes have occurred within local government, the police, the Fire Service and in children's organisations as a direct result of mortality review. In addition, a range of local-level health sector changes are also evident in mental health services, midwifery practice and in the closer alignment of SUDI services. The following improvements have occurred as a direct result of the local child and youth mortality review process.

- A simple system improvement was implemented in one DHB area following the death of an infant who required urgent transfer to another care centre. Communication with the other centre had been delayed at least an hour by the electronic switchboard and answering

system. Because this was not the first time such a delay had occurred, a list of the direct telephone numbers of clinicians at the other centre has now been distributed and laminated versions have been placed in appropriate locations throughout the DHB.

- Following mortality review of the death of a child in a fire, the development and implementation of Fire Service training programmes with local organisations that work with children was facilitated in order to reduce the risk of future death from fire.
- In one DHB it was recognised that lack of access to translation services for care of new migrant families was a concern in a case. The issue was flagged as a DHB risk and access was improved.
- Following a case where failure to attend an appointment was followed by a completed suicide, a DHB developed a “did not attend policy” within mental health services and the wider use in other services is being considered.
- In a DHB region inconsistencies in the collection and reporting of information following the review of sudden unexpected deaths in infancy (SUDI) were noted. The police representative on the local review group initiated improvements to their system at a local level that have since been taken up as a national initiative.
- In one region changes have been made to midwifery practice as a result of a midwife’s participation in mortality review. Information gathered in the review process led to changes in working with mothers in the methadone programme. The midwife had, as a result of reviews, made a strong commitment to provide more information on safe sleep environments and to advocate for SUDI prevention and risk reduction, particularly bed sharing. Modelling of this approach by the midwife and promotion to other midwives has resulted in more of the local midwives adapting their approach to better incorporate these issues.

### **5.2.1 The need for national action**

The CYMRC is working to develop a system for sharing innovations identified and championed by local child and youth mortality review groups across their national network and with other organisations that participate in the review process. The local review groups are clearly a powerful tool for local change, but some issues require national collaborative effort as well. These national-level actions may require ministerial support across a number of sectors to get traction and change.

## **5.3 Recommendations by the CYMRC on systems improvement**

National recommendations, prompted by local review findings, have identified key points of system change that need to be addressed if there is to be a long-term reduction in preventable deaths of children and young people.

### **5.3.1 Policy**

1. The Government needs to continue to promote intersectoral communication, planning and review. This needs to be in each department’s outputs, and funded.
2. The current restructuring of the health system provides an opportunity to better support a holistic approach to Child and Youth, to increase collaboration and co ordination and reduce

service gaps by providing oversight from a single section or division within the Ministry of Health or National Health Board.

3. Co-ordination is needed between sectors to develop effective responses that address the types of deaths that cross boundaries between government agencies. Driveway deaths, farm transport deaths and recreational off road are examples where leadership and co-operation are required to reduce the number of deaths and injuries.

### 5.3.2 District Health Boards

4. The health sector has a duty to use appropriate risk assessment tools and where risk is identified interventions should occur.
5. All DHBs need a team approach and leadership to create and support a holistic approach to child and youth health. The CYMRC recommends a portfolio manager for children and youth or similar in every DHB.
6. All DHBs should have a system to plan and implement transition of young people from paediatric to adult services.
7. Additional services should be developed that recognise and meet the needs of young people (defined as those aged 12–24 years), and improve access for those living in rural areas.
8. All DHBs should develop a pathway outlining local care after the death of a child or young person, including planning for access to appropriate post mortem examinations where indicated.
9. All DHBs should ensure systems provide access to sustainable paediatric pathology services in every district.

### 5.3.3 Practice points

10. Professionals must recognise that the transition between care providers can be a vulnerable time for children and adolescents.
11. Professionals should consider how systems ensure continuous care after referral or discharge and for those that do not attend appointments.
12. Professionals should engage in ongoing training across all the sectors working with children and young people, particularly health, to ensure the legislated pathways for sharing information about risk are understood and managed collaboratively.
13. Professionals have a responsibility to recognise when interpreters are needed and to make sure they are available and provided.

“When we link data from different sources after death, we frequently recognise where the system of care could be improved before death. We all need to keep thinking about how we can link data better to support care of the living.”

**Nick Baker – Chair CYMRC**