
**CHILD DEATH INQUIRY –
GROUP ANALYSIS**

**CHILDREN WITH
COMPLEX MEDICAL NEEDS**

FINAL REPORT

October 2004

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Introduction

Child Death Inquiries

Child Death Inquiries have occurred in Victoria since 1985. Individual Child Death Inquiries are undertaken for all children and young people who die during the period of time that Child Protection Services are involved with the child and their family, or where a child dies within three months of Child Protection having closed the case.

Child Death Inquiries for individual children are established by the Executive Director, Community Care, and are generally undertaken by a senior professional in the field who is not associated with the region in which the death occurred, or an external reviewer with relevant experience.

At times, themes or issues may be identified in a single case or group of cases and a Group Analysis is recommended by either the Reviewer of a Client Death Inquiry, the Victorian Child Death Review Committee (VCDRC) or the Executive Director, Community Care. The decision to conduct a Group Analysis is made by the Executive Director of the Community Care Division. A Group Analysis provides for broader analysis of specific or systemic issues and identification of good practice, as well as gaps or other issues in service provision.

The VCDRC overviews the Child Protection system's child deaths within a broad context. Its aim is to provide a multi-disciplinary focus on child deaths and to identify ways in which preventative and early intervention services could improve the health and welfare of children at risk. It also provides advice and comment on any practice issues, patterns and themes which may emerge from the inquiry process. The VCDRC overviews all individual Child Death Inquiries and Group Analyses. (see Appendix 1 for VCDRC Terms of Reference).

Purpose

The purpose of the Group Analysis on children with complex medical needs who died during Child Protection involvement is to identify patterns and recurring themes in the assessment and case management of this group of children and their siblings, and to identify strengths and issues in the case practice and service provision to this group. It will also consider strategies to improve case management and service provisions to this group and their families where appropriate.

The terms of reference for all Child Death Inquiries are:

- To establish the facts of the Child Protection case.
- To ascertain whether established Departmental procedures, standards guidelines and protocols were followed in the management of a case.
- To examine whether case management decisions and actions of the Department of Human Services and other agencies, were adequate and appropriate in providing a service to the client. This examination should be considered in the context of: the *Children and Young Person's Act 1989*; established practice knowledge; and professional wisdom.

For the majority of cases included in the Group Analysis, these Terms of Reference had been examined previously in the individual inquiries for each death. In the few instances where the Inquiry was not completed, the examination was well under way and relevant information was made available to the Panel. The Terms of Reference related specifically to this Group Analysis were to:

- Examine the cases where a prognosis of limited life expectancy, or a serious medical condition, results in a lack of attention to other elements of risk and lack of assessment of overall parenting capacity;
- Consider how case planning regarding a child with a prognosis of limited life expectancy, or a serious medical condition, relates to and impacts on the case management of the child and their siblings; and
- Identify and examine other common themes that arise from the cases included in the group analysis.

Background

The Child Death Inquiry Unit has maintained data on the deaths of children receiving Child Protection Services since 1989. Since that time there have always been children who died as a result of an acquired medical condition, or who died due to another cause, but had an acquired medical illness.

In March 2002, the VCDRC considered a case of a child who had significant medical issues prior to her death. The Reviewer of this case had recommended that a Group Analysis be undertaken with other similar cases where a prognosis of limited life expectancy, or a serious medical condition, results in a lack of attention to other elements of risk and lack of assessment of overall parenting capacity. The VCDRC requested that the analysis also consider how case planning regarding a child with a prognosis of limited life expectancy, or a serious medical condition, relates to and impacts on the case management of their siblings.

Following examination of this report, the VCDRC wrote to the Executive Director, Community Care requesting that a group analysis be undertaken into cases where a child with a prognosis of limited life expectancy, or a serious medical condition had died. Prior to and since that time a range of other Child Death Inquiries were completed where children had a prognosis of limited life expectancy or a serious medical condition.

The Child Death Inquiry Unit identified 17 cases where children who died had complex medical needs and/or a prognosis of limited life expectancy during the period between 1 January 2000 and 30 June 2003. All the children were known to Child Protection prior to their deaths and involvement of Child Protection Services ranged from a few days of contact to extensive intervention.

Methodology

In July 2003, the project brief for this group analysis and a Panel of three members were endorsed by the Executive Director, Community Care Division. The Minister, Community Services also provided endorsement for the project brief. All Regional Directors and relevant program areas within the Department of Human Services were advised of the Group Analysis in writing.

The panel was comprised of two members who were external, and one internal to the Department of Human Services. The Panel members were:

1. Dr John McNamara (Independent Chairperson)
Consultant Paediatrician, Royal Children's Hospital (recently retired)
2. Ms Julie Langdon (Panel Member)
Director, Langdon Consulting and social worker
3. Mr Tim Harrop (Panel Member)
Community Services Manager, Barwon South Western Region

The panel members were selected for their interest in this group of children and the relevant experience they bring to the Group Analysis. The panel members between them had extensive paediatric experience at the Royal Children's Hospital and overseas, management of hospital and non-government agency programs in the disability, early intervention and child protection fields, and management of Department of Human Services Child Protection and Disability programs in rural regions.

The panel was provided with executive support by Margaret Hosfal and Lara Singal from the Child Death Inquiry Unit.

A literature search was undertaken and the panel confirmed the 17 cases to be included in the Group Analysis. Victorian service provision initiatives that could inform the Group Analysis were examined.

The Panel considered individual inquiry reports, regional documentation, case summaries of the Child Protection files and the comments provided by the VCDRC following their review of the Child Death Inquiry Reports. Subsequently they identified a range of issues raised by the cases.

At the commencement of this Group Analysis, Individual Child Death Inquiries were completed for 13 of the cases. These reports had been reviewed by the VCDRC, and their comments were provided to the panel. Child Death Inquiries had commenced for the remaining four cases, and regional documentation, and a Case Summary were available to the panel. These were included in the Group Analysis because they were considered to be clear examples of cases that raised issues presented in the Terms of Reference of the Group Analysis and occurred within the defined time frame. In two of these cases drafts of the Child Death Inquiry reports were completed and available to the Panel. These two cases were reviewed by the VCDRC during the course of the Group Analysis.

On the basis of the information available and the Panel's review of the cases, two half day forums were convened to promote consultation and information sharing on the key identified issues. Broadly, the forums covered:

1. The interface between the medical and child protection systems
2. Service system responses to children with complex medical needs and/or limited life expectancy

The first forum was attended by 40 participants including

- Medical practitioners from metropolitan and rural hospitals and private practice;
- Social workers and program managers from public hospitals;
- A Coroner;
- Chairperson of the Consultative Council on Obstetric and Paediatric Mortality and Morbidity; and,
- a range of professionals from the Department of Human Services including managers from the High Risk Infant Program, Child Protection, the Court Advisory Unit, and the Metropolitan Health and Aged Care Division.

The second forum was attended by 42 participants including:

- Disability program managers from non-government agencies;
- Disability managers and program staff from Department of Human Services Regions and Head Office;
- Family support agency managers;
- Legal Services manager;
- Family Choices manager;
- Early Intervention Services managers;
- Foster Care managers;
- Victorian Aboriginal Child Care Agency (VACCA) manager;
- Regional and Head Office Child Protection staff (including High Risk Infant) and Early Intervention professionals from the Department of Human Services.

The interest from the field in relation to these forums far exceeded the expectations of the Panel, and many more people attended than initially envisaged. Evaluation of the forums provided by participants indicated that the high attendance had inhibited the ability of some attendees to contribute. However a high level of appreciation for the forums was expressed.

Information from the forums was compiled and used to inform the Panel's analysis of the issues raised by the 17 children with complex medical needs and the recommendations of this report.

Service Context

Literature Survey

A search for literature on child abuse issues and children with complex medical needs or children with disabilities revealed that there has been limited research published in this area. This understanding is supported by international researchers to whom this chapter refers.

From a broader contextual perspective, Australian researchers, Jenny Hynson et al (2003) comment that

Many children who previously would have died early in life now survive for long periods with high degrees of disability and dependence; this has profound implications for families, service providers and the broader community.

This change in survival rates has been noted by many researchers.

Mausner (1995), based in the US, starts with the premise that over the past 30 years, rapid advances in medical technology have resulted in a marked increase in the number of children surviving with significant medical and developmental difficulties. With a trend away from institutional care, in addition to these technologies, there is an expectation that parents will provide care for children with significant disabilities at home, often without adequate support services.

Advances in medical technology, especially in neo natal and paediatric intensive care have provided the chance of survival for extremely low birth weight premature babies and for children who have experienced a range of traumas and illnesses.

Mausner argues that emerging services have not adequately recognised the support needs of children and families whose children have special care needs (Shelton 1989). The article looks at "Families Helping Families", a pilot project in the US, that links families of medically involved and severely disabled children with 'provider' families who can learn and care for children and provide respite care on a regular basis.

He notes that home care now involves complex services such as apnoea monitoring, intravenous therapy, tracheostomy and gastrostomy care, as well as more sophisticated technological support eg ventilator assistance. This contributes to families facing tremendous emotional and practical challenges.

Hynson et al. point out that for infants, life-threatening illness may mean physical symptoms, separation from key attachment figures and disrupted routines. They also note that grief reactions in parents to a child's death can be complicated, and siblings are almost universally distressed but feel unable to share their grief with already overburdened parents.

While the children examined in the Group Analysis had a range of complex medical conditions, most also had an associated intellectual disability, acquired brain injury, developmental delay or physical disability. As a result, literature related to children with disabilities was sourced for this Analysis. Much of the literature available related to children with disabilities over the age of five years, while the majority of the deaths included in this Analysis were infants and children less than five years. Nevertheless, some of the findings were considered informative and relevant to the children examined in this Group Analysis.

Disability and child abuse - United States and Britain

Cowan and Warren (1990) note that there is a substantial body of literature that examines the extraordinary stresses on parents with children who have disabilities (Hobbes et al 1985, Murphy 1982) and that parental stress can contribute to abuse (Straus 1980).

Many of the articles focus on the relationship between child abuse and disability and the prevalence rates of abuse in this population of children. Cooke and Standen (2000) note that studies in the US and Australia (for example, Westcott and Cross, 1996, and Marchant and Page, 1992) identified the vulnerability of children with disabilities to abuse. Evidence in the United States (Crosse et al. 1993) suggested that children with disabilities were 1.7 times more likely to be abused than children without disabilities.

Another US study (Sullivan and Knutson, 2000) reported a 9% prevalence rate of abuse for non-disabled children and a 31% prevalence rate for children with disabilities. They found that children with disabilities were 3-4 times more likely to be maltreated than other children, with the highest levels being for emotional abuse and neglect, the lowest levels for sexual abuse.

Kelly cites Glaser and Bentovim (1979) and Diamond and Jaudes (1983) who suggest that children with disabilities are more likely to be neglected. Many studies addressing neglect focus on whether adults, especially mothers with disabilities are more likely to neglect their children. Tymchuk and Andron (1990) concluded that these mothers were more likely to neglect their children, but less likely to physically abuse them; that much of the abuse was unintentional, and with support and information this group could adapt their child care practices.

Kelly also points out that emotional abuse is the most problematic form of abuse to define, complicating matters further for children with disabilities.

A number of studies report a disproportion of children with disabilities in recorded cases of physical abuse. Oliver (1988) estimated that at least 5% of children's disabilities are the direct result of violence against them by parents/carers.

Working Together to Safeguard Children (UK) indicates that presence of multiple disabilities increases the risk of both abuse and neglect. Westcott (1993) raised three core issues that increase the vulnerability of children with disabilities:

1. the greater use of institutional care
2. their physical dependency
3. the barriers to communication effecting many children

Wardhaugh and Wilding (1993) also support the view that institutional care can lead to a climate of increased vulnerability. Westcott (1991) describes children in institutions as powerless and voiceless with no influence over the care they receive.

Physical dependency in out of home care means exposure to a wide range of adults in a range and intensity of personal services, which increases the risk of abuse. Kelly (1992) argues that specialised forms of care increase both the number of potential adult abusers and opportunities for abuse.

Good practice in residential settings for children with disabilities requires suitably trained staff with supervision and accountability, a positive child orientated ethos, promotion of communication, consultation with children and provision of choice, guidelines for behaviour management, therapeutic intervention and personal care, comprehensive education and social care plans involving parents, staff and children.

A study referred to by Cooke and Standen (2002) examined a group of children in Britain with and without disabilities who were receiving child protection intervention.

While most lived at home, 17% of the disabled group lived elsewhere including adoptive family, foster care, extended family and residential care. 57% had no father at home compared to 35% in the non-disabled group. Of the children with disabilities 83% had learning disabilities; 17% had physical disabilities. People reporting protective concerns for children with disabilities were different from those reporting about children without disabilities. A greater percentage of reports came from parents and teachers for children with disabilities, while for non-disabled children, the reports came from social workers and health workers. Children with disabilities were less likely to be recorded on the Child Protection Register and therefore less likely to receive a Child Protection Package.

The same study also interviewed British social workers who worked with abused children with disabilities. It concluded that the overall sense was that there was a tendency not to see the abuse of children with disabilities.

It was suggested that this related to lack of knowledge and support, and other complications that arise, such as cost in terms of time and resources. It suggested that abuse may not be recognised until it was 'fairly gross', that even when cases were recognised, poor recording meant that cases of good practice were lost, and less satisfactory responses were not noted so improvements could not be considered. Social workers felt they did not have sufficient training about the interface between disability and abuse, which raised their stress and anxiety levels.

