Respite Services for Children with Life-Threatening Conditions

FINAL REPORT

the Nucleus group

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CONFIDENTIAL

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EXECUTIVE SUMMARY

Respite plays an important role in the range of support services for children with life threatening conditions and their families and carers. Respite is a key support to families by providing short-term breaks and opportunities for the carer to pursue interests and attend to responsibilities not associated with the care-giving role. Respite has positive effects on family function including refreshing and revitalizing parents, providing time for other family necessities and time for the needs of other children. Respite has been identified as one of the most important elements of the service system in sustaining family support and service arrangements.

The importance of respite is outlined in the statewide paediatric palliative care policy, *Strengthening care for children with a life threatening condition: a policy for health, palliative care, disability, children's services and community care providers 2008-2105.* Principle 3 – 'best possible care at all times' notes that access to a diverse range of respite options is a vital component of care.

Respite and short-term care programs operate in all jurisdictions across all client life stages and are seen as strengthening the support arrangements that operate within the family. Respite services available to families with children with life threatening conditions are provided through a range of service models and can have a generic or specialised focus.

In 2009, the Nucleus Consulting Group was contracted by the Department of Human Services to map respite services and funding available in Victoria for children with a life-threatening condition and to identify whether the current range of options meets demand. Nucleus used a range of data collection methods including surveys of respite providers and families, a focus group with families and interviews with key stakeholders. The level and quality of survey responses from some services was disappointing even though repeated attempts were made to engage them. While this made it difficult to draw conclusions about some aspects of the review, there is clear support for the following:

- There are a range of different funding sources and packages available for respite, but it is a complex system for families and stakeholders to navigate. This is compounded by apparent variation between local government areas and regions in the availability of respite services, particularly in relation to in-home respite provided through the Home and Community Care (HACC) program.
- There is generally a lack of understanding by services of the needs of families and children with life-threatening conditions and the majority of in-home services are unable and lack the capacity to provide the level of care and support required by children from this group. Out of home services appear to be more able to meet the needs of the target group, but there are still a significant proportion that are unable to accept children with complex medical needs.
- Those respite services that care for children with a life-threatening condition make considerable effort to accommodate specific requests by families for respite but forward planning for families is a problem. Many report they have to fit in with the service and the service system rather than the services fitting in with them. Families require greater flexibility and availability of services with particular needs at weekends and during school holidays.
- Families consider a service to be effective if the service understands the child's condition and circumstances and is well prepared to care for and support the child. Families want respite services to have adequate staffing, well maintained facilities, and for their child to have an enjoyable and stimulating time while at respite.

- A range of service barriers and gaps have been identified including issues around the complexity of the child's condition and skills of staff, uncertainty by services about eligibility, difficulty in navigating the system, and inappropriateness of some facilities due to the physical features of the facility or other children attending. Services are not spread equally across regions and some regions, such as the North and West Metropolitan Region, have relatively fewer options than others.
- Most families prefer in-home respite so they can be available for their child however there is a lack of appropriately trained carers to provide this. Out of home respite is still required however for longer breaks, but options are limited particularly in regional areas.
- Long waiting lists for disability packages mean that some families are disadvantaged as they cannot access or purchase 'top up' respite, case management or education and training for carers. Those without a disability are not eligible for a package, i.e. children with cancer, and must rely on scarce existing services or limited funds through the palliative care program.

Recommendations

1. DHS Cancer & Palliative Care Unit and Disability Services Division work together to implement the initiatives recommended in this report.
2. Develop and implement an information and education strategy for respite providers on the needs and requirements of families with children with a life-threatening condition.
3. Streamline processes for families by having a centralised point for information on available respite services, referral, case management and the development and provision of care plans and manuals.
4. Fund palliative care consortia to build relationships and referral pathways with disability and HACC services in order to facilitate flexible respite solutions.
5. Provide additional funding to the VPPCP to enhance their education/training and clinical support role to local government and other respite providers.
6. Explore options for the utilization of VSK organisational expertise in pro viding specialist respite for children with a life-threatening condition to assist other respite providers to expand or extend their services.
7. Consider the provision of operational funding for VSK House.
8. Review future needs for out of home respite in the northern and western suburbs.
9. Review expenditure patterns and guidelines for the Flexible Support Fund managed by the VPPCP to determine future requirements.
10. Provide funding in rural areas to support innovative occasional out of home respite services.
11. Develop protocols to enable regional families to access the closest available service.
12. Explore the possibility of establishing a statewide register/bank of nurses that could provide respite in-home and out of home where needed.
13. Establish a high level Committee with representation from key stakeholders including Disability Services, the Cancer & Palliative Care Unit, HACC, the Australian Nursing Federation and the Municipal Association of Victoria to examine barriers and develop solutions to overcome issues restricting the provision of respite to families of children with a life-threatening condition.
14. Maintain and further develop service maps to enable a greater understanding of availability and requirements.

INTRODUCTION

BACKGROUND

Historically, palliative care services have usually been developed for people with life-threatening illnesses or progressively deteriorating conditions that are beyond curative treatment (or where people choose not to pursue curative treatment). Most services were provided for people with cancer who are generally older and have limited life expectancy. Service planning occurred on the basis of the distribution of populations of older people.

More recently there has been growing recognition that other groups may require palliative care including people with neurological conditions and younger people with life-threatening conditions such as neurodegenerative conditions and cystic fibrosis. In May 2008, the Department of Human Services (DHS) in partnership with key stakeholders launched the statewide paediatric palliative care policy, *Strengthening care for children with a life-threatening condition: a policy for health, palliative care, disability, children's services and community care providers 2008-2015.*

A range of challenges must be overcome in implementation of the policy, including:

- Quantification of the level of demand for services.
- The relatively low number of children requiring care.
- Access for rural and remote communities.
- Capacity to develop paediatric care skills among medical, nursing and allied health personnel (particularly those working in rural communities).
- Cultural differences that exist in attitudes and needs for palliative care among different community groups.

The policy recognises that life-threatening conditions for children include not only life-threatening illnesses but also life-threatening disabilities.

The treatment and care requirements for children can be more specialised and the majority of paediatric palliative care is provided by the Royal Children's Hospital (RCH), Very Special Kids (VSK) and Southern Health. Children with life-threatening conditions will often require care over a longer period of time than adults and while most families prefer to care for their children in the family home there are additional stresses on parents and siblings. The policy therefore recognises that families require a diverse range of options, including respite, to assist in the care of children with life-threatening conditions and to alleviate pressure on families.

