FINAL REPORT

Review of Specific Grief and Bereavement Services funded by the Department of Human Services

On behalf of
Metropolitan Health and Aged Care Services Division
Department of Human Services Victoria

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the Nucleus group

Melbourne ♦ Canberra ♦ Sydney

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1 Executive Summary

The review used a highly collaborative approach with the four agencies and other stakeholders

The Department of Human Services provides approximately $870,000 per annum to the Centre for Grief Education (CGE), the Community Bereavement Service (CBS), Mercy Western Grief Service (MWGS) and the National Association for Loss and Grief Victoria (NALAG). This funding is used to provide a range of specialist grief and bereavement services including community education, information, professional training and clinical services. Grief and bereavement services are also provided by a wide range of private and public organizations using a range of approaches and service models.

The broad aim of the review was to determine the future role and focus of the four specific grief and bereavement services within the context of the wider service system. The review adopted a highly collaborative approach with the four agencies and a wider stakeholder group. The methodology for the review included the formation of a 'Leadership Group' comprising key representatives of the four agencies. This group drafted a Service System Framework for the future development of grief and bereavement services and identified structural options for the four agencies that best supported the framework.

Key Findings

Most people manage bereavement using natural supports but some people need specialist assistance

Most people manage grief and bereavement using their natural social supports. However, for approximately five to 10 percent of bereaved people experiencing complex grief, there is a need for specialist grief and bereavement interventions. In general, service responses to grief and bereavement should be timely, flexible and responsive to individual needs.

Greater community awareness of grief and bereavement is needed …

suggesting more integrated approaches to health promotion

Community capacity to support individuals experiencing grief and bereavement would be strengthened through greater community awareness and understanding of grief and bereavement. Hence, the community would benefit from the development of a stronger, more integrated grief and bereavement information and community education strategy. Such a strategy should be positioned on the community health platform, with expert resourcing and support provided by the specialist services. In addition, the grief and bereavement sector should also participate more strategically in existing community capacity building initiatives.

The grief and bereavement sector requires stronger planning, leadership and direction …

together with quality standards and evaluation processes

There would be significant benefit to the community and to the grief and bereavement sector by developing stronger sector leadership including consolidating current leadership activities. Importantly, there is a need for a future directions framework for grief and bereavement services to ensure future developments are well planned and effectively integrated with relevant initiatives. A set of service standards is required, particularly in relation to clinical interventions and there would be value in establishing a local evidence base for grief and bereavement services. Local research efforts might be encouraged through more strategic engagement with the tertiary education sector.

An increased focus is needed on training professionals in universal services …

and a self funding competency based approach to practitioner regulation

Information and training for frontline health and welfare professionals on grief and bereavement requires strengthening. Greater emphasis should be placed on up-skilling the generalist health professional workforce in providing grief and bereavement supports in the context of a statewide strategy. More flexible models of training and professional support are required for professionals practicing in grief and bereavement, particularly in rural regions. In addition, the quality of clinical practice would be improved by moving towards a competency-based approach to practitioner quality control, funded through practitioner contributions.

There is a need to foster a wider range of service responses particularly for under represented groups

Clinical interventions are required as part of an integrated response to grief and bereavement in the community. However, the greatest benefit is gained when these interventions are of high quality and carefully targeted at high-risk groups. There is a need to further develop alternative models of service for groups that are under-represented, for example men and people from CALD and indigenous backgrounds. Future service developments, including information provision, community education and clinical interventions will need to be broadened in scope and reach to maximise engagement with under-represented groups. In addition, future service development should also focus on enhancing social and volunteer models of bereavement support.

To meet future demand, the primary focus of specialist services should be on building the capacity of universal services

Anecdotally, there is a high level of unmet demand for grief and bereavement interventions (particularly in rural Victoria) that cannot be met with the existing specialist grief and bereavement resource base. Therefore the primary role of specialist grief and bereavement services in the future should be enhancing the capacity of universal services to provide grief and bereavement supports, most particularly through the community health platform.

The review developed an integrated Service System Framework and future options for the structure of the specialist grief and bereavement services. The Service System Framework received broad support from the four agencies and the wider stakeholder group.

The future directions are best be supported by consolidating funding and agency structures

The agencies did not reach consensus on a single structural option. However, three of the four agencies gave in-principle support to the formation of a new entity to deliver grief and bereavement services based on the revised structure proposed by the Centre for Grief Education.

Recommendations

- **The Service System Framework should be adopted as the blueprint for the future development of grief and bereavement services in Victoria.**
- **Funding for the four specialist grief and bereavement agencies should be consolidated into a single Funding and Service Agreement with service activities, outputs and targets aligned with identified priorities in the Service System Framework.**
- **The optimal structural arrangements for the four specialist grief and bereavement services would be achieved through the formation of a single entity based upon the revised structure proposed by the Centre for Grief Education.**

2 Introduction

2.1 Project Background

The Department of Human Services (DHS) allocates approximately $870,000 per annum to the Centre for Grief Education (CGE), the National Association for Loss and Grief Victoria (NALAG), the Community Bereavement Service (CBS) and Mercy Western Grief Services (MWGS) to provide a range of services that includes:

- Direct clinical services including bereavement counselling.
- Research, training, education, and consultancy on loss, grief and bereavement issues for professionals.
- Education activities and resources on loss and grief to the broader community.
- Assessment and accreditation of loss and grief practitioners.
- Information and support for self-help groups.

In addition, grief and bereavement services are obtainable in the community from a number of other sources (representing a diversity of approaches):

- Community based palliative care services (bereavement counselling).
- Private practitioners.
- Funeral services.
- Community Health Services.
- Voluntary support groups.
- Telephone counselling services.
- Coroner's Court.
- Issue-specific services for example the National Trauma Clinic, Road Trauma Support Team.
- Local Government services.
- Church, community and welfare organisations.
- Individual public and private schools.

There are also a number of self-help and support groups within the community, including SIDS and Kids Victoria and The Compassionate Friends.

2.2 Purpose of the Review

The aim of the review was to determine how the four specific grief and bereavement services funded by DHS could be optimised to strengthen the resilience of the community in dealing with loss, grief and bereavement, including clarification of their respective roles within the wider service system.

The objectives of the review were to:

- Determine the priorities and opportunities for the four funded services including clinical services, training, education, research and consultancy within the broader system.
- Clarify the respective roles, responsibilities, strengths and weaknesses of the four funded services and identify synergies/opportunities that may be promoted between the services to maximize client outcomes.
- Ascertain the accessibility to services by those in the community requiring grief and bereavement services and how current services can best meet those needs.
- Identify issues currently affecting service provision (such as, but not limited to, current accommodation) and provide options for resolution.
- Develop recommendations addressing the above objectives and an implementation plan.

2.3 Review Working Party

A Working Party was formed by DHS to oversee the review and provide expert input and advice. Given the nature and process of the review it was not seen as appropriate to include the services under review in the Working Party. For this reason, Working Party membership included representatives from areas within DHS that had a strategic interest in the outcomes of the review. Due to difficulties in engaging a consumer representative for the Working Party, the Health Issues Centre agreed to provide a representative. A list of Working Party members is provided in Appendix 5.

2.4 Key Research Questions

The review developed a set of key research questions, approved by DHS, to guide data collection and analysis. These included:

1. ***What are the essential elements of an effective service system to strengthen and support the community in dealing with loss, grief and bereavement as a result of death?***

   This question encompassed factors such as:

   - The needs and primary support requirements of persons experiencing loss, grief and bereavement.
   - The roles of the wider service system and the specialist services and their interrelationship.

- The priorities for service provision in relation to needs of service users, service providers and the community in general.
- Service demand and equity of access.
- The existing evidence base for service models and service systems.

2. ***What are the strengths, weaknesses and opportunities for each of the four funded agencies?***

   This question encompassed factors such as:
   - The operating environment and infrastructure issues for individual agencies.
   - The optimal configuration of the broader service system and the role of specialist agencies within this system.
   - Agency strengths and expertise.
   - The role of partnering and collaboration.
   - Evidence based practice.

3. ***How should the four agencies, both collectively and individually, best support the development of, and manage the transition to, an optimum service system for persons experiencing loss, grief and bereavement in Victoria?***

   This included an examination of factors such as:
   - The match between an optimal service system and the current service system.
   - Future service system development.
   - The priority needs of service users in relation to available resources.
   - The future strategic focus, strengths and roles within the service system of individual agencies.
   - Future service demand.
   - Agency/program business planning and viability issues.
   - Opportunities for partnering and collaboration.

3 Methodology

The review adopted a highly collaborative and consultative methodology with the four agencies and the broader stakeholder group in order to achieve the highest possible degree of ownership of the review outcomes. Key elements of the project methodology included:

- A literature review.
- Scoping the strengths, weakness, opportunities and challenges for the four agencies.
- Initial consultation with external stakeholders.
- Contextual policy analysis.
- Identification of key sector and agency issues and the development of an 'Issues Paper'.
- Formation of a Leadership Group comprising representatives of the four agencies that developed a draft Service System Framework and identified options for the future direction and structure of the specialist grief and bereavement agencies.
- A second round of consultation with external stakeholder on identified key issues and the draft Service System Framework.
- Final Analysis and reporting.

Details of each stage in the methodology are provided in the following section.

3.1 Literature Review

A brief literature review was undertaken that focused on two key research areas:

- Evidence about the efficacy of service system structure in relation to grief and bereavement services.
- Evidence about the efficacy of grief and bereavement interventions including intervention targeting.

The search methodology included general and academic web searches and direct access to citations not on line. Each of the agencies was invited to provide research information or leads they thought relevant. Contact was also made with the International Working Group on Death, Dying and Bereavement (IWG)[1] for expert views and opinions relating to the two areas under review. Notes of the literature review can be found at Appendix 1, and key findings are integrated within this report.

In summary there is little if any research on service system development, but some anecdotal agreement from key international figures on what type of services work best and who should deliver these services. This includes agreement on the need within the service system for specialist grief and bereavement capacity for the small percentage of persons experiencing complex grief. There is little research on the training/competencies required of interveners but broad agreement that persons delivering specialist grief and bereavement interventions require specialist skills.

There are numerous research sources in relation to the effectiveness of interventions including intervention targeting. However, it is worth noting Neimeyer and Hogan's observation (2001) that "although the human experience of bereavement has been studied, it has not been studied well". In general the evidence suggests that there should be a focus on boosting social support systems for the majority of bereaved people – for example, through community education, information and support groups. For the minority of people (approximately five to 10 percent) whose grief is traumatic or complicated, there seems to be the need for specialist interventions provided by professionals with specialist skills. The more complex the grief process is for individuals the better the chances of such interventions leading to positive results (Schut et al, 2001).

3.2 Agency Scoping

In general, the agencies welcomed the review and considered it an important development in the grief and bereavement sector. Agencies generally recognised the weaknesses in the current service system and expressed a commitment to identify improvements and work collaboratively to seek solutions.

A half-day forum was conducted with each of the four funded agencies; participants at the forums included members of the committee or boards of management and key staff. The aims of the agency forums were to:

- Build a profile of each agency including its strengths, weaknesses, future opportunities and challenges.
- Identify each agency's perspectives on service and service system change and redevelopment opportunities and issues.

[1] The IWG is composed of clinicians, researchers and educators dedicated to the development of knowledge, research, practice and education dealing with death, dying and bereavement. Membership is through invitation and there are currently 138 members internationally.