Some suggestions for improvement were for disability workers to be attached to Child Protection teams, that Child Protection work be carried out in disability teams and Child Protection teams to have clearly defined protocols with disability teams that carry out assessments. The requirement for better communication between the teams was a clear theme.

Paul and Cawson (2000) argued that research on risk assessment indicated that the organisation of services and the lack of knowledge of disability in Child Protection services reduced the likelihood of identifying abuse. Child Protection professionals do not have specialised knowledge of disability and are therefore unable to recognise signs of abuse in children with disabilities. Further, Disability specialists may have no knowledge of Child Protection. The traditional separation of disability and Child Protection services maintains professional ignorance (Cleaver et al 1998).

Paul and Cawson also argued that children with disabilities are more vulnerable than others but unlikely to receive protection and help from Child Protection and therapeutic services because:

- . many are unable to communicate their experience verbally
 - . they may not be believed as a result of their impairment
 - . behaviours indicating abuse may be misconstrued as part of their disability
- (Kennedy 1992, Marchant and Page 1993, Cross 1998).

In addition to examining the vulnerability of children with disabilities to abuse, some literature also looks at disability as the outcome of abuse (Kelly, 1992 Appelbaum 1980, Brandwein 1973, Cadol 1976). Souther (1986) suggests that between one third and one half of the disabilities were caused by abuse.

Some more recent documentation focuses on the social context that contributes to child abuse and children with disabilities. Goldson (2001) argues that children with disabilities become stigmatised, depersonalised, devalued and sometimes blamed for their disability. Hence they are often treated with impunity and exploited. Goldson suggests a range of risk factors for these children including:

- Social isolation that can result from family dysfunction, inadequate, immature, or disabled caretakers and poor access to services and child care. The stigma of having a disabled child can also lead to social rejection resulting in increased risk of abuse.

- Disruptions to parental and child attachment compromise parent/child relationships. Difficulties in coping with disability or illness, prolonged hospitalisations, and early separations are often experienced by children and parents. The negative attitudes of professionals and community, and parents assuming a quasi-professional role in relation to the care of their child may interfere with their primary role of being parents. All these factors may contribute to a lack of attachment.
- Parental denial of the need for medical care, missed appointments and the child's well-being not being sustained are all factors that may place a child at risk.
- Presence of stress especially if a parent or caretaker attributes all the difficulties to the child, can lead to stress between parent and child. Parents can develop a sense of inadequacy about caring for the child. A parent may be overwhelmed in caring for physical, emotional or behavioural needs, especially if there are no supports and respite.

Goldson considered that children with complex medical needs and disabilities require an environment where they can integrate with other children without illness or disabilities, early intervention of services and a link to a comprehensive medical system. Accessible care and continuity of care within the context of a family centred practice that is well co-ordinated is required, for example, a home visitor program with trained nursing staff to support and help families establish and maintain links with community services.

The issue of child protection training for health professionals providing services for children has recently been raised by Bannon and Carter (2003). In examining a review of Child Protection in Britain in relation to the death of Victoria Climbe undertaken by Lord Laming, they stress that a key message is that suspected abuse or neglect should be treated with the same level of urgency as other potentially fatal childhood disorders. In this context the importance of child protection training for relevant health professionals is stressed. It is also recommended that all consultant paediatricians should be updated periodically in their management of harm to children. The article argues that clinicians can fail to recognise and deal with serious instances of abuse.

Clinicians who encounter possible abuse must act promptly and make appropriate referrals to statutory agencies. Bannon and Carter suggest a range of reasons for paediatricians' reluctance to comply with this requirement. They include the stress of becoming involved with the child protection system, fear of challenging the doctor-patient relationship, intimidation and harassment by parents, fear of testifying in court and concern about sharing sensitive information with outside agencies challenging the principle of confidentiality. Some doctors feel uncomfortable about dealing with the uncertainty of the grey areas in child protection. The authors suggest that education and training for clinicians in history taking, clinical examination, documentation, communication skills and confronting abusive carers is critical.

Service Initiatives

There are a range of Department of Human Services provided and funded services that have some relevance to children with complex medical needs and their families. The service initiatives reviewed in this section are not exhaustive and are those the Panel has identified as having relevance to the group of children included in the study. There is however a range of other services based in the community and hospitals that are also pertinent to this group of children and their families.

Over the years a number of initiatives or programs have been developed to address a range of issues. Some of these services work with families who have

complex medical needs but the service system itself presents as a complicated system, which families and workers must navigate through. These services are based in different program areas.

Child Protection

Since the mid-late 1990s Child Protection Services have a range of strategies and programs that may be relevant to risk assessment and planning for children with complex medical needs and their siblings.

- Victorian Risk Framework

The Victorian Risk Framework (VRF) was fully implemented around the State in February 2000. It defines risk as the "relationship between the degree of harm and the probability of the believed harm occurring (or protection being provided)". In all stages of their work, Child Protection Workers gather and analyse information about the safety and well-being of children. The VRF spells out key dimensions of risk analysis. The Health and Welfare Dimension of the VRF is a means to assist workers to more accurately assess a child's developmental status, determine unmet developmental needs and identify specific needs for action. All the Children in this Group Analysis should have been assessed in the context of this framework, identifying their health, education, identity, emotional and behavioural development, family and social relationships, social presentation and self-care skills and each age base developmental stage.

- High Risk Infant Program

The High Risk Infant (HRI) Project was established by Child Protection and Juvenile Justice Branch after reports from the Auditor General in 1997, and the following concerns were highlighted by the VCDRC:

- Inadequate risk assessment and risk management
- Poor performance in court applications
- Difficulties in working with the wider service system

Subsequently, a High Risk Infant Manager was appointed in each region to develop and implement the project in a form that best fitted the specific need of the region. Specialist Infant Protective Worker (SIPW) positions were introduced to support and assist regional Child Protection Workers to deliver improved service delivery to infants and their families and to promote regional networks in the wider service system. Regions variously consider High Risk infants to be those either aged two years or less, or three years or less. Consequently a large proportion of deaths in this Group Analysis should have had involvement from High Risk Infant programs.

The HRI Program also initiated the Parenting Assessment and Skills Development Services (PASDS) which targeted Child Protection clients, providing services on an in-home or residential basis for families. Among the parenting risk factors identified for the target group of this program are mental illness, intellectual disability, substance abuse, experience of domestic violence, poor health, negative experience of the infant, difficulties with the infant, young parent and isolated parents. While most of the families in this Group Analysis would have at least one of these characteristics, having a child with complex medical needs and/or limited life expectancy is not specifically described as a risk factor.

- Integrated Strategy

In September 2002 the Community Care Division published *An Integrated Strategy for Child Protection and Placement Services*. The Strategy highlights the need for prevention and early intervention, and improved services for children and young people more deeply involved in the protection and placement system.

It provides significant data relevant to the current protection and care system as well as strategies for managing demand until 2005. The Department of Human Services tracks six key parental characteristics: psychiatric disability, intellectual disability, physical disability, family violence, alcohol abuse and substance abuse. This data has identified that over the past five years the proportion of parents in substantiated Child Protection cases with one or more of these characteristics had increased from approximately 40 to 70 per cent. The proportion with two or more characteristics has increased from 9 to 44 per cent. It indicated that about a third of parents have problems with alcohol abuse, one third with substance abuse, 19 per cent have psychiatric disability and over one half have experienced family violence. In addition, Indigenous children are overrepresented in child protection and placement services. The rate of notifications is five times higher for Indigenous than for non-Indigenous children.

The *Integrated Strategy* also makes a commitment to stabilising and improving out of home care. It notes that children and young people entering out of home care have increased by 4 per cent each year for the past four years. As the Department of Human Services aims to maintain rather than expand the out of home care system, there is a focus on prevention and diversion strategies. A range of principles for out of home care is identified.

- Innovations Projects

In 2003 eight Innovations Projects were funded by the Victorian Government and established in six local government areas, two working specifically with Aboriginal families. An additional \$18.9 million funding provided in the 2004 will expand the program to cover a total 29 local government areas; areas from which almost half of all Child Protection notifications are made in Victoria.

The aim of the projects is to divert vulnerable families from statutory child protection to community based services, minimise re-notification of clients and the progression of families into the child protection system, and improve service capacity for families who may not come into contact with child protection services.

The Innovations Projects are part of a network of co-ordinated community based services, including child protection, family support, health, justice and education. They offer low, medium and high intensity services that are comprehensive and flexible and are able to remain involved on a long-term basis if required. The approach involves assertive outreach, the capacity to respond to families demonstrating resistance and denial, and working with parents to address children's needs.

In the period January 2002 to September 2003, notifications to Child Protection across the Innovation Project sites have reduced by 7.5%, compared to the same period in 2001-02.

- Public Parenting

Public Parenting: A Review of Home-based Care in Victoria was published in June 2003 by the Department of Human Services. It noted that there is a widespread perception that children who are currently coming into care are more 'difficult' to care for. Stakeholders suggest a range of reasons for this including:

- Children having increasingly complex needs;
- More children with intellectual and physical disabilities;
- Increasing problems with substance abuse in parents and young people.

It is argued that there has been increasing pressure on relatively inexperienced caregivers to take on difficult children and young people, which increase 'burn-out' and placement breakdown, demand for higher skills and training and increased dependency on support services. It is argued that most Community Service Organisations consider that some children coming into foster care do not suit the current model. Suggestions include an intermediate model between residential and home-based care with an expanded range of care options.

Flexible Support Packages – Disability Services / Community Care/ Metropolitan Health and Aged Care

Throughout the 1990's a number of programs were established to enhance the capacity of the service system to effectively support families caring for children with significant disabilities. They were developed in different ways, with different Departmental Divisional responsibilities and funding lines and with different target groups; but have in common the provision of Case Management and flexible support packages to families caring for children at home who have significant disabilities. These programs include The Making a Difference (MaD) Program, Early Choices, Continuity of Care and The Family Choice Program. Consolidation of these programs has been occurring and since 1 July 2002 all four programs became aligned as Flexible Support Packages and are now managed by Disability Services.

- The MaD Program

The Making a Difference (MaD) Program is an ongoing program managed by Disability Services that commenced in 1992 to provide case managed provision of flexible support packages to families caring for children (5-18 years) with severe disabilities at home.

It is based on a holistic, family focused and flexible approach. Each agency with a MaD program has a co-ordinator position who works collaboratively with families to identify their needs and facilitate assistance. There is additional funding to be used in a flexible way to respond to the needs of individual families through paying for equipment, services and various costs a family may incur.

The care needs of the children on the programs are intense and complex and many involve multiple disabilities. An Evaluation completed in 1996 found that most families had a strong commitment to caring for their child at home, but needed assistance and effective support to sustain that capacity.

Families identified financial difficulties, family relationships that were under considerable pressure and strain, difficulties in accessing timely and sufficient respite and equipment, and many needed house, garden and/or car modifications. The discretionary funding available through the program was used to address these needs.

- Making a Difference (0 – 6 years/Early Choices)

MaD (0 – 6 years), formerly known as Early Choices, was established in the early to mid 1990s using the same model as the MaD program but is targeted at the younger age group of 0 – 5 year olds. It is based on child focused - family centred practice and on early intervention principles. It was managed by the Community Care Division and was initially funded through the Community Support Fund as a three year pilot. MaD (0 – 6 years) is now incorporated with MaD in the Flexible Support Packages and is managed by Disability Services.

- Continuity of Care Program

The Disability Services Continuity of Care Demonstration Project was established in 1993. The Demonstration Project was auspiced by Yooralla Society and originated from the Royal Children's Hospital Home Care Program. The latter program had identified that increasing numbers of families were caring for children with disabilities and complex support needs, who were not necessarily 'technologically dependent' but experiencing difficulties accessing services. The Demonstration Project was funded to provide individually tailored packages to 20 families to demonstrate the capacity of intensive community care through case management and brokerage funds. The aim was to identify weaknesses and inform changes to mainstream services in order to increase capacity to support these children.

Recommendations aimed at redeveloping the service system to achieve greater continuity of care to families with children with disabilities and complex support needs. One result was the development of Best Practice Principles for services for children in this group.

The Continuity of Care program continued on as a statewide service, managed by Abercare Family Services in the Western Metropolitan Region since June 1994. It is aimed at overcoming systemic barriers that prevent families from caring for children with significant disabilities and complex health related care needs and receiving the services and assistance they required. It was set up using a similar model as the MaD Program, with a co-ordinator and packages of flexible funding. Work with a specific family is generally subcontracted to a Making a Difference Agency to manage. Continuity of Care is able to provide a higher level of resourcing through flexible funding than is available through Making a Difference.

At the time of its establishment the Project was seen as interim and was to finish in July 1995, pending review and the development of another program for children with complex health needs, now called Family Choices. It was evaluated with the MaD Program in 1995-96, and continues to function under the auspice of the same agency.

- Family Choices

The Family Choices Program commenced in May 1997. It is a statewide program which provides home based support to families of children with high levels of complex ongoing medical care needs including dependence on bio-medical technology. This development follows the Committee on Services for Children with Disabilities and Complex Support Needs (Department of Human Services) final report in December 1996. The report was based on the findings of the Disability Services Continuity of Care Demonstration Project, and the findings of the Committee on Services for Children with Disabilities and Complex Support Needs established in 1995.