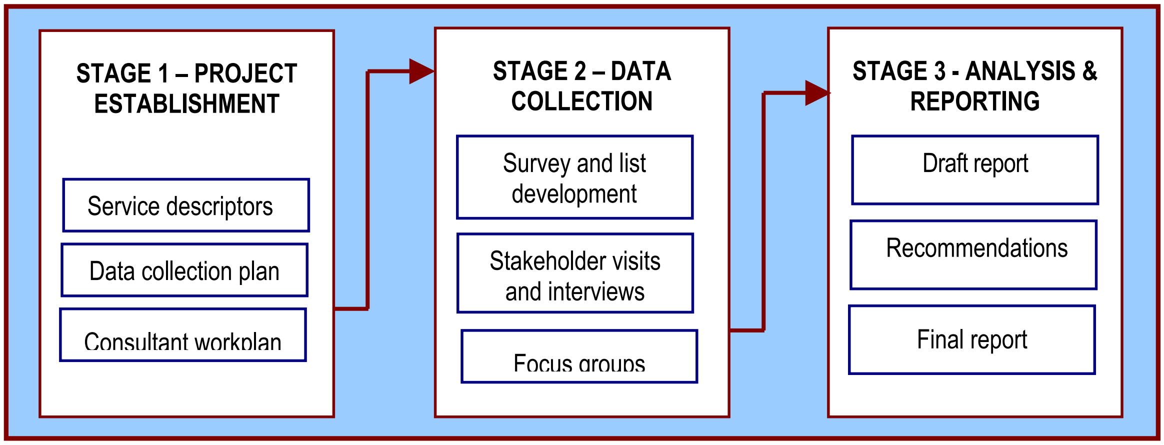
To begin to address the issue of respite, DHS has commissioned a service mapping project, to identify available respite services operating within Victoria, with a view to developing future service models that better meet the needs of children with a life-threatening condition and their families.

METHODOLOGY

In March 2009, DHS contracted the Nucleus Consulting Group to map respite services available in Victoria for children with a life-threatening condition and identify:

- Respite services (by type) and funding packages currently available.
- Whether the current range of options meet demand for the target group.
- The appropriateness of the skill base in existing respite services to provide care for children with a life-threatening condition.
- Recommendations to improve access to respite for children and their families and address identified gaps in service provision to meet future need.
- Preliminary cost estimates for changes/new services required.

Nucleus' approach involved three main stages as shown in the diagram below:



Initially, a service mapping framework was developed to specify all the data and information that needed to be collected to meet the project objectives and describe services within scope. Names of services to be surveyed were supplied by DHS, project steering committee members and other stakeholders.

Surveys, interviews and focus groups were used to collect data and information:

- All nominated respite services were asked to complete a survey seeking information about types of respite provided including eligibility criteria, accessibility issues (e.g. locale or cultural barriers, booking procedures, client fees, admission requirements, etc), service utilisation measures, demand measures including waiting lists, appropriateness of service options to presenting needs, and staffing structure and skill base at the service.
- Families and carers were able to complete a survey about their needs and experiences and possible barriers to obtaining respite. A focus group was also conducted with parents of children with a life-threatening condition. Issues explored included capacity of existing services to meet demand, nature of any perceived service gaps and/or ways that existing services could better meet needs, and barriers to respite access and how these might be addressed.
- Structured interviews were conducted with a broad range of stakeholders seeking information on current and future demand for respite services, nature of perceived gaps, barriers to access and additional services required to meet demand (and ideas about how to address any gaps between existing and possible future service levels).

Surveying local government HACC services was outside the scope of this project.

Respite Provider Survey
A wide range of stakeholders were contacted and asked to provide lists of known respite providers. This included disability services program managers in DHS Regions and, where they existed, searches of regional on-line directories. While these efforts were generally useful, a significant proportion of listings (in particular in some on-line directories) were incorrect or inadequate and included inaccurate descriptions of services provided and out-of-date contact names and numbers.

Most respite providers were contacted by telephone and then mailed an information sheet and survey. Where it was difficult to establish phone contact, background information and a request to participate was emailed.

A reminder email was then sent a few days prior to the due date for return of survey. Only a small proportion of surveys were completed and returned within the requested timeframe. Many providers were followed up by telephone and the survey period had to be extended by three weeks.

There were often difficulties in making contact with respite providers – sometimes it was difficult to pinpoint the appropriate person within an organisation who had responsibility for respite or who was tasked to complete the survey, and frequently providers did not return calls or returned calls after significant delays.

The list of prospective respite providers totaled 101 services. Fifteen were eliminated after stating during initial contact that they did not provide care to the target group; 86 providers were sent the survey with results as follows:

- Survey completed and returned – 40
- No response, followed up but did not return calls – 22
- No response, followed up but still didn’t complete – 23
- Declined to participate – 1

Of 40 completed surveys, two were from arms of the same organisation (and considered a single response) and six stated they did not offer respite to the target group; thus, 33 valid responses were received specifically relevant to children with a life-threatening condition. Of these, some did not answer all relevant sections on the survey and/or were not always able to provide specific information. Where necessary, Nucleus followed up these organisations to supplement/qualify material, although this was not always successful.

Although the survey produced some valuable information, the response overall was disappointing. The task was sometimes seen as onerous by providers, many of which appeared to be fully occupied with core priorities and often slow to return calls or to commit to the process. Other factors that may have limited response included that some had trouble understanding the target group as defined, some said they had previously supplied this information to others, and some were not disposed to cooperate fully on the grounds (they stated) of inadequate funding.

A list of providers nominated to receive the survey, and those that returned a completed response, is contained in a separate attachment to this report.

During the course of the project, in talking with respite providers and other programs, new services were sometimes suggested for survey (i.e. not on our original list). Where time allowed, a survey was sent to this group but mostly these suggestions came late (service names have been cross referenced against the original list and retained for further exploration if required).

Local governments and labor hire firms (i.e. companies supplying staff on a commercial basis) were not included in the survey given limited scope of the project and logistical issues with these groups.

Parents and Carers

A parent/carer survey was developed (modified slightly for bereaved families) and distributed via selected stakeholder organisations (including HeartKids, Very Special Kids, the Family Choice program at RCH, Compassionate Friends, the Monash Medical Centre and the Association for Children with a Disability). The survey was also available on-line. In total, 36 completed surveys were returned by families with a child with a life-threatening condition.

A parent/carer focus group was also hosted by Very Special Kids, attended by nine families. The project extends sincere thanks to the families that attended and to Very Special Kids and staff who were involved in setting up the event.

Other Consultations

Structured interviews and consultations were held with a range of other stakeholders. A list of those participating in this way may be found at Attachment A.