A summary profile of strengths, weaknesses, opportunities and challenges was developed for each agency. These profiles are not included as part of this report as they were primarily used as a tool to support the review process. Funded activity targets and most recent performance data for each agency were also examined. Some difficulty was experienced in reconciling service targets and reporting data periods. This was due, in part, to a lack of standardised funding and service agreement information across the grief and bereavement services.

3.3 Consultation with External Stakeholders

Consultations were held with a range of external stakeholders, either by individual interview or through targeted forums (see Appendix 2 for a list of external stakeholders). Stakeholder views were sought in the following areas:

- The fundamental requirements to strengthen the capacity of individuals and the community to better manage grief and bereavement.
- The strengths and weaknesses within the current service system and the key elements of an optimal service system.
- What role should the four specialist services play within the service system and how they should be structured/positioned.
- The role and effectiveness of clinical interventions.

3.4 Policy Context

A number of current government policy and directions documents were examined to establish the broader policy context for the review and to identify significant developments that may have relevance in future service system development. These included:

- Growing Victoria Together – Victorian Government, 2001.
- Partnership Strategy – Department of Human Services, 2002.
- National Palliative Care Strategy – Commonwealth Department of Health and Ageing, 2000.
- New Directions for Victoria's Mental Health Services – Department of Human Services, 2002.
- Review of Counselling Services in Community Health – Department of Human Services, 2002.
- Primary Care Partnerships – Department of Human Services.
- Discussion Paper – Best Practice Self-Regulatory Model for Psychotherapy and Counselling in Australia, Psychotherapy and Counselling Federation of Australia, 2004.

3.5 Identification of Key Issues

The key issues were identified by exploring key research questions via:

- Individual sessions with the four agencies.
- Semi-structured interviews with the external stakeholders.
- Findings from the literature review.
- Review of the key policy context.

An Issues Paper was prepared to outline the key issues including potential options. The key issues and discussion are presented in Section 4 of this report.

3.6 Leadership Group

Consistent with the consultative approach to the project, a 'Leadership Group' was formed to examine the key issues and identify future directions in relation to the project objectives. The group comprised two representatives from each agency, either a member of the Board of Management and Executive Officer or in the case of larger agencies the Chief Executive Officer and the Program Manager. Members of the Leadership Group are listed in Appendix 3. The Leadership Group met on five occasions and its key objectives were to:

- Develop a shared understanding of the prevailing policy and funding context.
- Endorse and prioritise the key themes and findings of the Issues Paper.
- Develop a Service System Framework for a more effective and efficient service system including key service elements, roles and functions of specialist agencies and universal services.
- Correlate agency strengths and weaknesses to the preferred Service System Framework and identify potential implications for each agency in the transition to the framework.
- Identify options for the future role, structure and focus of each agency.
- Identify the key issues in the implementation/transition to the preferred Service System Framework.

3.7 Second Consultation With External Stakeholders

A forum was held with external stakeholders to seek feedback on the key issues identified in the Issues Paper and on the proposed Service System Framework. Agencies that were unable to attend the forum were provided with a further, later opportunity to provide feedback to the review.

4 Findings and Key Issues

The following section outlines the key issues identified in the initial consultation with the four agencies and the external stakeholder groups as presented in the Issues Paper.

4.1 The Needs of People Experiencing Loss, Grief and Bereavement

There was broad agreement that the needs of individuals in relation to loss, grief and bereavement are highly individualised. There is a wide range of grieving styles and experiences. However, the fundamental needs of bereaved individuals are for support and acceptance. This includes recognition and validation of their grief and grieving style, from family, friends, employers and the general community.

Arguably, grief and bereavement and the needs of bereaved persons are not well understood within the general community. There was a general view that grief needs to be 'normalised' and that enhancing community understanding of grief and bereavement is an important objective.

Uncomplicated grief and bereavement is not associated with enduring negative consequences for most people. However, individuals experiencing complicated grief may be at increased risk for poor physical health outcomes (Centre for the Advancement of Health, 2003: 42 and 43).

The literature and sector practice and knowledge supports the view that the majority of bereaved people can function effectively after bereavement utilising their natural social supports and possibly some low-level interventions. However, for perhaps five to 10 percent of bereaved people experiencing complex grief, there is a need for specific grief interventions that should be flexible, responsive to individual needs and available at the time of need.

It is also worth noting that the needs of the community are being reshaped in part by the emergence of larger scale traumatic events such as disasters and terrorism. While broader service system responses are needed to deal with such events, there may be a role for specialist grief and bereavement services in supporting such responses.

In Summary:

- **The majority of people manage loss, grief and bereavement using their natural social supports.**
- **Service system responses to grief and bereavement should be timely, flexible and responsive to individual needs.**
- **Community capacity to support individuals experiencing grief and bereavement would be strengthened though greater community awareness and understanding of the needs of people dealing with grief and bereavement.**

4.2 Strengths and Weaknesses of the Current Service System and Elements of an Optimal Service System

The review sought views on the strengths and weaknesses of the current service system and on an optimal service system structure. A number of key elements of an effective service system were identified:

Leadership and Direction

One of the greatest perceived strengths of the current grief and bereavement sector is that it has predominantly arisen in response to community needs. However, there is a general view that many initiatives have been reactive. Almost universally, the four agencies and external stakeholders expressed the view that the sector lacks leadership and direction. The need for direction both from government and from within the sector itself was seen as one of the highest priorities. The majority of participants believed that the sector requires a future directions framework or policy.

There also appears to be different understandings in the sector around the definitions of loss, grief and bereavement, and differing opinions on how broad the focus of the sector should be. Some participants, both within the agencies and externally, argued that the sector should be expanded to cover 'whole of life cycle' losses. Others suggested that the system should be predominantly bereavement focused, as the experience of death was much greater than any of the other losses, although the symptoms of grief and the triggers of grief could be the same. DHS has indicated that its funding should be focused on grief and bereavement in relation to death.

The sector believes that loss, grief and bereavement impact very broadly on the community. Many participants therefore argued that the most effective way to strengthen community capacity in relation to grief and bereavement would be to

take a 'whole of government' approach to sector planning. Others expressed the view that such an approach may dilute energy and focus at a key point in the sector's development. An argument was put for a more pragmatic approach, initially focused on planning by the key government departments and the services directly involved. A whole of government approach may be overly ambitious at this stage in the sector's development.

The sector believes that the impact of loss, grief and bereavement are not well understood within the community or government. Therefore it argues that greater government engagement is needed to lead future developments. Parallels were drawn with the development of the palliative care sector a decade ago where government engagement was seen as a positive driver in the development process. Some participants argued that the specialist grief and bereavement sector should initially focus on strengthening its leadership and position in order to better inform and influence government.

There appears to be a level of frustration within the sector, both externally and within the four agencies, related to perceived fragmentation of services and in some cases duplication of roles. This view relates to services as a whole as well as the four specialist agencies. It was noted that the sector includes many more funded and unfunded services than the four agencies subject to this review. Within the four agencies, some concerns exist around duplication of roles (related primarily to CGE and NALAG), particularly regarding information, education and training functions. However, there were also concerns expressed around duplication of some of the CBS information and education functions. Some examples of service duplication or overlap were cited outside the four agencies, for example telephone information and support services.

Given the limited resources involved, many participants expressed the view that the sector can ill-afford to support less than optimal structures at what is considered a critical time in the sector's development. Many felt that the sector needed to show leadership in addressing current issues around service fragmentation and role duplication.

Most external stakeholders did not perceive the sector as currently having a peak or leadership body. In the past, NALAG was perceived as the leading body in the grief and bereavement sector – a position that has now changed in light of more recent events and developments. CGE is seen by many as a centre of excellence in relation to information, knowledge and education; however, CGE's role is generally perceived to be narrower than that of a peak body. Participants noted that the general public is likely to be unaware of the roles of CGE and NALAG, and that the current situation is likely to promote confusion.

The majority of participants in this review, both within the agencies and externally, believed that leadership and associated activities (such as advocacy, policy/direction development, and core functions around information, community education and quality) should be strengthened and consolidated. The majority of participants see the lack of an effective leadership structure as the sector's most significant weakness.

In Summary:

- **There is a need to develop a future directions framework or policy for grief and bereavement services to ensure that future development is effectively planned, well coordinated and linked with relevant government initiatives.**
- **For the present, planning and directions development should focus on strategic engagement with those departments/agencies directly involved in specialist grief and bereavement services, rather than a broader whole of government approach.**
- **Given the limited resources of the four funded agencies, there is an argument to place the primary focus of the specialist sector on bereavement.**
- **The community and the grief and bereavement sector would benefit from the development of a stronger leadership capability including consolidation of current leadership-related functions.**

Information and Community Education

The need for a continuum of information and education strategies ranging from raising public awareness to the provision of professional training and development was understood by the majority of participants. In its relatively short history, the sector has developed some good quality information and community education initiatives related to loss, grief and bereavement.

There were mixed views amongst external stakeholders regarding perceived duplication or overlap between the information and community education initiatives, particularly between NALAG and CGE. Some felt that the approaches were complementary in that they addressed different parts of the same continuum. However, most felt that the impact of current community education and development initiatives are compromised as current strategies lacked reach, systematic development and application. The current approach was also seen by some as inefficient and a poor use of available resources. This was particularly important against a background of relatively low levels of understanding about grief and bereavement in the community and limited resources within the sector.

Many participants saw value in the centralised development of core information and community education material that could be adapted and applied in local contexts. It was felt that such an approach would achieve higher community profile and greater effect. Some participants linked this approach to the development of quality standards for the sector and saw more systematic approaches to community information and education as best practice.

There is an argument to position information and community education initiatives for grief and bereavement within the Primary Care Partnerships strategy, particularly in relation to Community Health Plans. Community Health Services would provide an appropriate platform for the delivery of an integrated information and community eduction strategy. Within this context, the role of specialist grief and bereavement services would be to resource community health services around the development and delivery of information and education strategies.

In Summary:

- **The community would benefit from the development of a stronger, more integrated information and community education strategy in relation to grief and bereavement.**
- **There are benefits in positioning grief and bereavement information and community education upon the community health platform, with planning, expert resourcing and support provided by the specialist services.**

Professional Development

Professional development needs range from base level information and training for generalist health, welfare and educational professionals, to tertiary level training for specialist grief and bereavement practitioners.

As the majority of bereaved individuals do not require clinical interventions, most will not come in contact with a specialist grief and bereavement service. Therefore, participants argued strongly that information and training for frontline generalist health, welfare and education professionals should be strengthened. There was a general view that the level of contemporary understanding about grief and bereavement, and approaches to support, are not well developed amongst this group. In part, this is due to inadequate graduate level training for health, welfare and education professionals, but there is also a need to enhance in-service training and information provision to this group.

An argument was put by many of the external stakeholders and some of the funded agencies that the current information and education strategies targeted at professionals need to be refocused. There is an argument that the sector would benefit from an increased emphasis on base level information and training for general health and welfare practitioners. It was seen that frontline generalist professionals usually require:

- A contemporary base level understanding of grief and bereavement and approaches to support.
- Skills in identifying individuals who may be at risk of complex grief and who require clinical intervention.
- Access to updated service information for the purpose of referral.
- Flexible and timely training and information.

It was felt that many generalist professionals require timely, easily accessible information and training. Some argued that increased use of web-based resources (eg a highly visible web site specifically designed for generalist professionals) would increase generalist capacity in grief and bereavement.

There was general agreement amongst participants in the review and from the literature that specialist skills and knowledge are required for the delivery of specialist grief and bereavement interventions – most particularly in relation to complex grief. The general opinion is that the provision of grief and bereavement interventions by persons with inadequate skills and competencies can be detrimental. The evidence suggests that poorly targeted specialist interventions (i.e. those targeted at adults who are not experiencing complex grief) cannot be regarded as beneficial and may in fact cause damage (Neimeyer, 2000, Schut et al, 2001).