Responsibility for Family Choices was held by the Community Care Division of the Department of Human Services with a funding contribution from the (former) Acute Health and Disability Services Divisions. With the Flexible support package alignment it is Disability Services that now maintains responsibility for Family Choices.

Family Choices is auspiced by the Royal Children's Hospital (RCH). It was established following the consolidation of the Homecare Program, the Homecare Extension Program, and the Fragile Health Fund. Eligibility is based on a number of factors including that the child or young person must be 0-17 years of age, that the child or young person must require complex health related care and that

the child's family must require case management and extra funding to meet their child's needs at home.

The Program's key strategies include co-ordination of service providers, development of individualised programs of training, monitoring and support for workers and family members and case management using brokerage funds to top up families' existing entitlements. Like Continuity of Care, case management and the management of brokerage funds are sub contracted to other agencies, often but not necessarily, Making a Difference agencies.

The expected outcomes of the Program are:

- To enable children/young people with ongoing high medical needs to live with their families;
- To maintain or enhance the quality of life of children/young people with ongoing medical care need and their families;
- To reduce the length of stay in hospital and use of emergency services by children/young people.

Two families included in this Group Analysis used the Family Choices Program.

Disability Services

- State Disability Plan

The *State Disability Plan 2002 – 2012* was launched in September 2002 and was based on human rights and social justice principles. It assumes that people with a disability should enjoy the same rights, opportunities and responsibilities as others, and participate equally in the life of the community.

- Support for Children with Disability and their Families Review

In 2003 Disability Services commenced the *Review and Redevelopment of Support for Children with Disability and their Families*. Its aims include contribution to the development of Department of Human Services Early Childhood framework for children aged 0-8 and their families, minimisation of the number of children in out of home care and the time spent in out of home care and improvement in the quality of life of children in care. The project also aims to develop more collaborative partnerships between Department of Human Services programs and other Government Departments to support children and their families.

- Protocol Between Protective Services and Intellectual Disability Services

The *Protocol between Protective Services and Intellectual Disability Services* was completed in August 1993. It is recognised that this protocol requires updating and is currently planned for review.

Metropolitan Health and Aged Care

- Review of Victorian Paediatric Services, Latrobe University, December 2002

The Review of Victorian Paediatric Services was commissioned by the Metropolitan Health and Aged Care Division to inform the development of the Metropolitan Health Strategy and the Victorian Rural Health Human Service Strategy and was launched in September 2003.

The Executive Summary states that the key finding was that Victoria had a fragmented care system for children and adolescents and there was a need to focus on co-ordination of health care for this group. The Reviewers

recommended a single structure/unit to take responsibility for the planning and provision of health services on a statewide basis for this group. Among its recommendations some have specific relevance to Child Protection. These related to development of closer links between Child Protection and paediatricians, maternal child health nurses and obstetrics/neonatology services, and the establishment of community paediatric positions with a defined role in child protection services.

A response to the Review from the Department of Human Services has also been launched.

Summary

In summary, over the last ten years a range of service initiatives have been developed in order to provide support and assistance to families who have been subject to Child Protection intervention. The services are from a range of program areas including Disability, Early Intervention, Acute Health as well as Child Protection. Some of these services have worked with families who have children with complex medical needs and this was evident in the cases examined by the Panel.

The Panel noted that one feature of this cohort was the large number of support services involved with most families. It could also be stated that generally children from rural regions had less services involved than metropolitan regions.

One family had 13 services, two had 10 services, two had nine services, one had eight services, three had seven services, two had five services, and one had four services. The remainder had between one and three services each.

Services for parents included alcohol support, counselling, social work, homeless persons' program, housing, family violence workers, drug counselling, Office of Corrections, Crisis Assessment Team, Emergency Relief agency, welfare and parenting agencies.

The following list represents the services for children and their siblings that were identified in the Child Death Inquiry reports. They are probably an underestimation as, due to the numbers of services involved with most families, it is unlikely that all were accounted for by Child Protection workers at the time of involvement.

Table: Numbers of services provided to the 17 cases identified in CDI Reports

<p>PASD X 2 families Early intervention X 3 cases Specialist Children's Service X 3 cases Families First Strengthening Families X 2 cases Child and Family Services Intensive Family Support Service</p>	<p>Hospitals (17 hospitals listed, some families accessed more than one, some had no reference to hospital treatment) General practitioners/medical services X 5 cases Private paediatrician MCHN X 7 cases Royal District Nursing Service (RDNS) X 2 cases Cancer Support X 2 cases Palliative Care</p>	<p>Physiotherapy X 4 cases Speech therapy X 2 cases Occupational therapy Nutritionist X 2 cases Clinical psychologist</p>
<p>Child Care Day Care Aboriginal Agency X 3 cases Hospital Koori Liaison Officer</p>	<p>Family Choices X 2 cases Respite X 4 cases Foster care X 3 cases Accommodation Outreach Making A Difference Disability Services X 2 cases NGO Disability service NGO disability case management/residential care.</p>	<p>Home Help Feeding Assistance Meals on Wheels In-home care from Disability service</p>

Group Analysis Cases – Data Summary

In examining the cases of children with a medical condition and/or severe disability who died between January 2000 and June 2003, the Child Death Inquiry Unit identified 17 children to be included in this Group Analysis. The children were included on the basis of having a chronic medical conditions requiring complex and extensive specialist needs intervention. Some of the deaths were sudden but compatible with their recognised primary diagnosis. The majority however had a predictably poor prognosis. All had conditions that impacted on their functioning and age related development, and required a high level of carer intervention. The majority were considered to have disabilities. In addition, all had identified protective concerns.

The cohort did not include children who died with relatively short term illnesses, such as meningococcal infection or broncho-pneumonia. Young people with mental illness alone were also deliberately excluded, although a large proportion of the families had one or more members with mental health issues. It was considered that these children would be the subject of another group analysis on mental health and drug use, where their issues would receive greater focus.

This section will provide an overview of the characteristics of the 17 children and their families examined in this Analysis and whose issues prompted further consultation on broader systemic themes.

Age

53% of the children were in the under two-age group of high risk infants. Of these four were under six months, and five were between one and two years of age. Three were aged between 9 – 12 years and there was one adolescent aged 17 years.

Age	2 years and under	3 – 4 years	5 – 8 years	9 – 12 years	13 – 17 years	Total
Numbers	9	4	0	3	1	17

Gender

There were ten female and seven male deaths. No significance was attached to these differences.

Gender	Male	Female	Total
Numbers	7	10	17

Aboriginal and Cultural Background

Three of the children who died had Aboriginal backgrounds representing a disproportionately high number of the cohort, and reflecting the general overrepresentation of Aboriginal children in the child protection population. One family identified as Middle Eastern.

Location

Eleven of the deaths were from metropolitan regions, eight from rural regions. One had both rural and metropolitan regional involvement during the child protection history.

Placement

Eight of the children spent the greater part of their lives at home with one or both parents. Four lived with relatives. Two spent time in foster care, one of these most of her life; and one lived in a Disability residential unit on a long term basis. Five children spent significant periods of their lives with extended family.

Ten children spent a significant period or periods of time in hospital. Of these, one spent her three-month life span in hospital and another, aged 19 months, spent her life in a hospital, and followed by a hospice with only two days at home.

Notifications

Six cases had one notification. Of these, four went to Intake phase only and were open for six days. The remaining 11 have between 2 – 5 notifications. In one of the two cases with five notifications, the first four notifications were closed within one week of being received.

Numbers of Notifications	1	2	3	4	5
Number of children	6	3	3	3	2

Of the 17 deaths, ten had a protective order at some stage in the period(s) of Child Protection involvement. Two children were on Guardianship Orders to the Secretary, four resulted in Custody Orders to the Secretary and one was subject to a Supervision Order. Protective concerns were substantiated in 11 cases at some time during the Child Protection involvement.

Twelve of the 17 cases had neglect defined as the protective concern. In some of the cases the assessment of neglect included the inability to meet the child's medical needs, and five included the parent's consideration or stated wish for voluntarily relinquishment of their child. A minimum of two had identified attachment issues.

Three of the cases involved physical abuse.

Phase of Intervention	Intake	Initial Investigation	Protective Intervention	Protective Order
Number of children	4	2	1	10

Related Protective Concerns

One of the most significant features of these families was the high number of cases that had serious drug or alcohol abuse, mental health or family violence issues that impacted on the care of the child (ren). Many families had a combination of two or three of these protective concerns.

There were five families in the cohort of 17 where there was no recording of any of these issues.

Of the five families where concerns were raised about parental Intellectual Disability, in two of these cases, one parent in the family was registered as a client with Disability Services. In the other three cases, concerns had been identified that one of the parents in the family had limited intellectual capacity.

There were eight families in the cohort who were identified as having issues in relation to transience.

Presenting Issue	Drug &/or Alcohol Abuse	Mental Health	Family Violence	Intellectual Disability	Transience
Number of children/families	9	7	8	5	8

High Risk Infant Register

Of the 17 cases, it is noted that six cases were included on the region's High Risk Infant register. In five cases it was documented on the files that the High Risk Infant Team was involved in case consultation (and may have also attended case conferences) however, whether these cases were included in the High Risk Register is not clarified.

Siblings

The Group Analysis terms of reference include consideration of how case planning regarding a child with a prognosis of limited life expectancy or a serious medical condition relates to and impacts on the case management of the child and their *siblings*. Analysis reveals a significant incidence of sibling concerns which need to be addressed in case management. These issues will be examined further in a later section of this document.

Fourteen of the 17 children had one or more siblings. Eight of those children with siblings were female. There was a total of 29 siblings in the cohort, 15 were male, 14 female.

Age and gender of child at death	Number of siblings inc half & step siblings	Ages and genders of siblings
Female - 16months	4	Male- 15 years Female – 8 years Male - 6 years Male – died at 4 months in 1988
Female -19 months	2	Female – 11 years Male – 4 years
Male - 4 years	1	Female - 18 months
Male – 4 months	2	Female – 2 years Male – 1 year
Male - 2 years	2	Female – 5 years Female – 4 years
Male – 4 years	2	Male – under 4 Female – under 4
Female – 5 months	1	Female – 3 years
Male – 9 years	2	Male – 6 years Male – 2 years
Female - 3 years	2	Female - 6 years Male - 20 months
Female – 2 years	1	Female – 21 months
Female – 17 years	4	Male – 26 years Male - 21 years Female - 19 years Female - 11 years

Age and gender of child at death	Number of siblings inc half & step siblings	Ages and genders of siblings
Female - 2 years	2	Male – 4 years Female – 8 months
Female - 10 years	2	Female – 11 years Male - 9 years
Male - 11 years	2	Male - 18 years Male - 12 years

Seven siblings were two years and under, six were aged 3 – 4 years, six were aged 5 – 10 years, four were aged 11 – 12 years, two were aged 13 – 18 years, three were above 18 years and one had died at four months, prior to the birth of the child included in this cohort.

In one case where the child who died spent most of her life in hospital, an 11 year old sibling lived with extended family due to physical abuse by the stepfather, while the four year old sibling remained in the parents' care despite the protective concerns for his welfare.

In another family two siblings alleged physical abuse by their father but this did not appear to be followed up by Child Protection.

Several children shared genetic conditions with their siblings. For example, Fetal Alcohol Syndrome and Coffin Lowery Syndrome are definite associations. There were also suspicions of possible unrecognised chemical and genetic disorders, producing developmental problems in siblings that need to be highlighted. A completed medical diagnosis is mandatory, noting the potential for increased involvement in siblings, with implications for specific management.

Personal exposures to family disorders and social distress may similarly involve the physical health, developmental, mental and social well-being of siblings. Significant morbidity in these areas is evident in the study group.

Ten siblings were at some time accommodated in out-of-home care or on Custody orders for protection, frequently associated with physical abuse or neglect.

Non accidental injury was recognised in five siblings and sexual abuse or sexualised behaviour in three. Neglect is recorded in one case and may be an underestimate.

Developmental delay compounded problems for three children and there were instances of fire lighting and traumatised behaviour as well as general concerns for their well-being.

It is certain that without definitive studies these figures are an underestimation of sibling morbidity in families with limited resilience and social connectedness.

Observations of this group substantiate that many siblings are high risk, vulnerable individuals who may share the medical disorder of the child who died and be exposed to identical family pressures including abuse, neglect, developmental delay, disordered behaviour and mental health problems.

Commentary from the VCDRC noted that the modern philosophy of care in palliation extends to grieving family members. Hynson et al, as previously stated, note that siblings are universally stressed but may be unable to share their feelings with already overburdened parents. This may also be extended to other family members including grandparents.

Year, Location and Cause of Death

Eight of the 17 deaths occurred in 2000, three in 2001, five in 2002 and one in the first six months of 2003.

The causes of the deaths as determined by the Coroner and recorded in the autopsy reports were as follows:

- Three died of epilepsy;
- Two died of cancer;
- Two died of heart failure and a third following open heart surgery;
- One died as a result of choking;
- Five died as a result of a respiratory condition;
- One died of a rare enzyme deficiency associated with SIDS; and,
- Two had their death recorded as a result of their medical condition.

The locations of the children at the time of death were:

- Six died at home (one co-sleeping, one non-attended whilst bathing in company of an 18 month old sibling);
- Ten died in hospital;
- One died in hospice.