Key Findings

- ❖ It was often difficult to locate and contact providers of respite services for children with life threatening conditions.

RESPITE FUNDING

Both the Australian and Victorian Governments have responded to the needs of families for respite. A range of funding is available:

Program	Funding Source
National Respite for Carers Program	Australian Government Department of Families, Housing, Community Services and Indigenous Affairs (FaHCSIA)
Individual Support Packages	DHS, Disability Services
Flexible Support Packages	DHS, Disability Services
Aged Carer Respite Initiative	DHS, Disability Services
Respite (facility-based)	DHS, Disability Services
Host Family Program (Interchange)	DHS, Home and Community Care (HACC)
Respite	DHS, HACC
Linkages	DHS, HACC
Family Choice	DHS (funding pooled from three Divisions)
Flexible Support Funds for Children with palliative care needs	DHS, Palliative Care Program
Unassigned Bed Funds	DHS, Palliative Care Program
Very Special Kids	Private donations and DHS, Palliative Care Program
Early Childhood Intervention Services Flexible Support Packages	Department of Education and Early Childhood Development

The service system is complex for families and services to navigate. Families, palliative care providers, respite providers and other stakeholders indicated that families that do not have individual support packages are disadvantaged as they are unable to purchase case management, respite, training for carers and travel. Waiting lists for packages can be long.

Families and other stakeholders report there is often variation between regions and local government areas in availability of services, particularly in relation to HACC services. The majority of respite care through HACC is provided by personal care attendants who are unable to give medication and are not trained in tasks such as percutaneous endoscopic gastrostomies (PEG) feeding or suctioning. Personal care attendants can undertake these tasks but require child-specific training and back up. Some councils use HACC funds to purchase nursing care, but it was reported that others will not do so because of cost. Some stakeholders and families reported that some Councils appeared unclear as to whether children with life-threatening conditions are eligible for HACC services.

Key Findings

- There are a range of different funding sources and packages available for the provision of respite, making it a complex system for families and services to navigate.
- There is variation between local government areas and regions in availability of respite services, particularly in relation to HACC services.

CURRENT SERVICES

The survey of respite services sought information on two broad divisions of care: in-home and out-of-home. It also recognised that respite care of either type may be:

- Regular and/or planned, often accessed through a care package.
- Unplanned or driven by a crisis or emergency - these situations are many and varied and may be related directly to the child with complex needs (e.g. when the child is unwell and unable to attend usual activities) or to issues and needs of other family members (e.g. when other siblings are not coping and the parent needs to address these issues).

The following sections provide summary information and analysis from returned surveys. Please note however that some survey questions were left unanswered by some respondents and that a number of others provided limited specific detail. The poor response rate to the survey by some respite services is thought to be in part related to their lack of understanding of the needs of children with a life-threatening condition.

IN-HOME RESPITE

A summary of responses from services indicates that the following in-home respite services are available for children with life-threatening conditions:

	In Home Respite			
Region	Unplanned	Overnight Only	Day Only	Both Overnight and Day
Barwon South West	3	2	2	3
Gippsland				1
Grampians				
Hume				1
Loddon Mallee	1			1
North & West	1	1	1	3
Eastern				
Southern				2
All Metropolitan	1			2
Statewide	1	1	1	2
TOTAL	**7**	**4**	**4**	**15**

Eligibility
Fifteen services indicated that they had eligibility criteria (mostly relating to 'disability' rather than life threatening illness or complex medical need).

Fourteen services indicated that there were certain factors that would exclude a child from receiving service from their organisation. The most common of these included complex care requirements and/or procedures including the administration of medication. Some providers said that they would consider booking a nurse to assist with particular aspects of a child's care (that otherwise might require them to be excluded from the service) depending upon funding and/or availability of nurses.

Referrals and Bookings

Of those services that answered this question, six required a referral and six did not. Generally parents can self-refer but may require support from a doctor or other service provider; referrals may also be made by another provider.

Referral processes varied across respondents, and included:

- Individual assessments, paperwork and forms, often requiring liaison with medical specialists, therapists and doctors. Sometimes also a nurse or program manager was required to meet the child and family prior to acceptance.
- Nurses may be required to prepare and present specialised training programs for staff.
- Occupational Health and Safety assessment.
- Provision of emergency care plans.

Parents and case managers may be completing multiple assessments to access services.

Booking processes were often different between providers, sometimes involving the brokerage agency or the referrer, but most requiring numerous phone calls and completion of written information. Most services allowed parents to make specific requests relating to the respite care sought (e.g. dates, particular staff) and providers sought to match this.

Parameters of Service

Fourteen providers responded that they were able to cover nominated hours and eight of 15 respondents indicated that they set caps for maximum amounts of respite (generally based on funding constraints and/or predetermined rules).

Seven providers charged a fee for respite care while six indicated that they did not. Fees varied in amount and may be covered by a brokerage program.

Funding was generally through brokerage. Only one program used palliative care unassigned bed funds or paediatric palliative care flexible support funding.

Staff Qualifications

Few respondents provided specific descriptions of the qualifications of their staff. However, some of the pre-requisites noted included first aid and specific training for staff to meet the needs of individual children.

Some services had a division 1 registered nurse.

Where programs were funded by HACC, they adhered to program guidelines covering staff qualifications and experience.

Local Government HACC Services

Due to the focus of this project, no Councils were contacted in relation to in-home respite services provided under HACC; however consultation occurred with the Municipal Association of Victoria. Families and stakeholders reported wide variation in the levels of respite provided across local government areas and variation in whether they were considered eligible.

Statewide data on HACC respite services for children was reviewed however it is difficult to gain an accurate view of provision of respite to this target group. HACC clients may be recorded as the child or the carer, and if recorded as the carer, will not be reflected in the data. Reason for provision of respite, i.e. disability, is recorded, but in over 90% of records the disability type is not recorded and there is no category for palliative care.

Anecdotal comments indicate that one of the issues for local government is that a significant proportion of the demand from families is at night and weekends, where the cost of provision is high. When there are older children, families want their children to be taken out for activities and Councils then have to meet transport costs. Difficulties for Council also arise if respite is booked and cancelled, as industrial agreements require that staff are paid but the Council cannot claim the hours in these cases and has to fund this from its own budget. Cancellations may occur due to hospitalisation of the child.

A major issue for HACC respite is skill levels of staff, availability of back-up support and risk involved in caring for children with complex needs. Personal care attendants cannot give medication and unless they are trained specifically for each child, cannot undertake PEG feeding or suctioning. If a child requires medication or feeding during respite, either the parent must be on hand (reducing ability of the parent to attend to other tasks or rest) or a nurse must be called in with associated cost. Other issues such as travel impact on the provision of respite, particularly in rural areas.