Many participants felt that the needs of professionals practicing in grief and bereavement were generally well catered for by the current CGE and (to some extent) NALAG programs, particularly in metropolitan areas. The current training program conducted by CGE is seen as high quality and includes one-day workshops through to certificate and graduate level training.

However, several stakeholders in rural regions believed that access to training and education was a problem and there were concerns related to the cost of CGE programs. Some argued that there is a need for more flexible and tailored approaches to professional development. This might include, for example, access to grief and bereavement specialists who could support the training needs of organisations as they arise, rather than the organisation fitting a predetermined training agenda.

In Summary:

- **Information and training for frontline generalist health, welfare and education professionals on grief and bereavement requires strengthening in the context of a coordinated statewide strategy.**

- More flexible models of training and professional support are required for professionals practicing in grief and bereavement, particularly in rural regions.

Capacity Building

The majority of bereaved persons manage grief and bereavement with the support of natural helpers such as family, friends and community groups. As loss occurs within a social context there is a fundamental need for a supportive community to enable individuals to manage loss, grief and bereavement effectively. Some of the literature supports an increased focus by service providers on assisting the natural helpers of bereaved persons as an effective intervention strategy (Hansson and Stoebe, 2003).

There was almost universal agreement that community capacity building was an important strategic objective for the sector. However the current fragmentation of the sector is likely to impede effective strategic engagement in capacity building initiatives.

Most participants did not see the grief and bereavement sector as large enough to develop comprehensive community awareness building initiatives in its own right. Rather, a more appropriate approach would centre on strategic partnering through participation in existing and new community strengthening initiatives. The evidence related to risk and resilience factors in grief and bereavement would suggest that the most disadvantaged communities should be the primary target for such activities.

Many external stakeholders commented on the contribution that volunteers make to the sector through the provision of volunteer based support models (for example the Compassionate Friends program). The use of volunteer models was seen as a contributing factor in strengthening community capacity in relation to grief and bereavement.

In Summary:

- **There is a role for the grief and bereavement sector to participate in community capacity building initiatives designed to strengthen local supports most particularly in disadvantaged communities.**
- **An increased focus on volunteer based supports may enhance capacity building initiatives.**

Quality Assurance and Practitioner Regulation

There is general agreement that a system of quality control is required in relation to specialist grief and bereavement interventions. This is particularly true as there is anecdotal local evidence to suggest that practitioners with insufficient skill and competency can provide potentially harmful interventions.

Many participants supported the development of a set of service/practice standards specifically for the broader grief and bereavement sector. It was noted that a number of relevant related standards exist (particularly within the palliative care sector) that could be easily adapted for this purpose. A set of practice standards would underpin future sector development and be particularly useful in supporting universal services build grief and bereavement support capacity. The development of a set of standards for the sector was also seen as an important leadership function.

The majority of participants believed that some form of quality control for practitioners was important. However, many participants raised a number of issues in relation to the current NALAG practitioner accreditation program. The main criticism was that the system is not competency based and many believe that the criteria for accreditation are not sufficiently defined. There is also a view that the bar for accreditation has been set too low. Some concerns were raised about delays in the administrative process related to accreditation and the cost associated with maintaining accreditation. Some saw the current system as out of step with similar models overseas, for example the Association for Death Education and Counselling, which certifies rather than accredits and has an examination of competency and more rigorous expectations of supervised practice.

Other participants, most notably from universal services, cautioned against 'over specialisation'. It was argued that too much emphasis on grief and bereavement accreditation could inadvertently disempower generalist professionals such as counsellors in community health services and that the core quality focus should be on sound generalist clinical skills.

Some participants questioned the sector's capacity to viably sustain a stand-alone grief and bereavement practitioner quality assurance mechanism in the longer term. It was suggested that approaches should be explored in conjunction with the Psychotherapists and Counsellors Federation of Australia (PACFA), particularly in light of recent work around the development of best practice self-regulatory models for psychotherapy and counselling. In addition, the costs of grief and bereavement practitioner regulation and accreditation should be funded from member contributions in line with systems for other professional groups such as psychologists and social workers.

In Summary:

- **There is scope to develop a set of practice standards for grief and bereavement services particularly in relation to clinical interventions.**

- **The quality of clinical practice could be improved by moving towards a competency-based approach to practitioner quality control.**
- **Practitioners delivering grief and bereavement interventions require sound generalist clinical skills together with specialist grief and bereavement skills/ knowledge.**
- **Practitioner accreditation or regulation processes should be self-funded in line with other professional regulation systems.**

Grief and Bereavement Interventions

There is a clear understanding within the sector that the majority of people do not require access to specialist grief and bereavement interventions. This understanding and orientation is a significant strength of the sector.

Clinical interventions, such as bereavement counselling, were universally seen as a necessary part of an integrated service response for bereaved persons. There was little question that their existence within the service system is justified. The research literature indicates that the need for clinical interventions is correlated with risk and resilience factors. For example, Jordan and Niemeyer (2003) describe the following as high-risk groups:

- Men who lose spouses (particularly older and isolated males).
- Mothers who lose children.
- Survivors of sudden and/or violent traumatising losses (eg suicide, terrorist attacks, warfare, homicide and accidental death).
- Individuals with psychiatric problems (eg depression, substance abuse, post-traumatic stress and psychotic disorders, low self esteem/coping self-efficacy, high levels of dependency on the deceased and abuse/ trauma histories).
- Individuals manifesting high distress grief (eg depressive, anxiety or rumination symptoms) or who meet diagnostic criteria for complicated grief early in their bereavement experience.

The research also suggests (Schut et al, 2001) that the more complicated the grief process appears to be, or becomes, the better the chances of intervention leading to positive results. These findings underpin an understanding that exists within the sector that clinical interventions should be carefully targeted at high-risk groups, that is, individuals with complex grief. It was thought that more systematic screening processes could be developed to assist in the identification and referral of clients in high-risk groups.

There is evidence that men and people from CALD and indigenous backgrounds are under-represented within the current service system. Men are less likely to seek intervention in the traditional forms such as counselling and support groups. Some men may be more open to alternative activity based approaches or approaches that are provided in non-clinical settings such as workplaces. Some participants expressed the view that the current system places too much emphasis on clinical interventions and that other intervention strategies such as self help groups or social support groups should be expanded. This might be particularly relevant where cultural factors impact on the engagement in traditional service models.

There is scope to increase and support the development of community and volunteer based models of grief and bereavement support and explore new alternative models for under-represented groups. For example, in DHS' Hume Region the introduction of volunteer based Bereavement Support Teams in Palliative Care was correlated with a reduction in demand for clinical services. Further work is needed to explore the impact of lower level volunteer based models on the demand for clinical level interventions.

The majority of participants supported the existence of a telephone support capability for grief and bereavement. However, there appears to be a degree of confusion around the roles and overlap in the provision of telephone support and information services. Current services include: Lifeline, Care Ring – Suicide Help Line, Grief Line and the NALAG telephone information and referral service. Many participants felt that the primary focus of specific grief and bereavement telephone support should be around information and referral.

In summary:

- **Most people can function effectively after bereavement utilizing their natural social supports and possibly some low-level interventions. However, for approximately five to 10 per cent of bereaved people experiencing complex grief there is a need for clinical grief and bereavement interventions.**
- **Clinical interventions are required as part of an integrated response to grief and bereavement in the community. The greatest benefit to be gained from clinical interventions is when they are of high quality and are carefully targeted at high-risk groups.**
- **There is scope to develop more systematic screening strategies for use by health professionals to assist with the identification and referral of persons experiencing complex grief.**
- **Future service development should focus on enhancing social and volunteer models of bereavement support as well as clinical interventions.**

- **There is a need to further explore the development of alternative modes of service including the provision of information for groups that are under-represented eg men and people from CALD and indigenous backgrounds.**

Research

It is worth noting Neimeyer and Hogan's observation that "although the human experience of bereavement has been studied, it has not been studied well" (2001:111) and that the growth in bereavement studies, which could have laid a good foundation for grief interventions, has not done so. There needs to be more research in relation to bereavement interventions and their efficacy more generally. However, in addition to learning from international studies, research from or on Australian experiences should be considered an important adjunct to the development of the local grief and bereavement sector. There is a need for agencies delivering grief and bereavement interventions to consider collecting a wider data set including objective measures of wellbeing and general function. Many participants believed that specialist grief and bereavement services could play a role in supporting local research efforts, particularly in relation to intervention outcomes. However, most saw tertiary institutions as the most appropriate organisations to be conducting local research.

In Summary:

- **In addition to learning from international studies, there would be value in establishing a local evidence base for grief and bereavement services, most particularly in relation to the outcomes achieved through intervention, professional development, community strengthening and educational initiatives.**
- **Stronger sector leadership may encourage the development of coordinated research efforts across the tertiary education sector.**

Summary of Optimal Service System Elements

There is little research evidence to inform the nature of an optimal service system, however, relevant evidence and opinion appears to support the existence of a specialised grief and bereavement component within the broader service system. In summary, features of an effective service system would include:

- Integrated planning.
- A viable sector leadership structure.
- Highly visible and accessible information, referral and access points.
- Accessible locally based services, including clinical services.
- Coordinated community education and community building strategies.
- Quality standards for service delivery.
- Regulation of clinical practice.
- Coordinated information and training strategies for both generalist and specialist practitioners.
- Secondary consultation and flexible support for practitioners in the delivery of grief and bereavement interventions particularly in rural and regional areas.
- Local research with a focus on the efficacy of interventions.

4.3 Service Demand and Access

There was a general view that there are large service gaps particularly in rural areas and that the sector was significantly under resourced. Many participants noted that the system could not meet the demand for clinical services and that in many areas specialist services were not available at all. Most participants noted that the timing of service provision is particularly important and that long waiting periods for access to services were seen as very undesirable. Anecdotally, the needs of particular groups such as men, people from CALD and indigenous backgrounds and people with disabilities are not well catered for.

The issue of estimating the underlying demand for clinical intervention in Victoria is problematic. The research indicates that the need for clinical intervention is correlated with risk and resilience factors and between five and 10 percent of bereaved persons may require some form of clinical intervention. Some of the agencies suggested that this figure might be as high as 20 percent. It is also generally accepted that approximately eight to 10 family members are directly affected as a result of a single death.

There are over 32,000 registered deaths in Victoria each year (ABS, 2000), hence up to 320,000 people in Victoria are potentially impacted upon by the death of an individual related to them each year. When other people such as friends and work colleagues are included, the number would be much greater.

It is difficult to estimate with any degree of certainty how many people directly impacted upon as a result of a death require specialist interventions. Using the most conservative estimate, based on each death impacting on eight significant individuals and with five percent of these individuals requiring specialist intervention, approximately 13,000 people would require such services in Victoria each year. In the most recent reporting period (2002/03) CGE, CBS and MWGS together provided individual or group based counselling services to approximately 800 people.

In the absence of reliable data on clinical grief and bereavement interventions delivered outside the four agencies, it is difficult to estimate with any degree of confidence the level of unmet demand for clinical grief and bereavement interventions. The specialist services provided by the four agencies are predominantly accessed by persons living in relative proximity to the service. Clients generally see travelling long distances as a significant disincentive.