Medical Condition or Disability

The deaths of all 17 children could be directly related to their medical condition and/or disability. The following classification of medical conditions is arbitrary due to overlap that highlights the often multiple pathology of the frequent mix of congenital and acquired disorders with associated complications. Atypical and bizarre presentations of some of the conditions is notable to the extent that they may never be encountered by even very experienced physicians.

<p>Congenital: Genetic and Acquired Disorders</p> <ul style="list-style-type: none"> • Global developmental delay, rare enzyme deficiency (not specified), fulminant sepsis death (overwhelming infection), SIDS step-sister • Sacrococcygeal (spinal) teratoma (congenital anomaly). Surgical excision day 9, complicated by later malignancy* (see below). • Angelman's Syndrome. Congenital chromosome 15 disorder, death in bath. • Familial neurodegenerative disorder (primary cause not elucidated), died in sleep at foster care's home. Case closed three months prior to death. • Fetal Alcohol Syndrome, congenitally acquired, related cardiac disease, death from heart failure. • Infantile Marfan's Syndrome (chromosomal disorder), multiple cardiac valve lesions, death resulting from surgery for heart failure. • Spinal muscular atrophy (congenital, genetic). Terminal body mass 10 kilogram. Chronic respiratory failure. • Unspecified Mitochondrial disorder. • Coffin Lowery Syndrome (chromosomal disorder). Obstructive anoxic death. • Congenital severe laryngo-tracheo malacia, death related to adverse accidental surgical operative attempts at relief. 	10
<p>Perinatal Related</p> <ul style="list-style-type: none"> • Complicated prematurity (26 weeks gestation). Tracheobronchitis and bronchopneumonia. • Cerebral Palsy following maternal prenatal acute medical collapse. Death due to massive infection. • Prematurity (29 week gestation) with Acute Respiratory Distress Syndrome, mechanical ventilation, intraventricular haemorrhage, periventricular leukomalacia, epilepsy. • Prematurity (28 weeks gestation), maternal toxemia, cerebral palsy, spastic quadriplegia, epilepsy, stroke, lower respiratory tract infection, heart failure. • Neonatal Gram Negative sepsis, bowel resection, Short Gut Syndrome with malabsorption, severe liver dysfunction, total parenteral nutrition. Death with gastro intestinal haemorrhage. 	5
<p>Malignancy</p> <ul style="list-style-type: none"> • Neonatal hepatitis, hepatocellular carcinoma, liver failure. 	1 (+1*)
<p>Non-Accidental Injury</p> <ul style="list-style-type: none"> • Non-accidental injury proposed as explanation for sub-dural haemorrhages (drained), associated diffuse cerebral infarction, 28-week gestation premature. Subsequent hydrocephalus with shunt insertion, fractured humerus, later cerebral and intraventricular haemorrhages, cerebral palsy, epilepsy, scoliosis, blindness, gastronomy. Cause of death epilepsy at 10 years. 	1

In summary ten had congenital disorders, five had complicated perinatal backgrounds associated with prematurity, two suffered from malignancy, and it could be proposed that one resulted from non-accidental injury. Developmental delay was involved in at least 14 of this cohort.

The potential implications for other siblings appear not to be discussed as part of the diagnosis. In one instance there is medical failure to identify almost certain non-accidental injury relating to subdural haematoma, which would have severely impacted on the protective assessment.

Seven children had a prognosis of limited life expectancy recorded on the file. Two of the 17 deaths were unexpected sudden deaths, that is, one died while unsupervised in the bath, the other through surgical misadventure leading to post-operative death.

Appendix 2 provides more detailed information on the correlation between the medical conditions and protective concerns, and provides limited commentary in relation to each child, indicating the significance of the combined issues in each case.

Care Requirements

As the medical conditions discussed above indicate, all these children had significant and complex care needs.

- At least nine of the 17 children had long term feeding problems and a requirement for extra care assistance, including naso-gastric and gastrostomy feeding. Correlation exists with the degree of feeding difficulty and reduced prognostic outlook.
- Antecedent respiratory disorders included complications of new born lung prematurity and subsequently eight individuals were identified who experienced a variety of respiratory disorders including susceptibility to respiratory infection, apnoeic episodes, obstructive airways problems (including terminal), broncho pneumonia and progressive respiratory failure. Suction apparatus and auxiliary oxygen were identified in some individuals. Prejudicial respiratory function compromises life expectation.
- Mobility restriction problems are recognised in seven individuals due to intellectual disability and neurological disorders including cerebral palsy. One of the markers for poor outlook is restricted movement.
- Two children with malignancies received chemotherapy from specialist sources, requiring attendance at hospital, and for one, eventual hospice care.
- Seven or more children required surgical intervention at some stage of their complex medical disorder.

The frequency and extent of regular and emergency visits to medical resources, the notable range of allied health professionals, social support and welfare systems is inestimable and seriously effects all children and their carers as exemplified in this group.

This tragic group of children, who comprise the study group, depict an unusual collection of complex medical conditions with high incidence of congenital anomalies, perinatal conditions and malignancies. Concern for their well being is further heightened when Child Protection issues arise from the suboptimal care they receive from their parents in abusive and dysfunctional family circumstances.

A notable feature of the majority of children in this group is the presence, either primary or secondary, of significant neurodevelopmental delay which complicates the capacities of carers to manage subsequent basic needs, irrespective of often sophisticated medical procedures which may overwhelm the best intentioned and supported families. The evident incapacities of some parents to cope with dysfunction of their own lives indicate that they have little capacity to meet the special needs of their children. Failure to feed normally, chronic respiratory problems, movement disabilities, delayed communication, singularly or cumulatively, are seen as significant indicators associated with a poor long term prognosis.

Special attention needs to be paid to family situation where congenital disorders are evident and siblings are present in a family. In a number of cases where chromosomal disorders, structural abnormalities and fetal alcohol syndrome were identified, case files failed to indicate whether siblings were tested for similar issues. Well trained community paediatricians, as well as family doctors, have a role to play in supporting major metropolitan hospitals in cases of complex medical conditions

which may manifest in other family members and the need to assist all siblings may otherwise go under addressed.

Initiatives in paediatric palliative care need to be monitored, as expansions in the field are relevant to the care of children with complex medical disorders.

Discussion – Issues and Findings

In its analysis of the 17 cases, the Panel identified six key themes that incorporated a range of issues related to Child Protection involvement with children with complex medical needs and their families. Many of these issues were raised or reinforced by participants at the Consultation Forums. The issues are identified in this section of the report.

1. Assessment of Risk

Assessing Risk

One Child Death Inquiry Reviewer made the following comment:

“Conducting comprehensive assessments that consider immediate and future care and safety issues for children and young people, although fundamental, can be extremely challenging for professional practitioners in Child Protection. However, conducting comprehensive assessments that consider immediate and future care and safety issues for children and young people with a limited life expectancy, although fundamental, becomes exceptionally challenging for professional practitioners, not only in Child Protection but also in other allied professional fields.”

The risk factors for the children in this Group Analysis were compounded by their complex medical conditions. This issue was stressed repeatedly by Forum participants.

While a small number of the cases reflected a risk assessment based on a good understanding of the child’s medical condition, many, while being aware of the child’s medical illness, and related vulnerability, lack a detailed understanding of the condition and its implications for the safety and care requirements of the child. This lack of understanding has significant implications. Without understanding the specific needs, risks and vulnerabilities of the child, it is not possible to accurately assess parents’ ability to provide care and minimise risks. For example, some children in the cohort had difficulties swallowing, so additional attention to feeding was required to prevent obstructive inhalation. Most of the children required supervision beyond the normal level required for their age to avoid physical dangers and health risks, eg respiratory difficulties, seizures, hygiene problems.

It must be stated that while this was observed in many cases, there were some instances examined by the Panel where Child Protection workers did access medical information and used it extremely well in formulating the risk assessment and planning for the child’s future.

The cases in the Analysis indicated that for Child Protection to be effective with children with complex medical needs, it is crucial that Child Protection workers are able to undertake an adequate and comprehensive risk assessment that reflects the protective concerns, medical aspects and safety needs for these children.

In examination of the 17 cases, it was noted that six infant cases were included on the region’s High Risk Infant register. It is the view of the Panel that infants with complex medical needs and/or a limited life expectancy should be recorded on the region’s High Risk Infant Register and consequently receive the attention of more experienced Child Protection staff. In response to this Draft Report, some regions advised that they have decided not to maintain High Risk Infant Registers, and use other approaches with this group of children.

The Panel noted that in cases where good practice was evident, more experienced staff, including a Specialist Infant Protective Worker, appeared to be directly involved in case management.

In addition to Child Protection practices in this area, the Child Death Inquiry reports have frequently not adequately addressed the management of the medical component of the child's situation and its implications during the Inquiry process. In an audit of the 17 cases in this Analysis, interviews with medical staff involved with the case only occurred in four Child Death Inquiries. The reasons for this are unclear from the reports. However, it should be noted that the Child Death Inquiry process is voluntary and medical staff may argue that due to issues of confidentiality they are unwilling to participate in the Child Death Inquiry process.

Recommendations:

That Child Protection and Juvenile Justice Branch review its practice guidelines and instructions which relate to notified children with complex medical needs to ensure that an enhancement of the Victorian Risk Framework includes specific attention to the risk posed by the complex and repetitive nature of the medical treatment required in the home environment and whether the parents are likely to be able to cope over a prolonged period. *(Recommendation 1.1.2)*

That Child Protection and Juvenile Justice Branch review its practice guidelines and instructions which relate to notified children with complex medical needs to ensure that these children are recorded on the regions' High Risk Registers. *(Recommendation 1.2)*

That Child Death Inquiries specifically seek to identify the medical advice that was available to Child Protection staff at the time of notification on a child in order to determine the adequacy of the risk assessment. *(Recommendation 2)*

Risk Assessment and siblings

It is evident from many of the cases in this cohort where siblings are present, that Child Protection concentrated on the child with complex medical concerns and generally paid limited attention to the risk assessment of the other children.

Assessments also tended to have limited information, if any, on the impact of having a child with complex medical needs on siblings.

In the families reviewed in this Analysis there are a few examples where siblings also had a disability, sometimes similar to the child who was the Child Protection client. These children were also largely absent from the risk assessment.

Recommendation:

That Child Protection and Juvenile Justice Branch review its practice guidelines and instructions which relate to notified children with complex medical needs to ensure that an enhancement of the Victorian Risk Framework is developed for working with children who have been diagnosed as having a complex medical need or a limited life expectancy. This should also occur for siblings in such households to ensure that they are not at risk of abuse or neglect, and they have a reasonable quality of life. *(Recommendation 1.1.1)*

Magnitude of risk

A key dilemma identified by the Panel was whether the risk to this group of children placed with parents who had significant drug abuse, mental health, transience and/or family violence issues was unacceptable. It was considered that the needs of this group of children would challenge the coping capacity of any relatively well functioning family, however where family members have major problems themselves, the impact on their ability to care for their children is significant. While children who are generally well and do not have disabilities are also subjected to protective issues in such families, the vulnerability of children with complex medical needs tends to be heightened. The concern is the combination of the parental issues with the child's special needs and the associated risk factors.

Whether this client group should return home to their parent's care when there are significant protective concerns is an area which requires special consideration by Child Protection practitioners and other involved professionals. It was pointed out by a medical practitioner at the Forum that there has to be some expectation that parents can meet the child's needs before they are discharged from hospital into their parent's care.

In a few families examined by the Panel, assessments looked at the broader quality of the life of the child, however a salient feature in many was the focus of assessment being on the medical needs to the exclusion of other developmental requirements or the impact of parental risk factors. For example, a child who is frequently returned to hospital as a result of malnourishment or reinfections should be assessed for their overall well-being and the desirability to maintain the child with their family.

2. Court processes

A related matter identified is the ability or skill of Child Protection workers to adequately use medical issues and the consequential care needs as evidence in Children's Court proceedings (or on appeal to higher Courts) to argue for an appropriate and safe disposition for a child. This partially relates to the fact that Child Protection workers frequently have a limited understanding of the significance of medical issues and how to effectively link this to the risk assessment presented in the Children's Court.

Medical practitioners at the Forum expressed the view that it would assist Magistrates to understand the implications for the care of children with special needs if they had access to relevant medical information.

There also often appears to be limited support by medical specialists to provide evidence to courts. There were many instances where Magistrates returned infants with complex medical needs to families where significant protective concerns were evident, without understanding the specific care needs of the infant or child. The family's capacity to adequately meet these needs was not clear, and there was insufficient evidence to support the premise that the child would be safe, or would be provided with a reasonable quality of life. There were also instances where infants were placed in the custody of relatives by the Children's Court, about whom there was minimal information to indicate that the relatives were suitable or capable of providing the high level of support and medical expertise required by the infant's condition.

Under the *Children and Young Person's Act* (CYPA) (1989), unless abuse can be proved the assumption tends to be that the family is the best option. However, the fact that a family cannot care for a child appropriately and therefore, quality

of life may diminish below acceptable standards, is also important. This is where medical advice on care requirements is critical. Safety and the parent's ability to meet their child's needs, including their ability to acquire the necessary skills must be looked at in a context of a clear understanding of the requirements in providing adequate care to the child.

This issue has also been raised by a region. In response to the Draft Report, one region stated that Child Protection often encounters difficulties in the Children's Court in trying to prove applications based on the grounds of neglect and that legal tests applying to children with complex medical needs and limited life expectancy are often the same as for physically healthy children.