OUT OF HOME RESPITE

Sixteen providers offered facility based respite; others offered holiday or other respite, as shown in the table below:

	Out of Home Respite					
	Unplanned	Overnight Only	Day Only	Holiday	Both Overnigh and Day	Other
Barwon SW	3	3	4	4	4	1
Gippsland					2	1
Grampians		1	1	1	1	
Hume	3	1	1	1	4	
Loddon	2	1	2	2	2	1
North & West	2	3	3	1	2	1
Southern		1		3	1	4
Eastern	1				1	2
All Metropolitan	1			2	1	1
Statewide	3	3	2	5	2	2
TOTAL	**15**	**13**	**13**	**19**	**20**	**13**

Note some services in the table above only operate occasional weekends, i.e. six weekends a year.

Eligibility

Generally respondents indicated that eligibility criteria related to the nature/type of disability and/or other needs. Some providers cater to specific age ranges or target certain disease groups e.g. cancer or muscular dystrophy. Some programs specifically target children with high medical needs. An extensive range of conditions were able to be catered to covering congenital, chromosomal and degenerative conditions, medical needs and epilepsy.

Restrictions often exist relating to availability and level of funding and/or staff skills and capabilities (i.e. the capacity of staff to respond to a child's needs may limit eligibility). Children with complex medical needs or challenging behaviours are not eligible for some programs; some others access nursing care if funding is available.

Specific requirements may include completion of a detailed profile and/or medical assessment, or an assessment by an intake and response team or a nurse (this may include home assessment). Some programs require that the child is registered with the program, while others involve an independent panel review to grant access. Applications at some services are prioritized based on particular criteria.

Referrals and Bookings

Sixteen programs required a referral. Families may be able to self-refer (although this may require support from doctors and other programs or providers). Some requests for support may only progress to assessment if there is a vacancy.

Parents are often asked to nominate requests and services will try to match these; most providers will allocate available respite trying to match parent requests. Twenty-one providers are able to offer respite at short notice.

Sixteen providers allowed advance bookings to be made, usually to three months out. Some organisational processes may restrict forward bookings (e.g. bookings can be made only a few months in advance); this makes forward planning difficult.

Five providers said they had a waiting list, although there was limited information available on average waiting times. Similarly, only a few (four) providers detailed occupancy levels, reported rates varying between 60 - 100%.

Some services allow families to register on a cancellation list i.e. if a booking cannot take their place, it is offered to another family at short notice. One organisation allows families (as a supplementary procedure) to book respite on the basis that it may be cancelled if an urgent case presents requiring end of life care.

Parameters of Service

Hours of operation varied across respondents. A number of programs only operate at specific times e.g. one weekend per month, six times a year. Where this occurred, services said that it depended on physical and funding capacity; in some cases, the family may opt to ‘top up’ funding to purchase services e.g. open a bed.

Some providers are able to vary staffing depending upon children’s needs. Some are able to offer 1:1 support. Night time coverage needs to be considered as some programs may only be able to offer a ‘non-active’ night and this may not provide a suitable level of care for some children.

Twelve programs have a maximum amount of respite available to an individual family (where again, additional funding may be sourced to provide additional hours). Holiday programs and camps may be limited by availability of facilities.

Seventeen services charged a fee (although in some cases this is paid by a brokerage program). Some services can waive fees in specific circumstances.

Services are purchased via a range of brokerage programs and individual packages; some are block funded. Only one provider accessed palliative care unassigned bed funds and two used paediatric palliative care flexible support funds. Some providers are able to access philanthropic funding to help supports services.

Thirteen providers had links to other organisations and 15 reported having no links. The most common linkages were with RCH and VSK, and to a lesser extent to palliative care services and generalist providers such as GPs or nursing services.

Staff Qualifications

Staff qualifications varied across respondent organisations. Providers able to meet highly complex needs all had division 1 registered nursing support. Some others arrange and undertake specific training to meet the special needs of some children (sometimes negotiated via Family Choice at RCH), although the greater proportion do not adapt in this way and are therefore unable to accept certain clients.

All respondents described being able to support staff in their often demanding roles. Strategies included access to the employee assistance programs, counselling, debriefing and supervision of staff.

Innovative Services

Across Victoria, there have been a number of innovations developed to help meet the needs of particular families and groups. Of particular note is the *Goulburn Valley Support Group for Children with Special Needs*, established by parents of children with life threatening illnesses in 2005, which provides nine blocks of planned out of home respite (for four children in each block) each year.

The group books a local DHS respite house for either a weekend (two nights) or mid-week (three nights). At these times, the house is staffed 24 hours a day by a Division 1 nurse from Goulburn Valley Health (funded by the group) and two carers from the respite house (funded by DHS). A play therapist is also on hand during the day to organise activities for the children. The hospital provides certain equipment such as oxygen and intravenous poles.

The cost of each block of respite is $5,000, currently met by local services. The group reports high levels of satisfaction from families and enjoyment by children attending. The model has also been adopted in the Barwon South West Region by Boost4Kids auspiced by Gateways.

Key Findings

Limited response to the survey makes it difficult to draw conclusions about the availability or sufficiency of respite services for the target group; however, on the basis of responses received, there is support for the following:

- There is a lack of understanding by respite services of the needs of families and children with life threatening conditions.
- Most in-home care services cannot routinely provide the level of care and support required by children with complex medical needs or challenging behaviours. A few will arrange specialised training for carers and/or conscript a nurse to assist where required, but even where such provisions exist it is greatly restricted by availability of funding and personnel.
- There appears to be a greater range and number of out of home care services available to the target group (but this may be skewed by the omission of local governments and commercial firms from the survey). In general, this group of services also seemed more 'switched on' to the needs of families and children with life threatening conditions. Providers able to meet highly complex needs all had Division 1 nursing support; some others arrange and undertake specific training to meet special needs (but still a significant proportion do not adapt in this way and are therefore unable to accept certain clients).
- Booking and referral processes are often different across services but all generally involve detailed assessments, lots of paperwork and liaison with medical specialists, therapists and doctors. Often, this involves a level of repetition for families and in some cases may be onerous (although the need for services to meet duty of care requirements is understood).
- Most services make substantial efforts to accommodate specific requests from families in relation to the hours/times of respite and the rostering of known staff. Most services allow advance bookings, but forward planning can be a problematic issue for this group. Twenty-one providers are able to offer respite at short notice and where a fee may be applicable, many services have a capacity to waive charges in particular circumstances.