It is clear that the majority of people requiring clinical intervention are either not accessing services or are accessing services from sources other than the four services under review. This would include services provided through private practitioners, funeral services, community based palliative care, community health services, issue specific services and various community groups. Anecdotally, a high level of unmet demand exists particularly in rural and regional areas. Some generalist services such as community health services report waiting lists for counselling services of several months.

In Summary:

- **Further research is required to determine the amount and scope of specialist grief and bereavement interventions provided across the full range of public and private sector providers.**
- **Future service development, including information provision, community education and clinical interventions will need to be broadened in scope and reach to maximise engagement with under-represented groups.**
- **Anecdotally, there is a high level of unmet demand for grief and bereavement interventions particularly in rural Victoria.**
- **The demand for specialist grief and bereavement interventions cannot be met with the existing specialist grief and bereavement resource base.**

4.4 Service System Structure – Roles of Specialist and Universal Services[2]

There is little research evidence to inform optimal service system structure in relation to the roles of specialist and universal services. The capacity of the four grief and bereavement agencies is very limited in relation to the potential level of demand. This is particularly true in relation to clinical services and to a degree for information and education functions.

A number of factors inform the optimal positioning of universal and specialist services. Firstly, the four specialist services have very limited resources in relation to the potential service demand. Secondly, most relevant policy approaches at state and federal levels include a focus upon strengthening the primary care platform, developing community and government partnerships and building community capacity. Core themes include:

- A focus on prevention and early intervention.
- A focus on quality and outcomes for clients and communities.
- Improving local access, care coordination and strengthening relationships with and between local services.
- Strategies to manage increasing demand for health and welfare services.
- A focus on accountability and fairness in the application of limited public funds.

Resource issues and the broader policy context suggest that the core focus of specialist grief and bereavement services should be on capacity building. In particular, the focus should be upon strengthening, building and supporting local capacity to provide grief and bereavement services. This would include support to primary service platforms such as acute health, community health and welfare and education services.

There are a number of potential approaches to strengthening locally based grief and bereavement responses including strengthening the capacity of community health services and broadening the focus of community based palliative care services (both of which already provide some grief and bereavement supports). Community Health Services were seen as a central community based information source and contact point for a range of other services to meet a broad range of needs apart from grief and bereavement. The community based nature and broader focus of community health may be more likely than community based palliative care services to link people with complementary community supports. In addition, the health promotion focus of community health was seen to be a logical platform for the delivery of health promotion and early intervention initiatives in relation to grief and bereavement.

DHS has identified and is positioning community health services as the major publicly funded provider of counselling and local health promotion programs. Strengthening community health service capacity in grief and bereavement has the potential to address issues of inequality and disadvantage, improve access and assist in the local delivery of services. However, many community health services reported pressure on resources (including

[2] The term 'universal services' refers to those services that are available to the general community such as community health services, general practitioners, hospitals, schools, etc.

staff and facilities) and relatively long waiting times for counselling services.

Stakeholders identified the following practical supports that would be needed to build local community based grief and bereavement support capacity:

- Access to up-to-date information on grief and bereavement.
- Access to customised, local professional training and development activities.
- Access to secondary consultation and mentoring in relation to clinical services, for example co-joint casework, visiting and telephone support by grief and bereavement specialists.
- Local peer support networks for involved professionals.
- Support with the development of community information and awareness initiatives such as access to publicity and education material.

Some participants argued for closer integration of bereavement services and issue specific services such as trauma recovery strategies. Access to specialist traumatic bereavement support within regional Victoria is limited. The current strategy of DHS' State Emergency Recovery Unit is to normalise reactions to traumatic events and to encourage the use of local support networks. Past approaches to managing traumatic events may have lead to a 'de-normalising' of responses and an over-reliance on specialised interventions. There is a potential educative role for the specialist services in fostering contemporary understanding of responses to traumatic death within local networks.

In Summary:

- **The primary role of specialist grief and bereavement services in a service system should be upon enhancing the capacity of universal community services to support grief and bereavement needs. This could include a function to support universal services in the provision of clinical grief and bereavement interventions.**
- **There is an argument to centre the future development of local grief and bereavement support on the community health platform.**

4.5 Strengths, Weaknesses and Opportunities for the Four Funded Agencies

Each of the agencies within the review identified their key strengths weaknesses, challenges and opportunities in the context of considering the potential future development of the sector. The profile of each agency was quite unique – this may reflect the fact that each agency has developed in a context that has allowed them to determine their own broad priorities and directions. Common strengths included:

- Developed out of community need.
- Skilled and committed staff and volunteers.
- An understanding of the need to normalise grief.

Common weaknesses and challenges included:

- Lack of directional policy context.
- Financial viability.

Common opportunities included:

- Strengthening linkages and partnerships with the broader community services sector.
- Increased collaboration amongst the specialist services.

Each of the four agencies reported some operating issues associated with the delivery of services. In particular, several reported financial difficulties and were either reducing operations to balance budgets or providing subsidies from other sources to support ongoing operations. A summary of the key operating and infrastructure issues for each agency can be found at Appendix 4.

Potential Synergies and Future Roles

A strong feature of the sector is a very high level of commitment and passion for the work that is undertaken to support Victorians with loss, grief and bereavement. There is almost universal recognition that the sector can be improved within the limited resources available and a general willingness to collaborate to examine the best way to support the community.

In summary:

- **There is a general level of commitment and good will to work towards improving the provision of grief and bereavement services for the community.**
- **There is strong support, within the four agencies and particularly amongst the external stakeholders, to create a viable sector leadership capacity. There is scope to do this within existing resources.**
- **There is potential to improve the current reach and scope of information, community education and professional training activities through more strategic and integrated approaches.**
- **There is scope for closer collaboration between the agencies, in particular between CGE and NALAG, to improve sustainability through more efficient use of finances and infrastructure.**
- **Broader accessibility to grief and bereavement interventions could be achieved through a stronger focus by specialist grief and bereavement services on supporting universal services to develop a grief and bereavement support capability.**

5 Proposed Service System Framework

A draft Service System Framework for the future development of grief and bereavement services was developed through the Leadership Group process. In developing the draft framework the Leadership Group considered the following:

- The key issues identified in the Issues Paper (as outlined in Section 4 of this report).
- The available resources of the specialist grief and bereavement sector.
- The relevant policy context and direction.

Feedback on the draft Service System Framework was sought from:

- On an individual basis, the four agencies in the review.
- External stakeholders (as listed at Appendix 3, via a Forum and through individual feedback).
- The project Working Party.

A final draft of the Service System Framework was prepared incorporating feedback from the consultations.

The review then prioritised elements of the Service System Framework according to the following criteria:

High priority

Service System Framework elements that should be considered for inclusion as a core activity within the current resource base.

Medium priority

Service System Framework elements that should be considered for inclusion as an activity in the current resource base, but at relatively low resource levels or for consideration in future years.

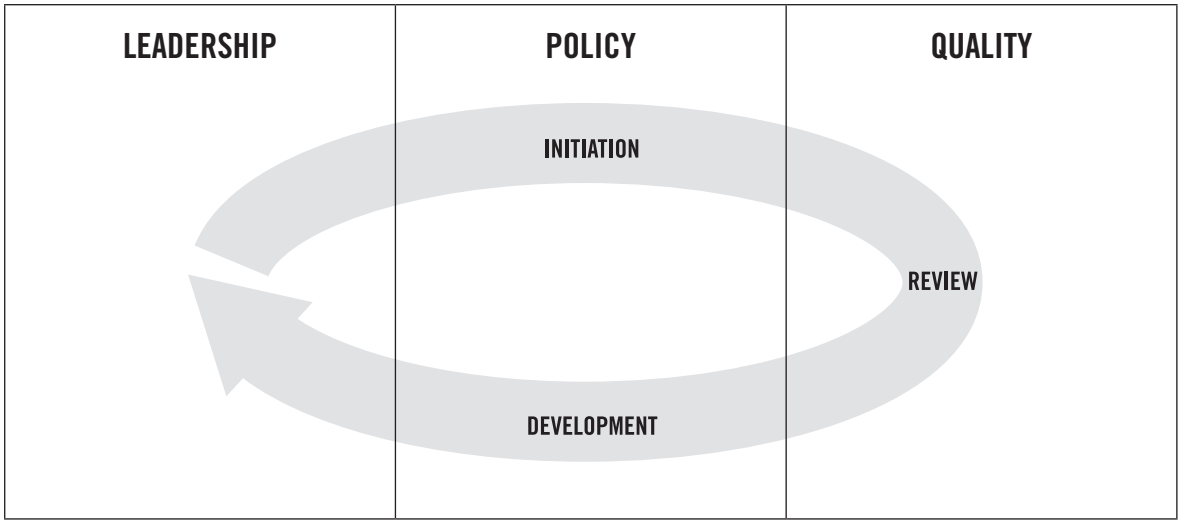
Low priority

Service System Framework elements to be considered for inclusion at the planning level but to be resourced from outside the current funding base.

The proposed Service System Framework is provided in the following section and is structured in two parts.

- Part 1 relates to leadership, policy and quality.
- Part 2 relates to service delivery.

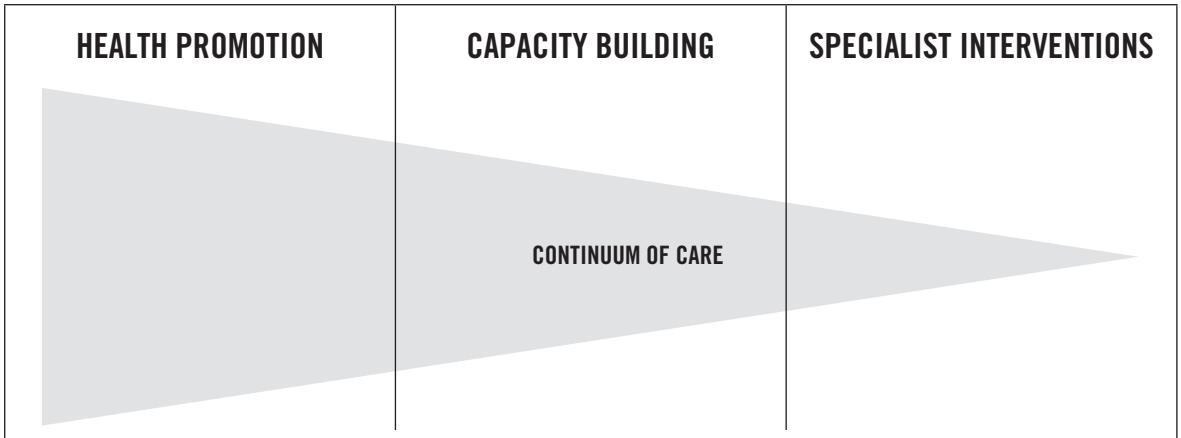
5.1 Proposed Grief & Bereavement Service System Framework – Part 1



Leadership – Aims and Objectives	Policy – Aims and Objectives	Quality – Aims and Objectives
■ To provide identity, focus and momentum for the development of future focused grief and bereavement services and responses by taking a lead role in: – Developing strategic partnerships between government departments, community and relevant organisations that will enhance the strategic development of grief and bereavement services and responses. – Advocating on behalf of issues in relation to grief and bereavement to raise community and government awareness and understanding. – Leading the debate about future service responses and service system development. – Influencing and harnessing key stakeholder support for the future directions of grief and bereavement services and responses.	■ To provide clear direction and context for the future development of grief and bereavement services and responses. ■ To integrate the future development of grief and bereavement services and responses with relevant government initiatives and policy directions. ■ To support the integrated development of a diverse range of grief and bereavement services and responses. ■ To obtain maximum value from the available public resources directed to grief and bereavement services and responses.	■ To ensure that interventions, services and strategies in relation to grief and bereavement are: – Of the highest possible quality. – Grounded in a contemporary evidence base. – Responsive to consumer needs. ■ To foster the development of a research/evidence based culture within the provision of grief and bereavement services and responses. ■ To identify the current scope of service response to grief and bereavement and community needs in relation to grief and bereavement across Victoria.