3. Long term out of home care

At least three of the parents in this Analysis actively stated to Child Protection that they no longer considered themselves in a position to care for their child. In one of these families, two siblings had the same medical condition and the parents requested long term residential care for both. One family had drug use and family violence issues, another child had a parent with mental health issues that appeared to be triggered by stresses associated with caring for the child with disabilities.

These families had five, four and two notifications respectively. They had significant support services in place at the time that they were requesting out-of-home care.

In the case where care was requested for the two brothers, inadequate bonding and physical and emotional stimulation, verbal abuse to the children, environmental neglect as well as indications of the parents not coping with the boys' behaviour were identified as issues. At the time of the last notification, the father advised Child Protection he could no longer cope with the boys and wanted permanent out of home care. A Protection Application was issued on the grounds of emotional abuse in response to his request. Using this pathway to obtain a permanent placement is not necessarily the most appropriate course of action and examination of alternative strategies is warranted.

Another case involved a nine year old with multiple disabilities. Since the first notification, the case was managed by a non-government agency. Environmental neglect and failure to provide food and safety were the identified concerns. Immediately prior to his death, the parents agreed that the grandmother could have long term care of their child. However, this arrangement was not agreed upon until after five notifications were made to Child Protection.

Another child spent time in respite and foster care and in the latter part of his life was rarely at home. Nonetheless, there was no sense of long term planning for this family reflected in the file. This child had regular hospital admissions, including many described in the file as social admissions on occasions when his mother was reluctant to take him home. He was provided with respite and foster care and rarely spent time at home. The assessments by Child Protection appeared to be responses to specific crises. However, a fundamental decision about whether or not this child could be cared for adequately within his own family was required.

In eight out of seventeen cases, Child Protection intervened on a short-term episodic basis, by referring the family to a service, eg. respite, speech therapy or Making a Difference, then closing the case. No sense of longer-term assessment or intervention for planning was evident by reading these particular case files.

In response to the Draft Report, Early Childhood Intervention Services expressed concern about involvement of long term out of home care where young children are involved and stated that families should be supported to care for their children at home. Where placement is necessary, transition for the child should be as smooth as possible and involve pathways for family participation and contact. The Panel supports this position.

4. Support for child protection workers

Working with children who have complex medical conditions, in particular those with limited life expectancies, and their families, is not a usual experience for Child Protection workers. It is an experience that can be emotionally challenging and lead to fear, anxiety and/or a sense of having inadequate skills to deal with the issues that have to be confronted. These responses in Child Protection workers can impact on their interaction with the family and their capacity to conduct an adequate risk assessment. In one Child Death Inquiry report examined by the Panel, the Reviewer commented that good intervention requires a balance of theoretical knowledge and knowledge of 'self'. In her conclusion to the Inquiry she noted that:

Protective intervention in cases where a child or a parent has a limited life expectancy poses particular difficulties and dilemmas for the Protective Worker. These cases highlight the complexity of balancing the need to minimise harm to the child, the emotional needs of the parent, and the impact of this on the workers involved.

This has implications for Child Protection workers' ability to undertake their role effectively and most are not experienced practitioners to deal with grief and loss issues. Supervision and support should take these issues into consideration.

The Child Death Inquiry reports generally made no reference to the impact of a child's terminal condition on the worker or related training needs. In the opinion of the Panel, this issue requires further consideration by Child Protection managers and should be incorporated in training provided to both Child Protection Workers and their managers.

Recommendation:

That Child Protection and Juvenile Justice Branch incorporate training in relation to the impact of a child's terminal condition on Child Protection staff into a relevant training course and that this training be aimed at Child Protection workers and managers. (*Recommendation 3*)

5. Planning and Decision Making

Child Protection focuses largely on addressing immediate risks through episodic intervention. *Protecting Children – The Child Protection Outcomes Project* (2003), (referred to as the *Outcomes Project*) states that the system:

is effective in identifying and responding to critical episodes of allegations of child abuse and neglect, with emphasis on determining the substance of a notified episode and acting decisively.

This aim is consistent with the intent of the *CYPA*. The Outcomes Project also states that since the time the Act was drafted in 1989 there have been significant increases in families with substance use, psychiatric illness and domestic violence issues, with two-thirds of substantiated notifications concerning neglect and emotional abuse.

The majority of children with complex medical needs examined in this Group Analysis have this type of family background, and are consistent with findings of overseas and Australian research that state that most of these children are the subject of neglect or emotional abuse rather than other abuse types.

Consistent with the *CYPA*, the majority of these families have received short term, episodic case management intervention that addresses the presenting crisis and immediate protective concerns, and often only dealt with the medical concerns. Families were referred to services and the case was closed. For example, one CDI Reviewer commented:

when the Region was satisfied that the medical situation was sufficiently stable, the Protection Applications were withdrawn and the case moved once again towards closure, without full assessment and resolution of the range of protective issues identified.

Eleven of the 17 families had more than one notification, where repeated intervention of this nature occurred.

The chronic and complex medical issues combined with chronic family problems mean that short term case planning and management has limited effectiveness. The majority of these families required long-term engagement from the early stages of their child's life, and case planning that was dynamic and ongoing to prevent crises. Regular reviews of the case plan and its implementation were required. Such a strategy is consistent with the thinking in the *Integrated Strategy*, the *Innovations Projects* and the more recent *Outcomes Project*.

The majority of the families in this group did not receive long-term case management. Some received longer term case management from non government case management programs such as Family Choices or Making a Difference funded by Disability Services, however these programs may not be equipped with a child protection focus that is required to support and monitor the entrenched, long term social problems in these families. Like all workers they also face the complex dilemma of balancing the safety and support needs of the child and the emotional support needs of the parent.

For many of the children with limited life expectancies, planning should take into account responding to the deterioration of the child's health within an expected time frame, and where appropriate, the palliative care requirements that will arise requiring realistic palliative care plans. The implications for other family members, including siblings, should also be an integral component of case management. While it is the role of medical professionals to be involved in this planning, it is also important that Child Protection, where it has case management responsibility, and/or non-government case managers, have a planning and support role in these areas.

Recommendation:

That Metropolitan Health and Aged Care Division considers the merits of monitoring recent developments in the field of paediatric palliative care and this information is available to Child Protection on a case by case basis for the benefit of children with a limited life expectancy. (*Recommendation 9*)

Planning and case conferencing prior to discharge from hospital were identified as an issue in many families included in the Analysis, and this was raised by Forum participants as requiring further attention. Major concerns were that advice of hospital discharge did not occur in all cases, that a large number of children with complex medical needs and serious protective issues were leaving hospital with limited discharge plans and that appropriate professionals did not attend scheduled case conferences. One perspective shared by a number of Forum participants was that it is not uncommon for hospital case conferencing or discharge planning to occur without the involvement of Child Protection staff in cases where protective concerns had been identified.

One Child Death Inquiry Reviewer noted:

A key practice deficit in this case was that the advice of the Specialist Infant Protective Worker (SIPW) to hold a hospital discharge meeting was not followed. The discharge meeting would have assisted in the clarifying of roles, responsibilities and accountability process for all the workers involved with this family.

With the infants in this group, the protective focus was frequently on the concerns at the time of birth and/or while the child was in hospital, but the case was closed without adequately planning for the future needs of the infant. For these families hospital discharge planning and case conferencing must involve Child Protection, and should occur with adequate time to enable the establishment of arrangements on a collaborative basis with the parties concerned. The range of professionals attending case conferences and discharge planning meetings will influence the quality of available information and the consequent assessment and planning that occurs.

As Hynson et al (2003) argue, decision-making should involve the child where possible, the family, and all the health professionals providing care. This was demonstrated in one case in this Group Analysis where the Child Death Inquiry Reviewer noted positively that:

Case planning occurred regularly and meetings raised and dealt effectively with the relevant issues in relation to Martin's [pseudonym] care arrangements and life choices. All involved parties were invited to and generally attended at these meetings. The family was also invited to these meetings...The Region was also proactive in its approach to case planning, as once extended family members had been identified; they too were invited to participate in case planning discussions and decision-making.

Recommendations:

That Child Protection and Juvenile Justice Branch, regional Child Protection representatives and Health Divisions work in partnership to develop a protocol with major obstetric and paediatric hospitals to ensure that in cases of children with complex medical needs, who are subject to a current protective notification, that a case conference be convened prior to discharge, and that discharge planning occur which clarifies roles and responsibilities. *(Recommendation 5)*

That Child Protection and Juvenile Justice Branch review its practice guidelines and instructions which relate to notified children with complex medical needs to ensure that regional staff more assertively seek adequate medical and specialist advice, including advice from Disability Services and Specialist Children's Services, in order to develop a better understanding of the care requirements that would inform the risk profile of the child and to determine whether transition support from hospital to home could minimise identified risk factors. *(Recommendation 1.3)*

6. Quality of Life

On reviewing and considering these 17 cases, it is the Panel's view that most of the children lived to an age within the predictions of their life expectancy given their medical condition. However, the Panel has serious concerns regarding quality of life resulting from the circumstances in which these children may have lived eg, family violence, drug and alcohol use, failure to thrive because of poor nutrition and stimulation, and repeated admissions to hospital related to medical complications, poor hygiene and neglect in the home environment. One CDI Reviewer commented in relation to a particular case:

The importance of medical neglect as a protective risk was clearly identified, but only in terms of the urgency of receiving appropriate and ongoing medication. Unfortunately the understanding of the effect on James' [pseudonym] quality of life as a result of the ongoing instability, transience and medical neglect was not articulated by the hospital or requested by the Region.

Quality of life is compromised by the deficits within the family environment, however the suitability of hospital settings is also questionable and the availability of suitable alternatives to both may be limited. In relation to an infant who spent her three month life in hospital and where there were difficulties finding relatives or foster carers that could work with her medical needs, the CDI Report commented:

From the Hospital's perspective, hospitals do not provide a reasonable quality of life and are therefore not an appropriate alternative to foster care. Children do not respond well to multiple handling, many do not have parents who visit, and children are exposed to diseases and the secondary trauma of seeing other children return from procedures.

In some cases in the cohort, the children were placed at risk by residing in an environment where there was chronic neglect. Research has demonstrated that chronic neglect frequently leads to developmental delays. There were approximately six cases in this Analysis where the child had a developmental delay as part of their disability, as well as suffering chronic neglect within the family situation.

There were another five children who had severe medical conditions who lived in homes where they were chronically neglected. There were significant protective concerns for these children within the family and potential for their intellectual, social or emotional development was very poor. The Panel questioned whether there was in fact any benefit in them remaining at home.

Attachment issues are of special concern with this client group and were apparent in a number of the families in this cohort. Literature supports that parents often have difficulty in attaching or bonding to a child who is frequently out of their care due to hospitalisations or respite stays. Extended hospital stays can be one factor that affects attachment, another may be the parent's feelings towards their child who has a medical condition or disability. One perspective from hospital staff attending the Forums was that if a parent fails to visit their child in hospital, steps need to be taken to try and facilitate attachment before the child is discharged to their parent's care. In some of the cases, parental visiting was considered inadequate and indicative of a lack of commitment. For example, in the case of a three month old infant, the CDI report stated that he:

was not in the care of his parents but, remained in hospital for a significant period during the protective intervention. This decreased the probability of physical harm but, did not preclude emotional harm, as identified, in the notification as a lack of attachment and bonding with his parents, from occurring.

Recommendation:

That Child Protection and Juvenile Justice Branch review its practice guidelines and instructions which relate to notified children with complex medical needs to ensure that prevention of neglect and emotional harm is a primary focus in service planning and decision-making particularly the transition from hospital, case planning, the court process and palliative care. (*Recommendation 1.4*)

7. Information and Communication

It is evident from the cases in this Analysis that when working with children who have complex medical needs, a critical component of Child Protection casework practice involves consulting with a range of medical professionals about the child's diagnosis, treatment and care arrangements. In the process of this Analysis it became evident that there are differences between the Child Protection and medical systems that have wider implications for effective communication and information exchange between the two fields. These differences impact on outcomes for children with complex medical needs and their families who are subject to Child Protection intervention. The Panel notes that some concerns about communication discussed here also relate to other children with Child Protection intervention who are admitted to hospitals.

A range of issues was identified through the process of the Group Analysis that relate to the interface between Child Protection and the medical practitioners.

A key issue examined by the Panel involves the exchange of information between Child Protection and medical professionals. It is widely acknowledged that good communication between professionals and family members is important in providing adequate service delivery to families. Nevertheless communication is a

repeated concern raised by Child Death Inquiry Reviewers. In one case examined by the Panel, the VCDRC commented that:

Recent cases have highlighted to the Committee that when children have complex medical conditions, or there are conflicting diagnoses, protective workers must have access to medical information and advice, to assist them to understand the implications of the child's health condition, including treatment. This advice is vital so protective workers can effectively assess if parents/carers have the capacity to provide medical care and meet all their children's needs.

Furthermore, a Child Death Inquiry Reviewer noted on one case:

More information could also have been obtained in relation to any medical diagnosis or assessment of Reece (pseudonym). The absence of this information meant that the medical risk factors were not clearly identified nor could a plan be developed which would ensure that Reece's condition was appropriately monitored and treated by his parents and grandmother. Nor was it clear what the implications of Reece's medical condition would be for Maternal and Child Health Nurse visits and assessments.