PARENTS AND CARERS

FAMILY SURVEY

A survey was distributed to client families by a number of services (parents could also complete the survey on-line if more convenient). The following section provides a summary of information from returned surveys and from the focus group

Respondent Characteristics

In total, 36 families responded to the survey (including nine bereaved families).

All children of respondents had been 0-6 years old when first diagnosed with a life threatening condition. The table below shows the age of the child for each respondent family (note for bereaved families, the age given is that at which the child died):

Non Bereaved	
0-6 years	8
7 – 12 years	13
13 – 18 years	6

Bereaved	
0-6 years	6
7 – 12 years	2
13 – 18 years	1

Children had a range of conditions and diagnoses including progressive neurological conditions, chromosomal abnormalities, congenital abnormalities, syndromes, cancer and epilepsy.

Respondents included 33 parents, two foster parents and one grandparent, of ages as shown below:

Age of Respondent	Number	Family Type
Younger than 20 years	1	Two parent family
31 – 40 years	10	
41 – 50 years	13	
51 – 60 years	1	Foster parent
61 – 70 years	1	Foster parent
Over 70 years	1	Grand parent

Family composition included 25 families of two parents and two or more children; five two parent families with the one child; two single parent families with two children and two single parent families with an only child.

One third of families (twelve respondents) were from rural regions:

Barwon SW	4
Gippsland	5
Grampians	1
Hume	1
Loddon Mallee	1

Eastern	9
North & West	9
Southern	6

Additional Support Needs

Parents were asked to describe the nature of their child's additional support needs. All reported that the child required 24 hour care and/or had complex care needs. Other descriptors provided by respondents included:

- Requires total care/frequent medical appointments/allied health support.
- Frequent/uncontrolled/unpredictable fitting.
- Wheelchair bound/non-weight bearing/unable to walk.
- Requires nocturnal ventilation.
- Requires feeding tube/medicated via feeding tube.
- Medically vulnerable – frequent chest infections/dehydration/renal failure.
- Challenging behaviours.

Use of Respite

Thirty respondent families had used respite care at some time. Of the families that had not used respite, reasons cited were:

- Did not know that it was available.
- Did not know of a service in the area with appropriately trained staff.
- Staff did not have the appropriate training to care for the child.
- Respite was not available at the time.

The types of respite used by respondent families as well as their assessment of the assistance it provided them is shown in the table below:

	Type of Respite Used		**Helped the Most**	
	In home	**Out of home**	**In home**	**Out of home**
Unplanned	4	6	1	4
Overnight	5	16	3	14
Day	26	8	17	6
Holiday		3		2
Other		2		2

Factors in the families assessment of the relative assistance provided by the different types of respite were difficult to distinguish. Most described general benefits applicable to most forms of respite, such as the relief and rest achieved by having a break, that a break was a necessity for self preservation and that it allowed the parent to focus on the needs of other family members for a while.

Factors noted in creating an effective service included that:

- Service was understanding.
- Service was well prepared for the child.
- Families were confident in the staff/the staff knew the child.
- The program was happy and fun filled.
- Family had option of staying on site – so could have a break or participate in fun activities with their child but some relief also obtained.
- Quality of physical facility.
- The quality of care was the same as that provided at home.

Over the past twelve months, non-bereaved parents described the following pattern of usage:

Times used	**In home**			**Out of home**				
	Unplanned	Overnight	Day	Unplanned	Overnight	Day	Holiday	Other
None								
Once		1		2	3	2	4	
2-3		1	2		5			
3-4			5		2	2		1
4-5		1						
6-7			2					
8-10					2	1		
> 10		1	10					1

The amount of respite used by these families is shown in the table below:

In home (hours)	
<20	4
21-60	5
61-99	2
100-160	7
500+	1
No response	18

Out of home (nights/days)	
1-5	5
6-10	5
11-15	3
16-20	2
20+	1
No response	16

Families were asked about the availability of respite care for their child with a life threatening condition:

Response	Available when required	Sufficient amount provided
Nearly always	8	7
Always	6	4
Sometimes	2	5
Hardly ever	9	6
Never	3	5
No response	6	8

Availability and Access

Issues raised by families in relation to the availability of respite included:

- Would like more at peak times/would use more if available.
- Very difficult with our provider – staff are not reliable.
- Waiting list is very long.
- Limited access in a rural area.
- Carers needed to be specifically trained.
- Support was offered very late in child's life.

Many families reported difficulties in accessing respite for reasons including:

- Cancellation at short notice due to the needs of other families.
- Lack of information/misinformation about service availability.
- Families had to find out about options themselves – either accidentally or through other families.
- Child not liking carer and therefore difficult for families to leave child.
- Difficult to offer regular work to care staff as the child may spend frequent unexpected periods in hospital leaving care staff without work or income.
- Staff required specific training.
- Lack of understanding of the child's needs.
- Staff not confident in caring for child.
- Long waiting lists.
- Strict criteria.
- Places not 'appealing' and parents are not happy to leave their child.
- Would like flexibility - system makes you have set times and days.
- Regional boundaries – having to travel long distances as child not eligible to attend nearby service as it was not in region that family belonged to.
- Long distances to services make it impossible in emergency situations.

Many respondents had raised issues with their service provider when a problem arose, with a proportion reporting that they were unable to obtain a satisfactory resolution. Comments included:

- Very difficult – stopped using the service.
- Facility has their hands tied because of bureaucracy and rules.
- Easier not to bother and just keep the child at home.
- Don't want to rock the boat.
- Unhappy with care but no other options available.
- Negotiating issues, red tape and basic excuses is very draining.

Other respondents said they did not raise issues because they felt very vulnerable and 'lucky' to get service they got.

Staff Experience

Fifteen respondents felt that caregivers had the appropriate skills and training to support their child, however some did not believe this (and a significant number of respondents did not answer this question). Specific training needs identified by respondents included:

- Administration of medication.
- Food preparation.
- Behavioural issues.
- Willingness to develop a relationship with the child and make time enjoyable.
- Understand that a child is bright and intelligent and has a physical disability.
- Understand how quickly a child's condition can change.

Respite Needs

When asked about future respite needs, common responses from families included:

- Flexibility.
- Respite that is fun for the child.
- Well maintained attractive facilities.
- Adequate staffing.
- Activities and outings.
- Respite for special occasions.
- Reliable booked respite so the family can plan a holiday.
- Support when the child is in or has been in hospital, or when the child is not well enough to attend school.