Leadership – Strategies	Policy – Strategies	Quality – Strategies
■ In partnership with DHS and the sector develop a shared vision, mission, values and principles statement for the grief and bereavement sector that will underpin future directions. **(High Priority)** ■ Develop and maintain a strategic partnership with DHS to support future service system development. **(High Priority)** ■ Develop and implement systematic strategies for the inclusion and ongoing engagement of the sector and service users in relation to: – Policy and directions development. – Advocacy on grief and bereavement issues. **(Medium Priority)** ■ Provide advocacy and representation of the issues in relation to grief and bereavement to: – Raise community awareness. – Inform public policy development. – Support the mainstreaming of grief and bereavement services. **(Medium Priority)** ■ Develop strategies to influence and engage key stakeholders to achieve stakeholder support and commitment to new policy and directions. **(Medium Priority)**	■ Led by DHS and in partnership with the sector generally, develop and promote a statewide grief and bereavement policy direction that supports the ongoing implementation of the Service System Framework including: – Development of grief and bereavement. capacity within the universal service platform. – Strategic development of specialist grief and bereavement services. – Development of a diverse range of service responses to grief and bereavement. – Development of linkages with related department and government initiatives. – Development of peak demand response strategies and integration with related areas such as emergency recovery. – Equitable distribution of available resources. – Best value. – Increased service accessibility. – Defined pathways, referral and entry processes. **(High Priority)**	■ Building on existing work and in partnership with DHS and the sector, develop and periodically review a set of Quality Standards for application in the delivery of grief & bereavement services including: – Health Promotion and Community Education activities. – Capacity building. – Specialist interventions including practitioner competency. – Volunteer supports. **(High Priority)** ■ In partnership with the grief and bereavement, community and tertiary sectors, encourage the ongoing development of a local evidence base focused upon the effectiveness and quality of services and strategies. **(Low Priority)** ■ Capture and disseminate relevant findings from international research. **(Medium Priority)** ■ In partnership with DHS and the sector, and in consultation with service users, conduct periodical evaluations of the service system framework to inform ongoing development. **(Low Priority)** ■ Investigate options for involving consumers of grief and bereavement services in development of grief and bereavement strategies. **(Medium Priority)** ***Undertake the following projects*** 1. Map the current scope of grief and bereavement service delivery and community need across all sectors. **(Low Priority)** 2. Develop systematic targeting/ screening processes that can be applied across the state to identify people who may require targeted specialist interventions. **(Medium Priority)** 3. Undertake a local research project to determine risk factors associated with adverse outcomes of grief and bereavement. **(Low Priority)**

5.2 Proposed Grief & Bereavement Service System Framework – Part 2



The continuum of care wedge represents the relationship between the Service System Framework and the needs of the population. Most people will use their natural social supports; hence increasing community understanding and capacity will strengthen the resilience of the community in dealing with grief and bereavement. Supporting the universal service platform will improve service access and provide local service responses. A small percentage of people in high-risk categories may require specialist grief and bereavement interventions.

Health Promotion – Aims & Objectives	**Capacity Building – Aims & Objectives**	**Specialist Interventions – Aims & Objectives**
■ To strengthen the resilience of the community and the capacity of individuals in dealing with grief and bereavement by: – Increasing community understanding about grief and bereavement. – Normalizing individual and community responses to grief and bereavement. – Building community capacity to support individuals affected by grief and bereavement.	■ To build the capacity of universal services to provide grief and bereavement supports and responses by: – Supporting the mainstreaming of grief and bereavement supports within the universal service sector – in particular Community Health. – Increasing understanding of grief and bereavement and contemporary intervention/ support approaches within the universal service sector. – Increasing the capacity and competency of generalist professionals in providing grief and bereavement supports and interventions. ■ To foster the development and integration of a diverse range of support responses to grief and bereavement by: – Promoting collaboration and partnership between the voluntary and other specialist grief and bereavement services in ongoing service and service system development. – Increasing the connectedness of the grief and bereavement sector through the support and development of sector networks.	■ Improve the health and well-being outcomes for individuals or groups of individuals who are at most risk of developing significant adverse responses or outcomes as the result of complex grief and bereavement. ■ Develop and maintain a specialist grief and bereavement intervention expertise base and capability that has as its primary functions: – To support and resource the ongoing development of the capacity of universal and other services in the delivery of grief and bereavement interventions. – The direct delivery of specialist grief and bereavement interventions to individuals who require such interventions.

Health Promotion – Strategies	Capacity Building – Strategies	Specialist Interventions – Strategies
Information and Community Education ■ Develop and systematically disseminate current evidence based information on grief and bereavement that can be used in a wide range of health promotion and community education applications by services and/ or as part of existing health promotion activities or initiatives. **(High Priority)** ■ Provide strategic advice and expertise in the development and implementation of broader health promotion strategies and initiatives in relation to grief and bereavement. **(Medium Priority)** ■ Develop targeted grief and bereavement community education strategies/material that can be integrated with existing health/ community education strategies, targeting the general community and other specific groups such as CALD communities, Indigenous communities and rural communities. **(High Priority)** ■ Develop a media and promotional strategy that can be used to: – Support and resource local promotional and media activities. – Provide expert comment in response to significant events. – Raise general awareness about grief and bereavement. **(Medium Priority)** ***Participation in Community Capacity Building Initiatives*** ■ Provide strategic input and engagement with relevant existing community capacity building strategies and initiatives, for example: – Neighbourhood Renewal. – Stronger Families Stronger Communities. **(Medium Priority)**	***Information*** ■ Develop coordinated and targeted information development and dissemination strategies targeted at health professionals (that provides timely, readily accessible and highly usable information), through development or enhancement of resources such as: – A practitioner focused website. – Practice guidelines. – Fact sheets. – Journal. **(High Priority)** ■ Develop strategies for systematic information exchange between the specialist grief and bereavement sector and universal and other grief and bereavement services. **(Medium Priority)** ■ Develop strategies for facilitating public and professional access to grief and bereavement information and appropriate services including: – Supporting the development of local information and referral capacity of universal services. – Responding to general information and referral requests from the general public and professionals. **(Medium Priority)** ***Strategic Alliances and Networks*** ■ Develop strategic partnerships, alliances and networks with voluntary/mutual support grief and bereavement organisations and other specialist organisations with a view to encouraging diverse but integrated responses to grief and bereavement, for example: – Carers Victoria. – Lifeline. – Compassionate Friends. – Crisis Support Service. **(High Priority)** ■ Develop strategic partnerships, alliances and networks and/or participate in relevant forums and initiatives with a view to influencing related service system developments regarding grief and bereavement, for example:	***Specialist Interventions*** ■ Provide targeted direct specialist interventions to individuals at risk of developing significant negative health and well-being outcomes. Although access would be needs based, in general it is expected that this group may include, for example: – Suicide bereaved. – Children. – Sudden and traumatic death. – Younger bereaved partners. – Parents. The direct services provided would include: – Individual counselling. – Group programs/counselling. – Family Counselling. Specialist services would be open to access by clients in any part of the State. **(High Priority)** ***Research and Development*** ■ In partnership with the tertiary education sector develop an independent review and evaluation strategy for specialist interventions designed to: – Evaluate the outcomes for clients receiving specialist intervention in order to determine the effectiveness of interventions. – Inform the future development of specialist interventions. **(Low Priority)**

Health Promotion – Strategies	Capacity Building – Strategies	Specialist Interventions – Strategies
	– Primary Care Partnerships. – Community Health Plans. – Primary Mental Health Teams. **(Medium Priority)** ***Education and Training*** ■ Develop and systematically deliver flexible, evidence based education and training programs with the primary purpose of building grief and bereavement capacity within the universal service sector, targeted at: – Counsellors/practitioners in community health services. **(High Priority)** – Primary Mental Health Teams. **(High Priority)** – Other generalist health, welfare and education practitioners such as nurses, GPs, social workers, etc. **(High Priority)** – Volunteers in grief and bereavement support programs. **(Medium Priority)** – Specialist grief and bereavement practitioners. **(Low Priority)** ***Secondary Consultation*** ■ Develop and provide secondary consultation services to practitioners in universal and other services with a particular focus upon Community Health Services by: – Providing phone consultation, support and advice regarding individual cases. – Providing limited face-to-face consultation/support and advice regarding individual cases and or group programs. – Providing advice, support and mentoring to local counsellor/ professional networks. – Providing advice and information to assist practitioners in universal services to refer clients to other services if appropriate. **(High Priority)** ***Research and Development*** ■ Provide consultation, support and advice to organisations in the development of local grief and bereavement support programs. **(Medium Priority)**	

6 Options for the Future Structure of Grief and Bereavement Agencies

The Leadership Group considered how the four agencies might respond to the Service System Framework including options for the future structure of the agencies. It should be noted that the group's willingness and openness to consider the 'bigger picture' issues and preparedness, in the main, to set aside individual agency issues enabled this discussion to occur.

The group canvassed four main structural options that might support the Service System Framework as follows:

1. A **strategic alliance** of the existing agencies with agreement to jointly deliver elements of the Service System Framework.
2. The formation of a **new entity** through the modification of the CGE constitution and structure to deliver elements of the Service System Framework.
3. The **separation of 'leadership' and 'service delivery'**, that is a separation of the functions described in the Service System Framework parts one and two.
4. **Bundling and competitive tendering** of the current grief and bereavement funding based on specifications developed from the Service System Framework.

The Leadership Group did not reach consensus on a preferred structural option. However, three of the four participating agencies (CGE, CBS and MWGS) indicated in principle support for Option 2. This option was initially proposed by the Centre for Grief Education with the endorsement of its Board of Management. The four options are described in detail in the following section with an analysis of the advantages and disadvantages of each and critical success factors.

6.1 OPTION 1 – Alliance

An alliance model would be established by formalising the relationship and involvement of the four organisations to deliver services and activities in accordance with the Service System Framework. All agencies would remain separate legal identities, however:

- An instrument such as a Memorandum of Understanding (MoU) would be put in place and 'signed off' by each of the four agencies to reflect the partnership approach to delivering services in accordance with the Service System Framework. This would include:
  - A governance level commitment to the Service System Framework.
  - Agreed roles and responsibilities of the alliance partners.
  - Agreed review and evaluation processes.
  - Agreed dispute resolution processes.
- This model could involve:
  - Consolidation of DHS funding into one Funding and Service Agreement (FSA) tied to the Service System Framework and the identification of a lead agency to hold the FSA; or
  - Four separate Funding and Service Agreements tied to the Service System Framework.
- Delivery of the activities and services elements of the Service System Framework would be divided up, either brokered (in the case of a lead agency arrangement) or otherwise agreed in the MoU.