A notable feature identified by the Panel was that in a number of cases there was no evidence that appropriate medical information had been obtained from medical practitioners when conducting the protective risk assessment. The Panel also concluded that in many of the cases considered, the CASIS (Client and Service Information System) case notes reflected a limited understanding of the child's medical condition.

As stated earlier, an effective risk assessment for children with complex medical needs requires an understanding of the child's medical condition, its implications for the child's care requirements and relevant treatment options. This includes accessing information from medical practitioners relating to the parents' or caregivers' ability to address the child's medical needs.

It is also noted that DHS Disability Services and Specialist Children's Services may be able to provide professional advice and information on various disability types and related care needs. If they are involved it is likely that they would have some history and be able to assist with risk assessment issues.

Forum participants also repeatedly raised the need for clear information from medical practitioners regarding the requirements of the home environment in order for a child to live safely and be provided with a reasonable quality of life.

In cases examined for this Analysis, the lack of medical information was further highlighted by the significant protective concerns that may have restricted the parent's ability to provide a reasonable level of care. An understanding of expectations of the caregiver in relation to the child's specific medical and health needs is critical in case work practice with this group of children.

In the opinion of the Panel, and information from Forum participants, it appears that the lack of medical information accessed by Child Protection can be exacerbated by some medical professionals' limited understanding of risk assessment and the Child Protection process. A basic understanding by medical professionals of Child Protection and the legislation is crucial if they are to provide appropriate advice to assist in formulating risk assessments and guide risk analysis.

Recommendation:

That the Child Protection and Juvenile Justice Branch evaluates existing Child Protection training and professional development resources for doctors to ensure that they have a better understanding of issues relating to child abuse, child protection and mandatory reporting. (*Recommendation 10*)

It was also raised by Forum participants that Child Protection requires readily available paediatric advice to assist in incorporating medical issues in the formulation of risk assessments. In instances where numerous medical practitioners are involved with a child, medical advice can be at times inconsistent. It is the opinion of the Panel that Child Protection workers require access to independent paediatric advice that is also able to assist in the resolution or management of conflicting medical information, enabling Child Protection to make informed recommendations about appropriate action.

The Panel recognises that initiatives have been developed in some regions to allow Child Protection workers access to paediatric advice, however, this is not universal across the state.

Recommendation:

That regional Child Protection Managers, in conjunction with Metropolitan Health and Aged Care, Rural and Regional Health and Aged Care and the Child Protection and Juvenile Justice Branch, seek to improve access to designated paediatric expertise to provide consultation on medical conditions, and the related care implications, and to provide liaison between Child Protection and medical staff. (*Recommendation 8*)

The formal process of communication between Child Protection and hospitals was also an issue. Forum participants indicated that there was a disjuncture between practices in hospitals and in the community (including Child Protection). It was considered that Child Protection and non-government agency staff generally have a minimal understanding of hospital settings. Conversely, it was also stated that staff in hospitals generally have a minimal understanding of the practices of organisations outside their own.

Some participants considered that the fields of medicine and Child Protection spoke completely different languages.

During the Forum, comments were raised regarding the apparent lack of understanding within Child Protection about hospitals and how workers find it difficult to effectively navigate through the hospital network. Child Protection workers require a clear understanding of how the hospital system operates. Hospitals are complex organisations and having a basic understanding of the way they operate would enhance practice and improve communication between Child Protection and these organisations.

The intended meaning and intricacies of medical information can be frequently lost through translation. This may result in Child Protection not always receiving accurate or adequate information, which is then recorded on CASIS files and documented in court reports.

Recommendation:

That Child Protection and Juvenile Justice Branch pursues the offer of the Royal Children's Hospital social work staff to assist Child Protection workers to better understand the operations of the hospital system. That consideration is given to delivering this training to High Risk Infant Managers, Specialist Infant Protective Workers, Unit Managers, Team Leaders and new Child Protection staff.
(Recommendation 4)

One of the Forums discussed potential processes to enhance communication with hospital staff, which are particularly important in complex cases where a large number of practitioners are involved. One option is for Child Protection Workers to use the Social Worker as their initial point of contact in the hospital. The Social Worker has a liaison role between medical and other hospital health care providers, and can gather and translate the required information for Child Protection workers, and facilitate case conferences and meetings with medical staff when required.

Others suggested that one professional from Child Protection and the Hospital respectively should be nominated as the responsible contact person for each family. A broader view was that each organisation could identify key people as contacts.

A basic mutual understanding of the two systems is critical, not only in working with children with complex medical needs, but other children who are hospitalised during Child Protection involvement. Having medical professionals and Child Protection staff who are well informed about the other's approaches and processes, and the limitations of each system, is important for improved liaison, collaborative practices and better client outcomes.

Recommendations:

That the Department of Human Services seeks to communicate with the Royal Australasian College of Physicians, Victorian State Committee, Paediatrics and Child Health Division and the Royal Australian College of General Practitioners to strengthen links and improve access to paediatric and general practitioner services in rural and metropolitan areas. *(Recommendation 7)*

That Child Protection and Juvenile Justice Branch convenes future forums with professionals, both internal and external to the Department of Human Services, on the needs of children with complex medical conditions and a limited life expectancy in order to continue to seek a broader understanding of this client group and facilitate the exchange of information amongst professionals.
(Recommendation 11)

8. Systemic issues

Hynson et al (2003) argue that caring for a child with a slowly progressive illness may be a 'monumental task'. It means that:

parents may need to provide care around the clock, administer multiple medications, and learn "nursing tasks". (eg managing central lines, naso gastric feeding, and home ventilation). Parents have difficulty reconciling their dual roles as parent and "nurse". They are prone to exhaustion, financial difficulties and anxiety

This description can be used generally to describe the situations of families who are caring for children with complex medical needs. The majority of families included in this Group Analysis also had additional stressors and risks associated with entrenched parental issues that further effected their parenting capacity. The following was the experience of one family in the cohort:

The administration of parenteral nutrition needs to be done using strict aseptic technique, as there is a major risk of infection. Stacey's (pseudonym) grandparents were administering parenteral nutrition to Stacey up to four nights per week.

Stacey also had enteral feeds via a nasogastric tube, which were administered continuously over night, as well as bolus feeds of one hour duration, given four times a day. This process involves a nasogastric tube being passed through the nostril, down the oesophagus and into the stomach. This was necessary as Stacey took minimal (if any) oral feeds. (Child Death Inquiry Report)

As stated earlier, to assist parents to address the care needs of their children, a range of services has been introduced to these families, yet many parents continued to have difficulties maintaining their child (ren) at home, and in the opinion on the Panel, many children continued to be at an unacceptable level of risk.

Consistent with the Department of Human Service policy directions, the priority, where possible is for children to remain at home with their families. For most families with children with complex medical need or severe disabilities, their preference is to care for their children despite the many stressors it places on them. While most families in the general population in this situation require a range of support services involved, families in this Group Analysis generally had a large number of services in their lives. However, in many instances the lack of service co-ordination and episodic nature of the case management provided by Child Protection were features that appeared to limit more effective or intensive service input.

Some families had longer term case management from Disability Services, and two from the Family Choices Program appearing to provide better coordination and continuity of services. However these services are not established to address protective concerns.

The Forum participants indicated that there were no consistent service system responses for this group of children, and families with serious protective issues made service delivery increasingly difficult.

Specifically, the issue of pre-school children was also identified as a significant one by the Panel and reinforced by Forum participants. As the majority of this cohort was pre-schoolers, the need for development of better service provision alternatives for this group became evident. Apart from Family Choices for children with complex medical needs, Making a Difference (0 - 6 years) is the only other service offering case management and flexible packages for children under six

with developmental delays. The funding available from this program is not targeted at the complexity and intensity of services required by this group, and is able to provide less for each family than its counter parts designed for older children.

There appeared to be an agreement that the way forward was to create flexible programs, to enable individualized responses to be tailored to meet the requirements of each situation. While the effectiveness of programs such as Making a Difference (0 - 6 years) was acknowledged, it was considered that children with such complex medical needs and disabilities require a significantly higher level of resources. Family Choices can provide this but only for children with a recognised medical condition, not a disability. For children not eligible for Family Choices, Continuity of Care is the only program with more extensive resourcing. This program has static funding and is not readily available to new referrals.

The Panel supports DHS Disability Services work in development of Individual Support Plans as a way of ensuring a more tailored response based on individual need.

Recommendation:

That the Department of Human Services continues to address the need to minimise the number of programs and funding streams involved in providing individualised packages for children in order to reduce the barriers between the program areas and promote accessibility, flexibility and resourcing based on need. (*Recommendation 12*)

Out of home care as an option was discussed by the Panel and the Forum participants. As stated earlier, it was the view of the Panel that for many of the children in this cohort, remaining in parental care posed too great a risk. Foster care agency managers at the Forum stated that generalist foster carers did not have the skills or capacity to provide the intensity of support required by this group, often on a 24-hour basis. This view is supported in *Public Parenting – A Review of Home-based Care in Victoria* (2003) that states that there is a perception that more difficult children are entering foster care including children with a range of disabilities which is placing more pressure on relatively inexperienced care givers and causing placement breakdown and carer burn out. Suggestions from agencies have included a more flexible funding model and development of intermediate models between residential care and home-based care.

One agency representative at the Forum suggested that contingency arrangements had to be used for this group of children because foster carers are unable to provide for this group of children. It was also suggested that there is no specific funding package available to meet the needs of this group of children so other arrangements have to be 'pieced together'.

In the past, the Family Options program, funded by Disability Services, has provided a small amount of home-based care for children with multiple disabilities, however, carers have been difficult to recruit. In some instances, extended family members can take on the responsibility with support, but this is not an option in many families.

Some children in this group remained in hospital or were frequently returned to hospital as 'social admissions', because parents were unable to cope and there were no other options. Hospital admissions are an extremely expensive alternative and unless required for medical purposes, are generally not suitable placements for children. This issue demonstrates a gap in accommodation and care options for children with high medical needs and a lack of co-ordination between program areas. It requires addressing at a broader systemic and cross programmatic level..

Respite care, either residential or in some instances family based, was used by many families. However, respite services generally do not have appropriate facilities or trained staff to meet the complexity and intensity of the medical requirements of these children. There are significant risks associated with medical intervention performed by unqualified and untrained staff, and there is significant tension in respite services related to the expectation that staff take on this role. There is also an undefined legal risk for DHS and NGO providers of respite services who knowingly try to fill this service gap with untrained staff.

Illustrations of the gap in service delivery include:

- One nine year old in this group spent the last three months of his life in respite on a part time basis and in hospital intensive care for the other days of the week.
- A four year old spent the last few months of his life in part time respite and part time foster care, again because his parents were unable to cope with his needs.

Currently there is no model of out-of home care that is able to fill the gap between hospital and respite care that can adequately meet the needs of these children (unless it is clear that palliative care is required).

It was clear to the Panel that no single program area or Division in the Department of Human Services had or should have responsibility for provision of services for this group of children, as the issues were usually inter-sectoral, involving Child Protection, Early Intervention, Disability and Metropolitan Health and Aged Care. In some instances, the Department of Education, and other State or Commonwealth government funded services may also play a role with these children.

The relationship between Child Protection and Disability Services was identified as an issue in some cases in this cohort, and was another area receiving attention at the consultation Forums.

In one case, the problematic relationship between Child Protection and Disability Services was highlighted by a Child Death Inquiry Reviewer. In this case neither program considered the child to be their responsibility and each attempted to pass on the responsibility to the other. There was also tension between the two programs in relation to which one would pay for the child's services. There were five notifications for this family over a four and a half year period. Child Protection sighted the child on one occasion. The family was being case managed by the Making a Difference Program. Child Protection and Disability are both part of the Department of Human Services which should have made service integration achievable.

One Child Death Inquiry Reviewer commented on the management of a case that:

the interface between the Disability Service System and the Child Protection System in situations of this nature lacks clarity and no clear pathways exist as to whether children should remain within the Disability Service System or transfer to the Child Protection System.

Furthermore, in response to the Draft Report, one region suggested statewide guidelines for greater clarity about provision of ongoing case management, monitoring, information sharing, collaborative practice and shared responsibility for children and young people and their families to enhance processes between Child Protection and key support service internal and external to DHS.

While there were issues between program areas, there were instances where the relationship worked well. For example, another CDI Reviewer stated:

One of the notable circumstances of this case was the effective working relationship that existed between the Regional staff, Disability Services and the Non-Government Disability Residential Service representatives. Important issues were clearly identified by these groups of people, as were future issues (ie. the need for palliative care for Martin's[pseudonym] older brother, Patrick[pseudonym] and in time for Martin himself). These issues were planned for and discussed in terms of the impact on the boys and on those who were working closely with them.

One of the Forums highlighted the fundamental differences and tensions between the Disability services sector and Child Protection.

There are strong philosophical values and beliefs in the Disability sector concerning empowerment, client decision-making and client choice and rights. These are important values that have brought needed change in the historical context of professional control and devaluing of individuals' rights and choices. These values, however, can be applied in a way that makes it difficult for staff to recognise neglect and child protection issues and to work collaboratively with Child Protection when issues have been identified.