Particular times when respite was required included:

- Weekends.
- School holidays.
- When the child or the parent have been ill.
- In times of crisis.
- After school and school holiday care.

FOCUS GROUP

Nine families participated in a focus group held at Very Special Kids. Most participating families came from the eastern or southern regions and all had children with complex care needs and life threatening conditions.

Key themes identified were:

- The need for information on available services/possible funding options.

  Many children in the target group have rare conditions and in some cases may not have a formal diagnosis. The nature of their conditions often means there is very limited information available for parents. Identification of the child's condition may happen in a range of settings; there needs to be a referral mechanism so that parents can find out what is available and how to access it. Many families currently report that they only find out about service options from chance meetings with other parents or informally through hospital staff. Even when a family has a case manager there can be issues as staff often change and knowledge of respite options for this group of children is very specialised.

- The need for flexible respite options.

  The care and support needs of the child and family members are dynamic and change frequently. The child's condition can change quickly, they may experience frequent hospitalization, and the needs of other family members and support structures can change also. The life expectancy of many of these children is unpredictable and longer term planning is difficult. Respite needs to be flexible and respond to a range of situations.

- Difficulties accessing respite.
  - There are numerous potential sources of respite funding, but each has a different application and approval process and must be applied for separately (and may even need to be obtained from multiple sources to purchase a single service). Parents are often reliant on a case manager, word of mouth or their own research to find out about funding they may be eligible for.
  - Due to the nature of the conditions, symptoms and treatments involved in caring for the target group, a high degree of family confidence in carers, their technical skills and knowledge of the child is required. Programs such as Family Choice involve parents in determining who will be part of the child's care team, and include educating care staff and school personnel about the child's needs. As with the general workforce, care staff change periodically and new staff with suitable skills and experience need to be found. This is an ongoing challenge.
  - Parents recognise the need for a break from their caring role and understand the benefits that a break will bring to them and the other members of their family. For many families the opportunity to have a family holiday or to participate in 'normal' family activities is not possible (for example, the child may not be able to travel in a car for long periods, or by plane, need multiple power points, have difficulty in maneuvering equipment, and become distressed in unfamiliar environments) and respite is the only option that will enable this to occur.

Key Findings

- ❖ Most respondent families had used respite care, most commonly in-home day care (often around four hours per week, most weeks of the year) and out of home overnight care (up to 10 nights per annum). Factors in the assessment of the relative assistance provided by different types of respite were difficult to distinguish (all were invaluable).
- ❖ Factors noted in creating an effective service included that the service understood the child's condition and circumstances of the family, and that the service was well prepared to care for and support the child.
- ❖ Families were evenly split on the availability of respite care for their child. Those that reported difficulties in accessing respite cited reasons including lack of information about available services and possible funding options, and lack of flexibility in the service meaning that it did not suit their particular needs. Families were also evenly split on whether they felt caregivers had the appropriate skills and training to support their child.
- ❖ When asked about future respite needs, common responses from families included greater flexibility and availability, well maintained attractive facilities, adequate staffing and the inclusion of activities and outings in the program likely to be enjoying and stimulating for the child. Particular times when respite was required included weekends and school holidays.

DEMOGRAPHIC TRENDS

Forecasting future demand for paediatric palliative care services is limited by a lack of definitive data and information. However, an increase in demand for general paediatric services will be experienced in coming years due to the overall increase in the birth rate. Over the period 2007 to 2017, the number of newborns is projected to increase by just under 1% per annum:

Year	No. of people aged 0 years	% increase from previous period
1996 Census	57,861	
2001 Census	56,044	-3.1%
2006 Census	63,199	12.8%
2007	67,221	6.4%
2008	69,526	3.4%
2009	69,712	0.3%
2010	70,065	0.5%
2011	70,515	0.6%
2012	71,044	0.8%
2013	71,638	0.8%
2014	72,259	0.9%
2015	72,899	0.9%
2016	73,560	0.9%
2017	74,197	0.9%

Data Source: 1996, 2001 and 2006 Census and Population forecasts as published by the Department of Health and Ageing May 2009

In developed nations, it is estimated that each year 10 per 10,000 children aged 0–19 years will require palliative care.[1] Based on this and relative projections for overall population growth, the following estimates can be developed:

Region	2007	2012	2017	Additional Children (2017 over 2007)
Barwon South West	103	104	105	2
Eastern	251	251	253	2
Gippsland	66	66	65	-1
Grampians	59	58	58	-1
Hume	66	65	65	-1
Loddon Mallee	86	86	86	0
North & West	393	425	459	66
Southern	311	330	350	39
All Victoria	1083	1134	1188	105

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[1] A guide to the development of children's palliative care services. Report of joint working party of the Association for Children with Life-threatening or Terminal Conditions and their Families and the Royal College of Paediatrics and Child Health. London: Royal College of Paediatrics and Child Health, 1997

The most significant growth in demand is likely to occur in the Southern and North & West Metropolitan Regions. The following tables show growth in demand by LGA within each region:

North & West	**No of Children Aged 0 – 19 Years**			**Additional Palliative Care Cases 2007 to 2017**
	2007	**2012**	**2017**	
Banyule	28,887	28,982	29,182	0.30
Brimbank	48,254	47,628	47,266	-0.99
Darebin	28,734	29,857	30,610	1.88
Hobsons Bay	21,468	21,896	22,156	0.69
Hume	50,406	53,208	56,388	5.98
Maribyrnong	14,300	16,019	17,755	3.46
Melbourne	11,493	13,794	16,648	5.16
Melton	27,090	35,681	44,668	17.58
Moonee Valley	25,299	25,957	26,410	1.11
Moreland	30,925	32,478	33,799	2.87
Nillumbik	19,058	18,569	18,346	-0.71
Whittlesea	37,824	41,835	46,744	8.92
Wyndham	38,224	47,538	57,337	19.11
Yarra	10,762	11,417	12,079	1.32
Sub Total	392,724	424,859	459,388	66.66
Children needing Palliative Care	393	425	459	

Southern	**No of Children Aged 0 – 19 Years**			**Additional Palliative Care Cases 2007 to 2017**
	2007	**2012**	**2017**	
Bayside	23,958	25,173	26,302	2.34
Cardinia	19,211	23,564	29,167	9.96
Casey	72,136	78,718	84,900	12.76
Frankston	33,304	33,726	33,661	0.36
Glen Eira	30,160	31,708	33,313	3.15
Dandenong	33,706	35,200	36,434	2.73
Kingston	33,261	34,346	35,318	2.06
Morn Peninsula	36,135	36,639	37,668	1.53
Port Phillip	11,786	13,186	14,471	2.69
Stonnington	17,154	17,746	18,480	1.33
Sub Total	310,811	330,006	349,714	38.90
Children needing Palliative Care	311	330	350	

Key Findings

- Forecasts indicate there will be increasing numbers of children in the Southern and North & West Metropolitan regions requiring palliative care in the future.