Option 1 – Key Advantages	Option 1 – Key Disadvantages
■ The dynamic interaction/partnership between agencies can potentially add value to a developing sector whereby the sum may be greater than the parts. ■ Capacity for the alliance/partnership to expand to include new or existing grief and bereavement or universal organisations. ■ Each partner has a clear focus on the delivery of certain service elements in accordance with the Service System Framework as defined in the MoU. ■ Simplified contract management, administration and accountability in the lead agency model for the lead agency and DHS.	■ The Service System Framework is vulnerable to shifts in strategic direction or priorities of individual agencies. ■ The required investment in the partnership and joint planning activities (to ensure the integrity of the Service System Framework) would be significant in relation to the size of the funding base. ■ Increased complexity of management and reporting arrangements at the agency level in the lead agency model, as subcontracts need to be developed and managed. ■ Limited scope for savings or efficiency gains over current infrastructure costs unless co-location arrangements were considered. ■ Potentially higher infrastructure costs. ■ The logical division of tasks/activities within the Service System Framework may not easily align with the current resource distribution of the four agencies. ■ Current financial and operating weaknesses of some agencies are not addressed.

Option 1 – Critical Success Factors
DHS funding is tied to identified Service System Framework elements with clear outcomes and performance measures. ■ A robust and binding governance level commitment is put in place and regularly reviewed. ■ Sufficient time and resources are devoted on an ongoing basis to the maintenance of the partnership and coordinated service delivery. ■ There is a willingness of agencies to shift their current focus (and possibly some funding if agencies continue to be funded individually) to align with the Service System Framework.

6.2 OPTION 2 – New entity

A new entity would be created by modifying and building on the structure of the Centre for Grief Education (CGE) to deliver services and activities in accordance with the Service System Framework. This would involve:

- Developing a new name and identity.
- Developing a new vision and mission for the organisation that is consistent with the new Service System Framework.
- Developing a new constitution, or revising of the current CGE constitution, that would provide for membership on the new Board of Management to be formed from representatives of the governance bodies of the current organisations. Options for this would include:
  - Equal numbers from each of the four organisations.
  - Weighted numbers to reflect current size and scope of the contributing organisations.
  - Identifying the skill set required on the Board of Management and selecting members from the current governance bodies who may bring these skills to the new organisation.
- Membership arrangements for the new Board of Management would be transitional, for say two years, then the Board of Management would be elected by the members of the new organisation in accordance with normal constitutional processes.
- Members of the existing organisations would automatically become members of the new organisation.
- A transitional/implementation group would be established (representing the four organisations) to oversee the transitionary process.
- Key staff positions for the new organisation, such as the Executive Officer, could be declared open and applications sought from existing staff or externally.

Option 2 – Key Advantages	Option 2 – Key Disadvantages
■ Improved long-tem viability and sustainability through the amalgamation of the funding base and agency structures. ■ Helps to address the current viability issues of the smaller agencies. ■ Reduces the risks associated with smaller and less robust governance arrangements. ■ Improved viability of the specialist grief and bereavement workforce through enhanced professional development, support and supervision functions. ■ Potential infrastructure savings and efficiencies through the amalgamation of sites and functions eg management, administration and accommodation costs. ■ Protects the integrity of the Service System Framework by having a single governance entity and strategic plan. ■ Potential to create a stronger public identity and profile including increased capacity to generate alternative revenue. ■ Increased capacity to harness and encourage the engagement of the tertiary education sector for research and evaluation. ■ Stronger governance, accountability and management structures as a result of increased size.	■ Potential for the loss of the current additional financial/in kind contributions by the agencies, in particular CBS and MWGS. ■ Potential to increase infrastructure cost through loss of engagement and support of CBS and MWGS ■ Initial establishment and restructure costs. ■ Potential for conflict of interest between service delivery and leadership functions – although not considered a significant issue. ■ Loss of diversity of approaches could lose touch with particular issues/areas. ■ Potential risk in losing the support base/membership of the current agencies. ■ The complexity and time involved in the process of achieving a new legal entity could distract from service delivery.

Option 2 – Critical Success Factors
■ Majority support from the four agencies. ■ DHS funding is tied to identified Service System Framework elements with clear outcomes and performance measures. ■ Adopting an inclusive and consultative approach with staff, agency members, stakeholders and the broader sector. ■ A positive communication strategy to sell the advantages of the new arrangements. ■ Additional 'one off' resources to support the transition.

6.3 OPTION 3 – Separation of Leadership and Service Delivery

This option involves a structural separation of leadership from service delivery functions. Within this primary parameter a number of structural options are available:

- A separate agency (one of the existing four) would deliver Part 1 of the Service System Framework and develop the leadership role as its primary focus.
- Part 2 of the Service System Framework would be delivered by another agency or agencies.
- This model would require an agreement between the agency delivering Part 1 of the framework with the agency or agencies delivering Part 2 of the Framework to ensure that the integrity of the Service System Framework was preserved. This agreement would be similar to that used in the Alliance Option.
- Delivery of Part 2 of the Framework could be structured in a similar way to Options 2 or 3. For example:
  - Consolidation of the service elements under a single organisation; or
  - Development of an agreement between the service delivery agencies to deliver various parts. Such an agreement would need to form part of the overall agreement between the agencies involved.

Option 3 – Key Advantages	Option 3 – Key Disadvantages
■ Avoids potential conflict of interest between leadership and service functions – although this is not considered a significant issue given the strategic nature of the Service System Framework. ■ The dynamic interaction/partnership between agencies can potentially add value to a developing sector whereby the sum may be greater than the parts. ■ Capacity for the alliance/partnership to expand to include new or existing grief and bereavement or universal service organisations. ■ Each partner has a clear focus on the delivery of certain service elements in accordance with the Service System Framework as defined in the MoA or other agreement.	■ Questionable viability of the leadership function as a stand-alone agency. ■ The Service System Framework is vulnerable to shifts in strategic direction of individual agencies. ■ The required investment in the partnership and joint planning activities (to ensure the integrity of the Service System Framework) would be significant in relation to the size of the funding. ■ Limited scope for savings or efficiency gains over current infrastructure costs unless collocation arrangements were considered. ■ Potentially higher infrastructure costs. ■ The logical division of tasks/activities within the Service System Framework may not easily align with the current resource distribution of the four agencies. ■ Current financial and operating weaknesses of some agencies are not addressed. ■ Only one agency (NALAG) supported this option. If this option were selected, MWGS would be unlikely to agree to amalgamate with other services.

Option 3 – Critical Success Factors
■ DHS funding is tied to identified Service System Framework elements with clear outcomes and performance measures. ■ A robust and binding governance level agreement is put in place and regularly reviewed. ■ Sufficient time and resources devoted on an ongoing basis to the maintenance of the partnership and coordinated service delivery. ■ The roles of the agencies are clearly promoted to avoid confusion and ambiguity regarding functions – particularly leadership. ■ There is a willingness of agencies to shift their current focus (and possibly some funding) if agencies continue to be funded individually to align with the Service System Framework.

6.4 OPTION 4 – Bundling and Competitive Tendering

This option was canvassed by the Leadership Group and further considered by the review; it would involve:

- Termination of the current Funding and Service Agreements with the four agencies related to the specialist grief and bereavement services. This could be done either at the end of the current contract period (July 2006) or through the provision within current Funding and Service Agreements for contract termination without fault (requiring three months notice).
- Development of new service specifications aligned to the Service System Framework for the consolidated funding pool.
- Tendering for the new contract and funding through either an open or selective tender process.

Option 4 – Key Advantages	Option 4 – Key Disadvantages
■ Provides opportunity to reframe the current funding and outputs without the constraints of current agency and program configuration. ■ Provides an opportunity for new organisations with relevant experience to provide DHS funded specialist grief and bereavement services. ■ May be perceived as fair and open as all agencies are treated in the same way.	■ Potential for significant disruption to service delivery in particular direct client services. ■ Potential to significantly damage the current goodwill within the sector. ■ May be seen as damaging and counter productive given the relatively recent and somewhat difficult history associated with other grief and bereavement service closures and establishment.

Option 4 – Critical Success Factors
■ DHS funding is tied to identified Service System Framework elements with clear outcomes and performance measures. ■ The process is broadly accepted by the sector as an appropriate response to the current issues. ■ A communication process is developed to clearly promote the rationale and advantages of the proposed approach. ■ The existing providers are effectively engaged in planning and implementation to minimise the potential disruption to services and activities.

7 Recommendations

7.1 Service System Framework

The proposed Service System Framework provides a clear direction for the future strategic development of grief and bereavement services in Victoria. In particular, the framework emphasises:

- The key role of the universal service platform in responding to community needs in relation to grief and bereavement.
- The strategic role of the specialist services in resourcing the universal platform in this role.

The proposed Service System Framework has received broad support from the four specialist grief and bereavement agencies, the external stakeholders consulted in the review and the project Working Party.

Recommendation 1

DHS should adopt the proposed Service System Framework as the blueprint for the future development of grief and bereavement services in Victoria.

7.2 Funding Arrangements for Specialist Grief and Bereavement Services

Current DHS funding for the four specialist grief and bereavement agencies is structured into four individual Funding and Service Agreements. Currently, there is no strategic linkage of the activities and outputs of these Funding and Service Agreements. There would be significant benefit in aligning the activities, outputs and service targets in future Funding and Service Agreement/s with the Service System Framework.

Recommendation 2

Current DHS funding for the four specialist grief and bereavement services should be consolidated into a single Funding and Service Agreement.

Service activities, outputs and targets for this agreement should be aligned with the Service System Framework.

7.3 Agency Structure

The review considers that the Service System Framework would be best supported through the consolidation of the current DHS funding and that this funding should then be managed by a single organisation. This arrangement would:

- Achieve the highest level of integration between the elements of the Service System Framework and best protect the integrity of the Framework over time.
- Achieve the highest level of integration between the specialist grief and bereavement sector and the universal service sector.
- Enable the development of the strongest linkage of the specialist grief and bereavement sector to broader service system developments such as Primary Care Partnerships.
- Provide the most robust platform for the future development of grief and bereavement supports in Victoria.
- Achieve the most efficient and robust arrangements in terms of operating and infrastructure costs and functions.

- Best enable the establishment of an appropriate new service site to meet current and future operating requirements.
- Address the current viability issues of some of the agencies and improve the long-tem viability and sustainability of the specialist grief and bereavement services.
- Provide strong governance and management arrangements for specialist grief and bereavement services.
- Allow for the subcontracting of framework elements where appropriate.
- Improve risk management and reduce potential risks to the sector and to DHS.
- Improve the viability of the specialist grief and bereavement workforce through enhanced professional development, support and supervision functions.
- Create the strongest public profile for the specialist grief and bereavement sector and related issues.
- Enhance the capacity of the specialist grief and bereavement sector to generate alternative revenue.
- Increase the likelihood of successfully engaging the tertiary education sector for purposes of research and evaluation.

Recommendation 3

The optimal structural arrangements for the four specialist grief and bereavement services would be achieved through the formation of a new entity based upon the current structure of the Centre for Grief Education (as defined in Option 2).

Appendix 1 – Notes from the Literature Review

Individual Outcomes of Grief and Bereavement

The Report on Bereavement and Grief Research (2003 Centre for the Advancement of Health) is a contemporary consideration of many aspects of grief and bereavement research. The report examined over 4,000 citations between 1985 and 2003; a survey of the members of the Scientific Advisory Committee of the project yielded 290 publications and a tree search of publications yielded 15 articles. Out of these, over 550 articles were deemed to be appropriate for investigation and over 100 met the inclusion criteria for the report.

Prior to considering the research on service systems and interventions, it is worth noting the research on the relationship between bereavement and physical and mental health. Most of the literature pertains to adults, with a broad age range from early 20s to older than 70. Duberstein argues that the "conclusion that bereavement is associated with increased mortality should be considered tentative" (2000:281); however, there does appear to be a link between bereavement and changes in multiple physiological systems (Hall and Irwin, 2001).