Child Protection is a statutory intervener and therefore works with families on an involuntary basis to reduce risk and protect children. Disability Services works with families on a voluntary basis and values empowerment, longer involvement, and continuity of care. Both groups have the welfare of the child as paramount, but working from different philosophical frameworks they operate from different perspectives of risk. However both have an important and valid role and contribution to make. Each service needs to recognise and value the expertise of each other as integrated parts of the service system and work is needed to educate each sector and build positive working relationships. Importantly both need to be actively involved in case planning and case management with clear roles and responsibility.

The Department of Human Services and agencies that deliver child and family services that interface with Child Protection appear to have a greater opportunity to develop a broader shared understanding of Child Protection.

Recommendations:

That the Department of Human Services ensures that Funding and Service Agreements with NGO providers of disability services include the requirement that the organisation's staff working with children and families have ongoing Child Protection education and training. (*Recommendation 13*)

That Child Protection and Juvenile Justice Branch review its practice guidelines and instructions which relate to notified children with complex medical needs to ensure that regional Child Protection workers actively involve disability service providers (internal and external to DHS) and Early Childhood Intervention Services in the case planning process. (*Recommendation 1.5*)

That a revised protocol between Child Protection and Disability Services be developed as a matter of priority and that the issue of parents who are caring for children with complex medical needs and who may require long term out of home care be considered. (Recommendation 14)

Many Forum participants considered that children should be viewed as clients of the Department of Human Services, not those of particular programs.

9. Legal issues

The work of Child Protection and non-government agencies that provide support to children and families is influenced by privacy and confidentiality provisions in legislation. In the past few years this has been further affected by the introduction of new privacy legislation at both State and Federal levels. This legislation includes the Commonwealth *Privacy Act 1988* and the *Privacy Amendment (Private Sector) Act 2000*, and the Victorian *Health Records Act 2001* and the *Information Privacy Act 2002*. Legislation pertaining to specific jurisdictions eg Child Protection also impacts on privacy considerations.

There is significant confusion in the medical and community sectors, and the legal field about the applicability and implications of these pieces of legislation, and their impact on the information that a professional or organisation is willing to provide to Child Protection staff.

Child Death Inquiries at times also have difficulty accessing information from professionals or organisations who argue that privacy and confidentiality provisions restrict their ability to participate in Inquiries. The Panel believes this limits the effectiveness of Inquiries.

Department of Human Services legal advisers have indicated that in many instances reference to privacy legislation is made to avoid providing information to Child Protection. It appears that interpretation of the legislation by health and other service providers can vary considerably, and often appears to be determined by the specific issues in a case.

As stated earlier, there is concern that Child Protection workers may not always obtain clear and reliable information. This in turn may compromise their ability to

convince the Children's Court of the significance of medical conditions in relation to risk or possible harm to the child.

There was considerable discussion of this issue at the consultation Forums, reflecting an overall sense of uncertainty and confusion. A request was made for the Department of Human Services to provide medical practitioners with a one page information sheet on the privacy responsibilities associated with both pre and post court referrals.

Recommendation:

That the Department of Human Services seeks a definitive legal opinion on the interaction and primacy of the *Children and Young Person's Act 1989*, the *Health Records Act 2001* and other privacy legislation during a Child Protection investigation as a matter of urgency. That such an opinion when obtained is communicated in a clear form to all relevant health professionals, particularly hospitals and paediatricians in Victoria. (*Recommendation 15*)

The second significant legal issue identified by the Panel and raised by Forum participants relates to the legal provisions that impact on parents who want to voluntarily relinquish care of their children because they no longer consider themselves able to provide adequate care.

A Child Death Inquiry Reviewer made the following comment in a Report:

One of the major issues highlighted by this case is the need to define clearly the process for dealing with families who are caring for children with disabilities, who even with support services, recognise their inability to provide care for their children and are stating clearly that they do not wish to maintain care. The parents in this case believed that they were acting in the best interests of all of their children.

Most parents, usually with assistance of support services, manage to care for their child with complex medical needs or disabilities at home. However, for a range of reasons, others do not consider they are able to continue in this role.

Department of Human Services policy direction appropriately states that all children should remain with their family, and if this is not possible, an alternate family placement should be found. The *CYPA* (s.87) states that the Children's Court "must ensure that a child is only removed from his or her family if there is an unacceptable risk of harm to the child."

It appears that the only apparent option for some parents to access long term out of home care is to approach Child Protection with a request to relinquish care and/or guardianship. This is only possible by Child Protection issuing a Protection Application under the *CYPA* (s. 63). Generally the provisions for neglect, emotional abuse or abandonment can be applied to these families.

In the opinion of the Panel, where the only option is out of home care, and protective concerns are not evident or significant enough to remove a child, use of the *CYPA* is inappropriate and hinders the potential benefits of case management, long term planning and participation of the family in the future of their child.

In one case in this cohort, two brothers were removed from their parent's care. The decision to remove the children and apply to the Children's Court for a

Guardianship Order was based on the parents' insistence that they could not cope with the children's high medical needs leading them to request permanent out of home care. It was not based on a risk assessment that reflected unacceptable risk for the children in their parent's care.

There are major concerns for families in these circumstances. Firstly, once the case becomes part of legal proceedings, the potential to resolve family issues becomes more difficult. Secondly, in many instances, parents have taken this course of action because they believed it is in the best interests of their child. Parents who wish to relinquish care of their children are often concerned that they may be blamed for the predicament of their child. However, because protective concerns must be identified, they are then legally placed in the role of 'bad parent', creating further distress for families who have often attempted to deal with the care of their child for many years.

Recommendation:

That the current legislative review of the *Children and Young Person's Act 1989* and the *Community Services Act 1970* examines options for an alternative pathway to long term out of home care for this client group where parents seek to voluntarily relinquish care of their child. (*Recommendation 16*)

Conclusion

The Group Analysis on the deaths of 17 children with complex medical needs has shown that most of the children in the selected group died within estimated life expectancy, given their complex medical conditions. However the Analysis has identified some issues and weakness in case practice and service provision, as well as some strengths and good practice. In focusing on issues and strategies to improve case management and service provision to this group and their families, it is the intent of the panel that good practice becomes more universal and that significant service system issues and blockages are highlighted and addressed.

Where good practice was evident, a major feature was a comprehensive risk assessment, focused both on the individual child and the family, and based on specific medical information identifying the child's care requirements. Child Protection staff made considerable effort to obtain information from medical practitioners, and where information and understanding was not available or insufficient, further research about the medical condition of the child was undertaken. Other features of good practice included timely case conferences (occurring prior to discharge of the child from hospital), good communication and collaboration, the use of experienced staff, inclusion of a wide range of players, comprehensive case planning and review, a high level of service coordination and maintaining longer direct case management involvement. Unfortunately in the majority of cases these features were not consistently present.

The broader analysis of this cohort of children has confirmed the view that the prognosis of limited life expectancy, or a serious medical condition, has commonly resulted in a lack of attention to other elements of risk or child wellbeing. It has also shown a lack of assessment of overall parenting capacity, particularly in the context of the specific needs of the individual child and family. Problems with assessment then tend to impact on the case planning and case management of the child and their siblings, complicated further by the multiple and often disparate services surrounding the family. It is crucial that any parenting assessment and case planning is done in the context of the specific needs of the child. In many ways the children in this group required more focused, organised and effective parenting than children generally. The consequences of not providing the care and parenting required for these extremely vulnerable children are serious, impacting on developmental opportunities and quality of life as well as survival.

Whilst these children require a higher level of parenting, in practice the parenting they received was of a relatively low standard. Overseas' surveys suggest that most children with disabilities suffer neglect or emotional abuse rather than other types of abuse and these types of abuse are generally more difficult to prove than physical or sexual abuse. These tendencies are reflected in the cohort of children examined in this Analysis.

The majority of children in this Analysis had very serious neuro-developmental problems which brought enormous care demands and would magnify other risks and stresses on siblings and families. These children's medical prognosis and their significant developmental delays and complexity of issues meant that there was little hope of improvement over time for families. This can be an extreme burden on parents and contribute to a sense of hopelessness with families that already have significant risk factors. These issues also impact on professionals and may contribute to some of the practice issues.

The Group Analysis has identified a number of patterns and recurring themes in the assessment and case management of this group of children and their siblings. These have been discussed through the overview and findings section of this report. The panel recognises that in most ways these children are atypical. What links the children together as a group are their extreme needs and vulnerability, their presence in the medical and child protection systems and the fact that they died at a young age.

The common practice and service provision themes from this atypical group are surprising similar. They show difficulties in obtaining or detailing a comprehensive risk assessment, obtaining adequate information, addressing the specific medical needs and management of the child and addressing the needs of siblings. The majority lacked comprehensive and long-term planning and did not address issues of the impact of neglect and other circumstances relating to the risk profile, on the quality of life of the child.

Perhaps the most common theme, impacting on many other areas, is the significant problems in communication and information provision between Child Protection, the medical field and the broader disability and family support services.¹ Systemic issues impacted greatly on the management of these children and their families. Improved service coordination, flexible funding models and service development to fill the significant service gaps for these children are urgently required. There were also some common legal issues.

These themes and issues have been addressed through recommendations which provide a way forward to improving practice and service provision to this extremely vulnerable group. Action from these recommendations will be important as there appears to be some resistance in parts of the service system to address issues concerning this group of children.

Further action from the recommendations will need to take account of the feedback received indicating that Practice Instructions in Child Protection may not be effectively utilised or enforced. Quality Assurance mechanisms will need further exploration and review.

There are considerable challenges therefore for the Department of Human Services and the wider service system. Work is required to address practice issues and promote inclusive, multi-disciplinary and multi-sectorial communication, cooperation and coordination. These are common issues; however they appear more complex, entrenched and strongly value based in regard to this group of children and families. The forums showed an energy that could be harnessed to improve these areas through joint work, education and development of protocols. Another challenge is to fill the identified and significant service gaps for these children and families. The panel acknowledges the important development already undertaken in case management and brokerage programs, Individual Support Packages and in cooperation between Divisions of the Department of Human Services to avoid duplication. For the issues identified in this report to be resolved, further cross Divisional work will be required both at a practice level (for example the clear issues between Child Protection and Disability Services), and at a service planning and resourcing level. Health, Disability and Child Protection programs need to deliver an integrated and responsive service. As one region commented in its written response to this Draft Report, there is a "need for co-operative and shared responsibility in these

¹ In response to the Draft Report, one region, in acknowledging these sentiments, also pointed out that key players in regional services increasingly understand these issues and are developing strategies to address them. Proposed reforms should apply across the services and program areas and consider analysing the range of responsibilities of stakeholders.

complex matters and for the other partners to exhibit ownership, not just presence”.

The responsibility for children with complex medical issues and their families is a shared one. A partnership approach between Disability, Health, Early Childhood Intervention and Child Protection Services is required to build collaboration and co-operation. Given the complexity involved with these cases and the specialised knowledge required, joint work with medical staff, as well as with government and non-government services providers is a necessity. Other program areas have a significant role to play in these matters and the responsibility does not lie exclusively with Child Protection. Successful outcomes will only be achieved through a cooperative and committed response throughout the service sector.

The population of children with complex medical needs and/or disabilities is likely to increase as a result of advances in medicine and technology, and generally better health in Western countries. As a result, the numbers of these children who are subjected to child abuse or neglect may also increase. While this is likely to lead to greater demand for medical interventions and support services, there is minimal data available on the prevalence of these children in the child protection system. It is therefore difficult to develop a general understanding and planning strategy for this group of children. Lack of data available on children with disabilities/complex medical needs who are subject to abuse or neglect is also a concern raised in the research from the US and UK.

Recommendations

Note: In making recommendations, this report has sought to utilise existing systems of quality improvement for Child Protection workers to improve and to implement practice consistently. Practice Instructions were seen as an appropriate quality assurance measure.

However, feedback received by the Panel indicated that the effectiveness of these Practice Instructions is being questioned within the Child Protection field and alternative quality assurance practices are in the process of being considered. It is not within the Terms of Reference of this Analysis to investigate this issue further. Child Protection therefore may need to consider alternative strategies for implementing some of the recommendations of this Group Analysis.

Footnotes in this section indicate responses to the Draft Report from regions and program areas.

Risk Assessment and Planning

1. That Child Protection and Juvenile Justice (CP&JJ) Branch review its practice guidelines and instructions which relate to notified children with complex medical needs to ensure that:
 - 1.1 an enhancement of the Victorian Risk Framework is developed
 - 1.1.1 for working with children who have been diagnosed as having a complex medical need or a limited life expectancy. This should also occur for siblings in such households to ensure that they are not at risk of abuse or neglect, and they have a reasonable quality of life
 - 1.1.2 that includes specific attention to the risk posed by the complex and repetitive nature of the medical treatment required in the home environment and whether the parents are likely to be able to cope over a prolonged period²
 - 1.2 these children are recorded on regions' High Risk Registers
 - 1.3 regional staff more assertively seek adequate medical and specialist advice, including advice from Disability Services and Specialist Children's Services, in order to develop a better understanding of the care requirements that would inform the risk profile of the child and to determine whether transition support from hospital to home could minimise identified risk factors³
 - 1.4 prevention of neglect and emotional harm is a primary focus in service planning and decision-making particularly the transition from hospital, case planning, the court process and palliative care
 - 1.5 regional Child Protection workers actively involve disability service providers (internal and external to DHS) and Early Childhood Intervention Services in the case planning process

² Disability Services had advised that they are currently working with Metropolitan Health and Aged Care Division to improve discharge planning procedures.