SERVICE BARRIERS AND GAPS

There are a number of barriers and gaps in respite care services for children with a life-threatening condition:

Children with particular conditions

- Many of the children in this target group have high level and complex needs, or very specific needs related to low incidence conditions, that a large proportion of non-specialist services are unable to meet.
- Some services are unclear about the eligibility of children with a life-threatening condition to receive services from them. There is also a lack of clarity regarding who this group of children 'with a life-threatening condition' may be and, as with the general community, a fear of death and dying.
- Some settings are inappropriate for children with life-threatening conditions. For example, it is difficult to mix very frail children with some others; some cognitively intact children are distressed when in an environment with children who are not able to interact and have highly complex needs; the physical design, fittings and equipment of some facilities may be unsuitable for particular groups of children.

Age groups

- Service options are often not specifically tailored to particular age groups (e.g. the needs and interests of younger children may differ from teenagers).

Geographic areas

- Although the survey response was incomplete, services do not appear to be spread equally across all regions. It would appear that people in northern and western metropolitan and regional areas have relatively fewer options than others, and that the North & West and Southern Metropolitan Regions will face increasing demand for services in future years.
- Transport to and from respite is an issue in rural regions, and is problematic when unplanned/emergency support is required.
- Funding rules and regional barriers sometimes require a family to travel further than the closest available service.
- There is variation between local government areas in the availability of in-home respite through HACC.

Types of care

- Many families prefer in-home respite so they can be available for their child and because it is an environment that the child is comfortable with. In-home respite can reduce anxiety for families because they understand the security of the home and can help to maintain a sense of togetherness within the family. In-home respite for children with life-threatening illnesses, both metropolitan and regional, requires more trained in home carers.
- There is a shortage of out of home respite particularly in regional areas where respite options are limited by the availability of programs that are able to meet complex care needs (particularly for blocks of time rather than just a night or two).
- Planned weekend and school holiday programs appear to be particularly hard to access.
- Emergency respite is in short supply however is a critical part of the equation for families with children with a life-threatening condition.

CALD groups

- The evolution of the sector has (in general) yet to extend to the tailoring of services specifically for people from diverse backgrounds. Most services will do their best to cater to particular cultural needs and wishes, however, while these efforts make some difference, most changes are superficial.

Lack of information

- Families have difficulty navigating the respite service system. Many regions have respite websites but they still require significant time and effort, and sometimes are not kept up to date.
- Families with individual packages often have the benefit of a case manager who can assist in navigation, but others don't and must rely upon their own efforts and informal (often imperfect) advice.
- Some services are difficult to contact and slow to return calls.

Funding restrictions

- The respite system is difficult to navigate for families and service providers.
- The availability of flexible funds and packages to purchase care tailored to specific family circumstances has been a significant development; families not able to access these forms of funding are disadvantaged.
- There can be long waiting lists for packages, sometimes up to two years, which can be problematic where children have life-threatening conditions.
- The nature of available service can depend on the type of funding that the child is receiving and the 'rules' associated with the care provision. Some packages may restrict what can be purchased, for example, the capacity to fund travel for carers to families and/or to training or for some specialist services might be the factor that helps to make respite 'work' (particularly for those in rural areas). Similarly, sometimes in-home respite is restricted solely to the child with a life-threatening condition and requires other arrangements to be made for the concurrent care of other children.
- Where families are required to top up funding and/or there are fees associated with respite that are not met from within funding, cost can be an issue (particularly given other financial burdens that may have resulted from the child's condition e.g. reduction in paid work to spend time with child).

Staff Skills

- Parents report difficulty in accessing respite with suitably qualified staff that understand and are able to address the child's specific requirements. Services do not always incorporate staff training and/or a level of qualification to address the needs of some groups.
- Some 'complex' tasks could be devolved if there were clear guidelines, proper assessment of the child and the situation, training and support for carers (including back-up). Personal care attendants can be trained to do PEG feeds, suctioning etc, but there are broader issues relating to task/role delineation (between nursing and care staff) that often prevent this occurring.
- Many facility-based services don't have 'active' nights and there are concerns that children won't be supervised or might not receive the attention they require through the night.
- In-home respite can sometimes be obtained through HACC or purchased with other funds, however most of these programs have been geared to the elderly and are provided by relatively poorly paid workers with limited skills. Some Councils will use HACC funds to purchase nursing care, but many won't as the cost is prohibitive.

Flexible respite options

- Flexible options including a range of types of respite care, that can be changed/shaped to meet changing needs and circumstances, are the ideal. Consultations have talked about families having to fit into services rather than the other way round; however, given the size and spread of the population, it is likely to be impractical to provide a full range of options all around the state.
- Environments need to be suitable for the child and offer the child a pleasant experience. Programs could be geared up to provide a more stimulating and enjoyable range of activities for the child.

SERVICE DEVELOPMENT

There are a range of options that might be considered to address barriers and gaps in service delivery. Implementation of a number of these would require collaboration and joint action from Disability Services and the Cancer & Palliative Care Unit, as many children with a life-threatening condition meet the eligibility requirements for both disability services and palliative care.

Better Information, Planning and Coordination

A service system must be able to provide both regular planned respite *and* be responsive at short notice when unpredictable needs arise. Short-term care needs to be provided as part of a coordinated, integrated package of support for families, rather than in isolation as a single type of support.

Awareness and coordination of services is seen as a key strategy in seeking to better define and strengthen respite outcomes:

- Provide education to respite services so they have an understanding of the children with life-threatening conditions and their needs.
- Ensure all relevant services are aware of eligibility criteria and steps that they should take to determine the care requirements and plan services for children with life-threatening conditions.
- Enhance respite planning for families with children with life-threatening conditions and regularly review the child's needs to ensure appropriate respite allocation. Planning should be holistic and consider the needs of all family members.
- Provide care manuals for each child so intake and care staff at different respite services are aware of what is required to adequately meet the needs of each individual and this does not have to be revisited.
- Fund access to case management for children with life threatening illnesses.
- Provide funding to palliative care consortia to build relationships and referral pathways with disability and HACC services in order to facilitate flexible respite solutions for families.
- Develop Fact Sheets explaining exactly what is available for families with a child with a life threatening condition and ensure these are widely distributed.
- Hold open days at respite centres so families can see them in operation.