Overall, the diversity of grief (for example, the relationship with the deceased, how they died and cultural/religious norms) makes it difficult to draw definitive conclusions about the associations between uncomplicated bereavement and negative outcomes. The Report on Bereavement and Grief states that existing research suggests that "uncomplicated bereavement is not associated with enduring negative consequences for most people", but that "individuals experiencing complicated grief may also be at increased risk for poor physical health outcomes" (Centre for the Advancement of Health, 2003:42 and 43). There are limitations to these findings, as the research concentrated on white middle aged or elderly women.

According to Bonanno and Field (2001:798), review of available evidence showed that "interpersonal losses tend to disrupt psychological and physiological functioning in most bereaved individuals for a period of one or two years. However, only a relatively small subset of bereaved individuals, usually 15 percent or less, tend to show more chronic grief reactions."

In summing up the available data on the relationship between bereavement and health, Stroebe, Hansson, Stroebe & Schut (1999) state that "Although it is still debatable which subgroups of bereaved individuals are most vulnerable, that the health of bereaved people in general is at risk (compared to their non-bereaved counterparts) has now been well established. There is no doubt that the costs of bereavement in terms of health can be extreme. Bereaved individuals suffer elevated risks of depression, anxiety and other psychiatric disorders, somatic complaints and infections, and a variety of other physical illnesses. They have higher consultation rates with doctors, use more medication, are hospitalised more often and have more days of disability. The risk of mortality is associated with many different causes including, particularly, suicide. Most recently … research has shown biological links between grief and these increased risks of morbidity and mortality" (Stroebe, Hansson, Stroebe, & Schut, 1999 p. 8).

The Economic Costs of Grief

No Australian peer-reviewed data is available on the economic impact of grief on the economy in general. One estimate of the economic impact of grief on American business has been published by The Grief Recovery Institute, 2003 – the "Grief Index"

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estimates of lost sales, estimates of accidents and illnesses affecting work time, estimates of business losses as the result of poor decision-making, employee wage and benefit statistics, and cost of training, retraining and replacing personnel. The estimate derived for the "hidden annual cost of grief in America's workplace" related to the death of a loved one is US$37.5 billion, based on an assumption of one primary workplace griever for each death. The estimated annual hidden cost of grief related to the death of extended family members, colleagues and friends is US$7 billion. These findings need to be considered with some caution however as the true economic costs of grief are difficult to quantify.

Australian Data on the Relationship Between Adverse Life Events and Health

In examining local data, the Australian Bureau of Statistics 2002 General Social Survey published in December 2003 (Pub. No. 4159.0) indicates that 20 percent of all Australians had experienced the death of a family member or close friend. Of

those people who had experienced the death of a family member or close friend in the last 12 months, 48 percent self-assessed their health status as either fair or poor. With over 32,000 registered deaths in Victoria each year (ABS, 2000) and with each death affecting eight to 10 family members, an estimated 320,000 Victorians are directly impacted upon as a result of these deaths. As these bereavements also impact upon extended family, friends, workplaces, and communities and as the support needs of the bereaved population often last for some years, the actual size of the bereaved population in Victoria is much larger.

Information from the International Work Group on Death, Dying and Bereavement

The International Work Group on Death, Dying and Bereavement (IWG) comprises clinicians, researchers and educators dedicated to the development of knowledge, research, practice and education in dealing with death, dying and bereavement. Membership is through invitation and there are currently 138 leaders in the field who are members, from all over the world. The views of IWG were requested on the role for specialist stand alone bereavement services and how these services should be integrated within more generalist health services. There were eight replies, citing different services systems in America, Canada, Australia, the UK and Hong Kong.

Overall, there was agreement that most people can function effectively after bereavement utilizing their social supports and possibly some low-level interventions, counselling or support groups. However, for five to 10 percent of bereaved people

in complicated cases it is necessary for practitioners to have a solid foundation in mental health, followed by subsequent training in the problems and particularities of complicated bereavement.

With regard to service systems, models that include specialist bereavement services were endorsed, with examples cited where social workers, psychologists and psychiatrists without specialist knowledge who did not understand grief issues potentially exacerbated client problems. The consensus was that where universal services provide intervention in complex cases without specialist expertise, there is a danger that the needs of bereaved people will be treated ineffectually or even harmfully.

A detailed response from California outlined the issues that had been raised there by the possibility of incorporating bereavement services into other generalist psychological services. The general opinion was that specialization in bereavement was an essential feature of the service system, noting that there are even sub-specializations in the field such as children with life-threatening illnesses. It was noted that clients see specialist services as meeting their specific needs, similar to seeing an osteopath for bone problems rather than a General Practitioner. Options noted for service system structure included a coordinated combination of mainstream support services supported by specialist resource services along the lines of the Centre for Grief Education.

Findings on Service System Issues

There appears to be little research on service system structure in relation to grief and bereavement services. The Report on Bereavement and Grief Research (Centre for the Advancement of Health, 2003) consistently refers to the 1984 Institute of Medicine Report on Bereavement as a milestone in bereavement research and compares findings today with those in 1984.
T
to) any empirical evidence.

Since then, there has been both quantitative and qualitative empirical research that pertains to the education and training of health care professionals, their reactions to bereavement, the stresses associated with providing care to dying and bereaved people and the provision of services to bereaved people in health care settings. However, in absolute terms, very little research covers this aspect of bereavement. Additionally, the research that does exist lags behind other bereavement research in terms of quality and methodological rigour.

Education and training of health professionals

Studies in which bereavement education is the primary focus of investigation are rare. The studies that exist in relation to end of life care, indicate there are significant gaps in physician education and training, both in the US and UK. There is a recognized need for special education and training for health professionals in caring for bereaved persons (Wright, Johns and Joseph, 2003). Interestingly, Neimeyer and Baker (2003) found in one study that, regardless of the type of interventions offered, clients with a more externalised coping style fared better with paraprofessionals, whereas those with a more

internalised coping style fared better with professionally trained therapists. Baker and Neimeyer see this area of therapist characteristics as warranting more research (2003).

There is no published empirical work on the use of screening tools for use, for example, in primary care settings, to help identify individuals experiencing or at risk of bereavement-related problems (although some largely untested tools may be in

area of the identification of individuals at risk for experiencing complications of bereavement.

Many health professionals experience grief themselves, sometimes profound grief, when a patient dies and this is related to the duration of care and closeness achieved. Female health care professionals report more symptoms of grief than their male counterparts. Some studies have shown that health care workers who receive education and training regarding death and dying are subsequently more comfortable in dealing with death.

Health care systems issues

Systems level issues include the extent to which bereavement-related services are being provided by health care institutions and organisations, the types of services provided and whether these services are appropriate and sufficient to meet the needs of those being served, including staff. Few studies have focussed specifically on bereavement services; most research that exists has been conducted on bereavement care provided by hospices.

In relation to hospices, most indicated that they used some type of bereavement assessment process to identify individuals who might be at risk for bereavement related problems, although services were provided to more than those at risk and few were referred out (Lattanzi-Licht, 1989 and Foliart, Clausen and Siljestrom, 2001).

Counsellors in primary care settings in the UK reported at least 20 percent of their cases as bereavement related and up to 50 percent for some (Payne, Jarrett, Wiles and Field, 2002). Few counsellors made reference to theoretical sources of 'name' authors, drawing on a variety of broad conceptual approaches to counselling bereaved persons.

In summary, there is little research on bereavement care provided by facilities other than hospices. There is a substantial literature presenting non-empirically derived or evaluated practice guidelines that suggest that many different people can and should care for bereaved people, however, that literature is not reviewed in the Report. There is no peer reviewed empirical comparisons of the effectiveness or cost-efficiency of different types of providers, or combinations of providers, providing bereavement care.

Anecdotal accounts indicate that most bereaved individuals and families seek support outside the health system. Health professionals should be able to respond compassionately to bereaved people and be able to recognize when some individuals are experiencing complicated grief. They should also be able to assess the likelihood that patients are at risk or are experiencing problematic grief reactions.

Questions that remain open include:

- Who should provide what type of more intensive interventions within health care settings?
- What types of education and training are needed to prepare and support health care providers in caring for bereaved people?
- How should bereavement care provided within the health care system (including the mental health system) be linked to non-medical resources, such as peer support groups and other community resources?

Findings on the Effectiveness of Interventions

The Report on Bereavement and Grief Research (Centre for the Advancement of Health, 2003) states that over the past twenty years there has been a proliferation of intervention programs for bereaved persons. They vary in terms of strategies used (eg group or individual interventions) and populations targeted (eg anyone bereaved, those experiencing complicated grief).

The offer of help is to "benefit the bereaved individual, to help him or her to deal with the emotional and practical problems following the loss of a loved one" (Schut, Stroebe M.S., van den Bout and Terheggen, 2001:705).

Jordan (2000:459) criticises mental health professionals and particularly grief counsellors for "adopting theory [on interventions] on conviction alone", yet there is "convincing evidence that many of the clinical constructs that have guided bereavement interventions over the years may be not much more than collectively shared assumptions", citing in support of this Bonnano and Kaltman, 1999 and Stroebe and Stroebe, 1991.

Schut et al, (2001) reviewed and critically assessed grief and bereavement intervention efficacy studies. For research purposes, Schut et al., (2001) divided interventions according to the target group and assessed each for their efficacy. Primary interventions are for uncomplicated grief; secondary interventions are for those at risk for complications, due to factors such as suicide/homicide for example; and tertiary interventions are for those experiencing bereavement problems often involving psychotherapeutic interventions.

The review found that: "the overall picture emerging from the studies of the effects of primary prevention interventions h
often seem temporary and sometimes negative results of the intervention have been reported too" (p.719). Additionally, "the review of high risk interventions presents mixed results: Effects, if found, are generally rather modest and there are some indications that improvement is only temporary … [Gender is an issue, there are] … strong, though inconsistent, indications of men and women reacting differently to the interventions [and there are suggestions that] … selecting participants raises

positive and lasting results, although the effects are often modest" (p.730).

The conclusion is that "the more complicated the grief process appears to be, or becomes, the better the chances of interventions leading to positive results" (p.731). Additionally, the analysis suggests that primary interventions may be less effective because the participants were *recruited*, that is they did not ask, but were offered support, whereas when the bereaved person asks for help, benefits increase. This suggests that the practice of offering support may not be useful. The timing of the intervention appears to play a role in efficacy for three reasons: firstly, early intervention may disrupt the natural course of grieving; secondly, they could interfere with support networks, causing them to withdraw; and thirdly, people may be prevented from finding their own solutions. The evidence is inconclusive.

A number of qualitative and quantitative reviews of research on bereavement have been published since 2000; the Report on Bereavement and Grief Research (2003) reviews these and summarizes information and conclusions. Recent research shows that interventions with *adults who are not experiencing complicated grief* "cannot be regarded as beneficial in terms of diminishing grief-related symptoms" (Schut et al.: 731), impart "essentially no measurable positive effect on any [outcome] variable" and "nearly one in two clients suffered as a result of treatment" (Neimeyer, 2000:546).

In fact, interventions for *adults experiencing normal (uncomplicated grief)* "are likely to be unnecessary and largely unproductive" (Jordan and Neimeyer, 2003), and may be harmful for significant percentage of people (Neimeyer, 2000). Findings suggest that interventions for *individuals at risk for complications of bereavement* may result in some benefit, at least in the short term … findings are inconsistent however, and vary based on factors such as the gender of the participants and whether participants were screened for risk before participating in the studies, which appears to increase the likelihood that the interventions would be successful (Schut et al: 2001, Goodkin et al, 2001, Hatton, 2003 and Chambers & Chan, 2003).