³ One region suggested, in relation to 1.3, 1.4 and 1.5, a statewide response for development of adequate practices and protocols for these types of cases, in addition to a regional response.

2. That Child Death Inquiries specifically seek to identify the medical advice that was available to Child Protection staff at the time of notification on a child in order to determine the adequacy of the risk assessment.
3. That Child Protection and Juvenile Justice Branch incorporate training in relation to the impact of a child's terminal condition on Child Protection staff into a relevant training course and that this training be aimed at Child Protection workers and managers.

Child Protection/Medical Services Interface

4. That Child Protection and Juvenile Justice Branch pursues the offer of the Royal Children's Hospital social work staff to assist Child Protection workers to better understand the operations of the hospital system. That consideration be given to delivering this training to High Risk Infant Managers, Specialist Infant Protective Workers, Unit Managers, Team Leaders and new Child Protection staff.
5. That Child Protection and Juvenile Justice Branch, regional Child Protection representatives and Health Divisions work in partnership to develop a protocol with major obstetric and paediatric hospitals to ensure that in cases of children with complex medical needs, who are subject to a current protective notification, that a case conference be convened prior to discharge, and that discharge planning occur which clarifies roles and responsibilities.
6. That the Department of Human Services seeks to communicate with the Royal Australasian College of Physicians, Victorian State Committee, Paediatrics and Child Health Division and the Royal Australian College of General Practitioners to strengthen links and improve access to paediatric and general practitioner services in rural and metropolitan areas.
7. That regional Child Protection Managers, in conjunction with Metropolitan Health and Aged Care, Rural and Regional Health and Aged Care and the Child Protection and Juvenile Justice Branch, seek to improve access to designated paediatric expertise to provide consultation on medical conditions, and the related care implications, and to provide liaison between Child Protection and medical staff.
8. That Metropolitan Health and Aged Care Division considers the merits of monitoring recent developments in the field of paediatric palliative care and this information is made available to Child Protection on a case by case basis for the benefit of children with a limited life expectancy.⁴
9. That the Child Protection and Juvenile Justice Branch evaluates existing Child Protection training and professional development resources to

⁴ Early Childhood Intervention Services supported the availability of information and knowledge of paediatric palliative care and the sharing of this information across program and practitioner boundaries.

doctors to ensure that they have a better understanding of issues relating to child abuse, child protection and mandatory reporting.⁵

10. That Child Protection and Juvenile Justice Branch convenes future forums with professionals, both internal and external to the Department of Human Services, on the needs of children with complex medical conditions and a limited life expectancy in order to continue to seek a broader understanding of this client group and facilitate the exchange of information amongst professionals.

Service Directions

11. That the Department of Human Services continues to address the need to minimise the number of programs and funding streams involved in providing individualised packages for children in order to reduce the barriers between the program areas and promote accessibility, flexibility and resourcing based on need.
12. That the Department of Human Services ensures that Funding and Service Agreements with NGO providers of disability services include the requirement that the organisation's staff working with children and families have ongoing Child Protection education and training.⁶
13. That a revised protocol between Child Protection and Disability Services be developed as a matter of priority and that the issue of parents who are caring for children with complex medical needs and who may require long term out of home care be considered.

Legal Services

14. That the Department of Human Services seeks a definitive legal opinion on the interaction and primacy of the *Children and Young Person's Act 1989*, the *Health Records Act 2001* and privacy legislation during a Child Protection investigation as a matter of urgency. That such an opinion when obtained is communicated in a clear form to all relevant health professionals, particularly hospitals and paediatricians in Victoria.
15. That the current legislative review of the *Children and Young Person's Act 1989*, and the *Community Services Act (1970)* examines options for an alternative pathway to long term out of home care for this client group where parents seek to voluntarily relinquish care of their child.⁷

⁵ One region suggested a central cross divisional statewide approach to support ongoing training and professional development in pre and post graduate medical courses, training facilities and universities.

⁶ One response suggested that ongoing education and training about Child Protection should extend to ECIS and Disability Services workers in both DHS and non-government services. Another response suggested development of a training program aimed at multidisciplinary staff such as Child Protection, Disability Services, hospital social workers etc in relation to sharing information, assessment and management of this group of children. A further response also suggested cross program training or those similarly affected by these issues including community based workers, promoting cross-programmatic liaison. Another suggestion was for further work to be undertaken on Child Protection and Disability Services education.

⁷ One region recommended that Disability Services be included as a key stakeholder.

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Appendix 1

TERMS OF REFERENCE OF THE VICTORIAN CHILD DEATH REVIEW COMMITTEE

- Review investigative reports of all deaths of children who have died while current clients or, within three months of case closure, of Child Protection Services and advise on any specific issues, which the Committee believes need addressing as a result of such a review.
- Advise the Minister of the implications of findings in given cases where necessary.
- Describe trends and patterns of child deaths.
- Analyse and comment on any themes, which may be emerging through the inquiry process.
- Identify the prevalence of risk factors, which existed in the population of children who had died, and recommend further investigations into particular groups as appropriate.
- As a result of the examination of investigative reports of child deaths, evaluate service and system responses to children and families who are considered to be at high risk and offer recommendations for improvement of responses.
- Prepare an annual report for the Minister of Community Services.
- Ensure that liaison occurs with relevant committees and processes, which review and consider deaths of children and young people when this will assist the Committee in its review functions.
- Provide advice to the Minister for Community Services on the Child Death Inquiry process.

Appendix 2

Age at time of Death	Medical Conditions	Protective/Familial Concerns & Commentary
16 months	Global developmental delay identified at five months. Rare enzyme deficiency stated but no details specified. Born four weeks premature and drug dependent. Family history of SIDS – step sister aged 4 months. Two other siblings suffered developmental delay post non-accidental injury and resided out of home.	Possible connection between SIDS step sister, developmental delay and reported enzyme deficiency did not appear to be examined. Diagnosis of enzyme disorder incomplete without documentation. Extreme risk factors, flawed premise that this child could be cared for safely by parents. Issues in relation to unsuccessful court outcomes raised.
19 months	Benign spinal congenital malformation excised day nine, proceeded to complicating malignancy. Hospice at death. Prognosis of limited life expectancy. Physical abuse of sibling.	VCDRC comment that modern palliative care philosophy states that workers must also care for the family that will live beyond the death of the child.
4 years	Angelman's Syndrome which involved fascination with water. Chromosomal 15 disorder associated with severe developmental problems and dependent existence, seizures, gait, movement, eating and swallowing disorders. Required braces for walking. Sensitive to light and partially blind. Death ascribed to 'dry drowning' apparently left unattended with 18 month old sibling in bath.	Death not expected in this syndrome in early life. Cause of death presumed drowning. (Full autopsy not available). High risk indicators mention unknown male figure without a strong parenting link in the home, a history of black eyes, unexplained bruising on the child and significant concerns expressed by the paediatrician. Reviewer indicated a check list could provide a helpful prompt for protective workers.
4 months	Extreme prematurity. Bowel complications requiring surgery. Respiratory difficulties. Premature birth leading to high medical needs. Co-sleeping with mother prior to recognised breathing cessation. Death due to bronchopneumonia.	Young Aboriginal parents, separated, concerns raised regarding their attachment to their newborn child. Case conferencing at Metropolitan neo natal unit led to infant being transferred to a regional hospital. VCDRC supported numerous recommendations made, which the Region subsequently addressed. Major aim to improve communication between regional and metropolitan hospitals.
3 years	Mother developed severe intra-natal respiratory complications and was placed on life support, resulting in infant with acquired brain injury, severe cerebral palsy and developmental delay, gastrostomy, susceptible to respiratory infections. Prognosis of limited life expectancy.	Significant family violence, criminal history, drug use, hygiene, attachment issues. Mother reluctant to engage with support services.

Age at time of Death	Medical Conditions	Protective/Familial Concerns & Commentary
2 years	Cerebral palsy, microcephaly, seizures, failure to thrive, naso-gastric feeding.	5 year old first cousin similarly affected. Consanguinity issues with mother and twin sister marrying brothers. Exemplary protective management supported by VCDRC and Group Analysis Panel.
6 months	29 week gestation, severe drug withdrawal. Respiratory Distress Syndrome ventilation. Significant brain damage, severe disabilities, required oxygen suction machine. Prognosis of limited life expectancy.	Drug use by mother throughout pregnancy. Suggested psychiatric services for dual diagnosis of mental health & drug abuse issues not pursued by Child Protection. Maternal grandmother - alcohol misuse – over estimation of her capacity to care for infant by Child Protection.
4 years	Liver cancer post neo-natal hepatitis. Prognosis of limited life expectancy.	Liver transplant recommended but poor candidate, mainly due to family & protective issues. Multiple notifications, transient between States. Father with mental health issues. Multiple problematic circumstances. Professionals had problems maintaining contact. Medical neglect identified as protective concern but focus remained on administering medication. Protective issues generally not articulated by hospital or requested by region.
5 months	Laryngotracheal malacia (floppy larynx), failure to thrive. Naso-gastric feeding.	Condition usually resolves spontaneously. Described here by competent specialist as worst case seen. Adverse incident during tracheostomy with cardiac arrest, not responding to prolonged resuscitation. Concerns relating to transience, inadequate care including medical needs, inconsistent attendance at medical appointments and conflicting medical opinions without recognition of resultant poor prognosis
9 years	Born 3 months premature. Related spastic quadriplegia, reliant on wheelchair, unable to speak, feeding and swallowing difficulties, epilepsy, paralysis to one side of face. Major stroke seven months prior to death, lead to serious brain damage, could no longer communicate. Gastrostomy feeding three months prior to death. Poor prognosis with relatively prolonged survival.	Relinquishment requested by family. Long history of family violence, drug use, chaotic family, parents had overwhelming problems with management of the child. Palliative issues relevant.

Age at time of Death	Medical Conditions	Protective/Familial Concerns & Commentary
3 years	Congenital heart defect resulting from Fetal Alcohol Syndrome. Prognosis of limited life expectancy not conducive to cardiac surgical management. Not expected to live beyond 2000, the year she died.	Parents with history of alcohol abuse, mental health & family violence. Older sibling with similar syndrome, status of another younger sibling not known. Medical Neglect. Older sibling with similar syndrome. Public health education issues arise with reference to preventative management through Aboriginal communities. Opportunity for greater "Working Together" between Child Protection and Mental Health.
3 months	Infantile Marfan's Syndrome. Condition effects connective tissue throughout body, leading to abnormalities of eyes and cardiovascular system. Prognosis of limited life expectancy – expected to live until 3 – 4 years. Never discharged from hospital.	Mother had long history of substance abuse, depression. Issue regarding communication of information between hospital and Child Protection. CDI Reviewer raised issues regarding support for Protective Workers when children have limited life expectancy.
2 years	Born with Negative Gram Septicaemia. Short gut syndrome. Surgery to remove part of bowel. Severe liver dysfunction. Extremely complex medical needs with gut malabsorption requiring total parenteral nutrition. Liver transplant mentioned.	Attachment to grandmother, parental medical neglect. Young parents. Younger sister had high medical needs and born premature with lung problems. Possible violence between mother and partner. Criminal and drug use history of father. Parents stated they could not care for older child due to medical needs. CDI Reviewer stated Child Protection over reliant on agency assessments.
17 years	Spinal muscular atrophy. Relied on wheelchair or carried from age 12. Increasing respiratory complications. Used daily oxygen. Prognosis of limited life expectancy. Cared for at home.	Local doctor played important role in child's life. Not contacted by Child Protection in assessment of medical condition, and treatment. VCDRC stated that a medical specialist dedicated to providing advice to Child Protection would assist in cases of children with disabilities and complex medical needs. Sexual abuse of older sibling.
2 years	Developmental delay, failure to thrive, visual impairment, seizures, apnoeic episodes, significant health issues from birth. Nutrients via naso-gastric tube. Low blood sugar. Possible inherited metabolic disorder related to mitochondrial disorder. Investigated at metropolitan hospital, specific details lacking.	Extreme protective issues. Premature maternal and infant discharge from hospital at 24 hours. Query shaken baby syndrome. Father had intellectual disability, mother personality disorder. Likelihood of physical and sexual abuse as children left with paedophiles. 4 year old brother with developmental delay

Age at time of Death	Medical Conditions	Protective/Familial Concerns & Commentary
		for which mother lacked understanding and punished with physical abuse. Raises questions of shared inherited metabolic disorder with neurological damage. Finalisation of medical information critical in complex medical cases.
10 years	Subdural haemorrhage and other intra cerebral damage resulting in gross neurological disability and other injury causing dependent existence and special needs care. Child lived most of life with foster carer.	Almost certain non-accidental injury. Subdural haematoma should in this context be a diagnosis of exclusion at least. Repetitive damage, parental comments and allegations and then eventual departure of mother to UK consolidated opinion. Siblings cared for briefly by grandparents due to likelihood of harm. In retrospect medical advice should have been more directive although permanent damage had probably been sustained. Non-performance of autopsy is noted. VCDRC stated that an assessment of the family should have occurred on the occasion of the 1 st cerebral haemorrhage.
11 years	Coffin Lowery Syndrome, retardation in physical and intellectual development	Older brother with same condition. Child Protection seen as gateway to disability services placement. Relinquishment rather than protective needs pre-empted removal of children. VCDRC stated that a paediatric consultant's treatment plan would have been useful in this case for advice on medical issues.

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