Expand Level and Range of Services

Respite is of great importance to families - a mix of options in a variety of settings is what's required. Services should be able to be supplied in a variety of ways e.g. facility based, host carer/family respite, paid carer schemes, in-home care, day and evening outings, holiday programs, camps and short stays, etc.

While limited response to the survey makes it difficult to be precise about particular areas and/or types of service in short supply, there are a number of initiatives that will improve overall access:

- Explore options for the utilization of VSK expertise to assist other respite services that express a willingness to provide support for children with a life-threatening condition.
- Target existing facilities that have a capacity to expand (e.g. offer additional weekends at facilities that currently offer only one weekend per month), on a trial basis if necessary.

- Target providers not currently servicing children with life-threatening conditions or only providing limited service – expansion or extension may be possible if support and funding was available.
- Prioritise those services that have a capacity to provide emergency/ short notice support, and those providing weekend and school holiday programs.
- Consider the provision of recurrent operational funding for VSK House.
- Review the future need for out of home respite for children with life-threatening conditions in the northern and western suburbs.
- Provide additional funding to the Victorian Paediatric Palliative Care Program (VPPCP) for the Flexible Support Fund and for an enhanced education/ training and support role.
- Encourage services to provide more activities for children with life-threatening conditions and more varied options e.g. camps, outings and recreation for children, that also contribute to meeting the emotional, social and developmental needs of children.
- Explore the provision of funding in rural areas to support innovative occasional out of home respite services similar to that provided by the Goulburn Valley Support Group and Boost4Kids in the Barwon region.
- Develop playgroups that include allied health support and social interaction.
- Encourage services to provide suitable and appealing facilities.
- Provide support for equipment, transport and vehicle modification.
- Develop protocols that allow regional families to access the closest available service, overriding any restrictions related to administrative boundaries.
- Explore the viability of a statewide register/bank of nurses that could provide respite in a variety of in-home or out of home settings.

Provide More Flexible Funding

Respite may be provided in many ways - navigating the multiple funding programs, services and levels of Government to obtain clear information on respite access and support has consistently been raised as a major issue:

- Provide more flexible funding (allowing funds to be used not just for respite care, but also for coordination and training of carers, transport, payment of care related fees etc)
- Ensure there is adequate education and awareness amongst families and services of how funding packages may be used.
- Provide DHS Regions or a key statewide service (e.g. VPPCP) with a pool of (recurrent) discretionary funds that may be used when other funding sources have been exhausted for particular families.
- Develop a priority system to ensure immediate access to funding/support for families whose children are deteriorating or families that have needs assessed to be urgent (e.g. main carer becomes sick, death in a family).

Workforce Development

Respite care for children with life threatening conditions relies on the availability of suitably qualified staff that understand and are able to address the child's specific requirements (even when facilities and infrastructure are available):

- Ensure adequately trained staff and coordinate training and support for staff including, where appropriate, palliative care training for staff in non-palliative care services.

- Address recruitment barriers and promote greater continuity in staffing through a range of workforce retention measures.
- Support councils and agencies to put forward staff who are qualified/interested in working with the target group and develop regional 'banks' of workers capable of meeting additional needs (specific additional training may also be provided).
- Provide additional funding to build on the VPPCP training role including extension to cover local government and other providers.
- Support regional areas with outreach using Internet, web cams and secondary consultation.
- Establish a high level Committee with representation from key stakeholders including Disability Services, the Cancer & Palliative Care Unit, HACC, the Australian Nursing Federation and the Municipal Association of Victoria to examine barriers and develop solutions to overcome issues restricting the provision of respite to families of children with a life-threatening condition.

RECOMMENDATIONS

1. DHS Cancer & Palliative Care Unit and Disability Services Division work together to implement the initiatives recommended in this report.
2. Develop and implement an information and education strategy for respite providers on the needs and requirements of families with children with a life-threatening condition.
3. Streamline processes for families by having a centralised point for information on available respite services, referral, case management and the development and provision of care plans and manuals.
4. Fund palliative care consortia to build relationships and referral pathways with disability and HACC services in order to facilitate flexible respite solutions.
5. Provide additional funding to the VPPCP to enhance their education/training and clinical support role to local government and other respite providers.
6. Explore options for the utilization of VSK organisational expertise in providing specialist respite for children with a life-threatening condition to assist other respite providers to expand or extend their services.
7. Consider the provision of operational funding for VSK House.
8. Review future needs for out of home respite in the northern and western suburbs.
9. Review expenditure patterns and guidelines for the Flexible Support Fund managed by the VPPCP to determine future requirements.
10. Provide funding in rural areas to support innovative occasional out of home respite services.
11. Develop protocols to enable regional families to access the closest available service.
12. Explore the possibility of establishing a statewide register/bank of nurses that could provide respite in-home and out of home where needed.
13. Establish a high level Committee with representation from key stakeholders including Disability Services, the Cancer & Palliative Care Unit, HACC, the Australian Nursing Federation and the Municipal Association of Victoria to examine barriers and develop solutions to overcome issues restricting the provision of respite to families of children with a life-threatening condition.
14. Maintain and further develop service maps to enable a greater understanding of availability and requirements.

ATTACHMENT A

A wide range of stakeholders contributed to the project:

Organisation	**How Involved**		
	Provided names of services to be surveyed	**Assisted with data collection from families**	**Stakeholder interview**
Association for Children with a Disability	✓	✓	✓
Carers Victoria	✓		✓
Commonwealth Carer Respite Centres	✓		
Compassionate Friends		✓	✓
Cystic Fibrosis Association	✓		
Department of Human Services ▪ Cancer and Palliative Care Unit ▪ Disability Services Division ▪ Children, Youth and Families Division ▪ Regional Disability Coordinators	✓		✓
Eastern Palliative Care	✓		✓
Goulburn Valley Support Group			✓
Heart Kids	✓	✓	✓
Leukodystsrophy Association	✓		
Melbourne City Mission			✓
Mercy Palliative Care			✓
MOIRA			✓
Monash Medical Centre		✓	✓
Municipal Association of Victoria			✓
Muscular Dystrophy Association	✓		
Paediatric Integrated Cancer Service			✓
Palliative Care Victoria			✓
Royal Children's Hospital ▪ The Victorian Paediatric Palliative Care Program ▪ Family Choice Coordinator	✓	✓	✓
Royal District Nursing Service			✓
Spinal Muscular Atrophy Association	✓		
Very Special Kids	✓	✓	✓
Wimmera Palliative Care			✓
Yooralla	✓		