With regard to interventions with *individuals experiencing complicated (traumatic) grief or depressions of bereavement*, Jacobs & Prigerson state that due to the recent emergence of complicated grief, no controlled studies exist that pertain directly to the treatment of traumatic grief (2000:479), but that in a review of studies of psychodynamically-oriented treatments and behavioural/cognitive treatments there were indications of "some proven effectiveness" and that they "hold promise for Traumatic Grief" (2000:488).

Neimeyer (2000:546) found that studies focusing on interventions for traumatic bereavement "showed a reliable positive effect" and that treatment-induced deterioration was substantially lower than it was found to be in studies of interventions with individuals experiencing uncomplicated bereavement.

Zisook and Schucter reviewed interventions for bereavement related depressions and relevant treatment studies and advocate "that all persons with recurrent mood disorder facing the imminent or recent death of a loved one be considered for prophylactic treatment – individualised for either antidepressants, psychotherapy or both" (2001: 789). This is because those who have experienced past histories of depression are more "susceptible to … clinical depression (Zisook and Schucter, 2001). Zisook and Schucter (2001) espouse the multiple benefits of support groups for the bereaved and that it is still to be determined whether support groups or individual therapy are more therapeutically effective for the bereaved.

Support groups are considered to be helpful by survivors of suicide, but the research findings are based on small, non-representative samples and research on other intervention types have had mixed findings (American Foundation for Suicide

Prevention, 2003). More research is needed on the effectiveness of interventions for suicide survivors. Online support groups have emerged since the early 1990s but there has been no systematic evaluation of group outcomes of online support (Colon, 2001).

Ayers and Sandler, 2003 and Ayers et al., 2003 reviewed interventions towards children and adolescents who have lost a parent and concluded that the evidence from the few controlled evaluations must be considered equivocal.

In considering grief arising from bereavement through disasters, Norris et al. (2002) espouse meeting the mental health needs of children, women and survivors in developing countries is important, as the impact and longevity of health problems affects a higher percentage than when an individual dies. They found that delayed onset of symptoms was rare (p.241) and that those at risk of long-term distress should be easy to identify early in the process. Niemeyer (2001) considered the bereavement implications of September 11, arguing that many of those bereaved through this trauma will not develop traumatic grief symptoms, whereas 15 percent of those bereaved non-traumatically will; however, those traumatically bereaved are at heightened risk for experiencing traumatic grief symptoms, requiring intervention. Niemeyer (2001:4) posits tha
these "at risk grievers seem to be uniquely responsive to grief therapy".

Jordan and Niemeyer, (2003) describe the following as being the high risk mourners:

- Men who lose spouses (particularly older and isolated males).
- Mothers who lose children.
- Survivors of sudden and/or violent, traumatising losses such as suicide, terrorist attacks, warfare, homicide and accidental death.
- Individuals with previous psychiatric histories (including depression, substance abuse, post-traumatic stress disorder and psychotic disorders, low self esteem/coping self-efficacy, high levels of dependency on the deceased and abuse/ trauma histories).
- Individuals manifesting high distress grief (eg high levels of depressive, anxiety or rumination symptoms or who meet diagnostic criteria for complicated grief) early in their bereavement experience.

Summary

There may be a number of reasons that underlie the above findings. Jordan and Neimeyer (2003) suggest that "grief counselling may not be needed by most mourners; grief counselling may not work in the form that it is typically delivered in research studies and the positive effects of grief counselling may be masked by methodological issues in the design and implementation of the studies" and that researchers should "concentrate their efforts on studying interventions targeted to persons at risk of experiencing complicated grief".

Hansson and Stoebe (2003) considered the evidence that formal intervention is generally not helpful or justified for older individuals who are experiencing uncomplicated grief and suggest that professionals might be best utilised providing support to the natural helpers (eg family, friends and religious representatives).

It is important to remember that cultural factors can impact on how grief is both demonstrated and handled (Maddocks, 2003). There has been little research on this and on specific groups of people experiencing bereavement, for example, gay and lesbian suicide survivors (American Foundation for Suicide Prevention, 2003).

As Jordan and Neimeyer (2003:780) point out, the "readiness to encourage all individuals to receive treatment needs to be replaced with an effort to customize interventions to the particular gender, personality, background, resources and perceived needs of individual mourners" and there is specific research which demonstrates the relevance of specific interventions with particular therapies (Winter, 1990 and Beutler, 2000).

Conclusion

It is worth noting Neimeyer and Hogan's observation that "although the human experience of bereavement has been studied, it has not been studied well" (2001:111) and that the growth in bereavement studies, which could have laid a good foundation for grief interventions, has not done so. There needs to be more research in relation to bereavement interventions and their efficacy (Centre for the Advancement of Health, 2003); moreover, there is very little research from or on Australian experiences and this would be a useful addition to the literature.

Stroebe and Schut (2001) have identified three factors that impact on grief: factors related to the death (eg sudden or anticipated); factors related to the individual (eg emotional stability, self esteem and religion); and factors related to interpersonal relationships (eg support system of family and friends).

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and mental disorder for a minority of bereaved people" (Stroebe, 2001:859). Bearing this in mind, from the available research

that there should be a focus on boosting social support systems for the majority of bereaved people – for example, through community education for generalised information and given their value, through support groups. For the minority of people whose grief is traumatic or complicated, there seems to be the need for individualised therapy, provided by a mental health professional. Finally, health professionals, social workers and others who come into contact with bereaved people should focus their attention on identifying and referring on those who are high risk mourners as described above.

There is also a need for rigorous research, as well as more dissemination channels for the findings of that research. Practitioners need to be more willing to learn from the findings of research and change their interventions targets and modalities to increase their effectiveness. There may well be a role for an organisation to provide the link between researchers and practitioners so that up to date research is utilised in the field.

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Appendix 2 – External Stakeholder List

The following groups were invited to participate in the review:

- Australian Association of Social Workers*
- Australian Psychologists Society
- Bereavement Support Groups Network, including:
  - Crisis Support Service (including Care Ring and Suicide Helpline)
  - Mental Health Fellowship
  - Royal Women's Hospital Pastoral Care and Spirituality Services
  - SIDS and Kids Victoria
  - The Compassionate Friends
  - Very Special Kids
  - Victorian Palliative Care Program
- Carers Victoria
- (A selection of) Community Based Palliative Care Providers
- (A selection of) Community Health Services
- Coroner's Court Counselling and Support Service
- DHS – Emergency Recovery Unit
- DHS – Mental Health Services Branch
- Funeral Services – Australian Funeral Directors Association*
- Grief line, Bethlehem Hospital
- Lifeline
- Palliative Care Victoria
- Irene Renzenbrink – Qualicom Consulting
- Victorian Divisions of General Practice*
- Victorian Victims and Referral Scheme*

* Denotes groups that were unable to participate.

Appendix 3 – Leadership Group Membership

Centre for Grief Education

Chris Hall – Director
Jayne Sydenham Clarke – Board of Management
Adele Hulse – President, Board of Management (alt)

Community Bereavement Centre

Lyn Hayes – Executive Officer, Eastern Palliative Care
Chris Peck – Manager CBS

Mercy Western Grief Service

Noala Flynn – Executive Officer, Mercy Western Hospice
Garret O'Dowd – Manager MWGS

National Association for Loss and Grief (Vic)

John Edwards – Executive Officer
Paul Tricker – Vice President Board of Management

Appendix 4 – Summary of Agency Operating and Infrastructure Issues

Centre for Grief Education

Financial	Infrastructure	Governance/Management
■ Weakening equity position over the last two years culminated in solvency concerns in Dec 2003 and resulted in a reduction of staffing and programs in January 2004. ■ The organisation is closely monitoring current financial performance and budgeting for a modest surplus in 2003/04. ■ For 2002/03 the DHS grant covered approximately 63 percent of expenditure. The remainder of income is predominantly derived from membership and education program fees.	■ Collocation of all services at the Monash Medical Centre has resulted in inadequate space for operations – particularly counselling services.	■ Governance and management systems well developed for a small organisation. ■ Business and management systems are sufficiently developed to support further expansion that would potentially lower relative administrative expenditure.

Community Bereavement Service

Financial	Infrastructure	Governance/Management
■ Eastern Palliative Care (EPC) reports that it currently provides a subsidy to CBS of approximately $127,00 per annum excluding the costs of corporate overheads. The source of this subsidy relates to service establishment income that has been carried forward and from other sources within EPC. ■ The DHS grant covers approximately 42 percent of current expenditure.	■ Strong infrastructure support is provided to the CBS from EPC including: – Finance – Occupational health and safety – Human resource management ■ The service operates from suitable physical premises with the capacity for expansion.	■ Strong governance and management systems are provided via EPC.

Mercy Western Grief Service

Financial	Infrastructure	Governance/Management
■ Current financial subsidy by Mercy Hospice to the MWGS is in the order of $25,000 pa excluding corporate overhead costs. The level of subsidisation may tighten but is expected to continue. ■ DHS funding covers approximately 76 percent of current program expenditure.	■ Strong infrastructure support to MWGS from Mercy Hospice including: – Finance – Occupational health and safety – Human resource management ■ Suitable physical premises with room for expansion.	■ Strong governance and management systems provided through Mercy Hospice.

National Association for Loss and Grief (Vic)

Financial	Infrastructure	Governance/Management
■ Committee of management is working to address past shortfalls in financial control and management. ■ Current operating budget reported to be in surplus but in part distorted by the effect of staff vacancies. ■ DHS funding covers approximately 67 percent of current budgeted agency expenditure. The reminder is predominantly generated by membership, accreditation and training fees. ■ Negative equity position reported in 2002/03. No audited financial statements are available for the two years prior. ■ Operations and service outputs have been hampered in the past by staff vacancies and loss of funds through fraud.	■ The current office accommodation is very small. There are some occupational health and safety issues for staff in relation to this. ■ Off site storage is required for agency records. ■ Location with a funeral company is seen as a negative. ■ IT systems require upgrade.	■ Governance and management systems require significant strengthening including relevant business and financial expertise on the Committee of Management.

Appendix 5 – Working Party Membership

Vivien Adler (Chair)	Manager, Palliative Care and Specialist Programs, Continuing Care Unit, Programs Branch, Metropolitan Health and Aged Care Services Division, Department of Human Services
Amanda Bolleter	Project Officer, Continuing Care Unit, Programs Branch Metropolitan Health and Aged Care Services Division, Department of Human Services
Harry Lovelock	Senior Project Manager, Service Policy and Analysis, Mental Health Branch, Metropolitan Health and Aged Care Services Division, Department of Human Services (to May 2004)
Cheryl Thomas	Senior Project Officer, Policy and Analysis Unit, Mental Health Branch, Department of Human Services (from May 2004)
Bridget Monro	Program Advisor, Housing, Unit, Operations Division, Western Metropolitan Region, Department of Human Services
Anna Rendis	Project Manager, Community Health Unit, Rural and Regional Health and Aged Care Services, Department of Human Services (to April 2004)
Sue Clarke	Senior Project Officer, Community Health Counselling, Rural and Regional Health and Aged Care Services, Department of Human Services (from April 2004)
John Richardson	Acting Manager, State Emergency Recovery Unit, Regional Operations Performance, Operations Division, Department of Human Services.
Panayiota Romios	Research/Policy Officer, Health Issues Centre Inc
Timothy Wilmot	Manager, Planning and Service Innovation, Family and Community Support Branch, Community Care Division, Department of Human Services