Submission to the
Senate Community Affairs Committee
Inquiry into
Palliative Care Service Provision in Australia

Pictured: Mark and Fiona Engwirda with their children (L-R) Harrison, Kate and James taken at Bear Cottage.

Mrs Fiona Engwirda

To the Senate Inquiry Committee,

As a family we have experienced first-hand the disability sector. Two of our three children have significant life-long disabilities. As a result of this experience we provided paediatric palliative care and complex medical care management to our profoundly disabled daughter, who passed away in May 2011.

We acknowledge the difference that exists between disability and palliative care but also the cross over that is intrinsically linked for many children with complex medical conditions.

It is our hope that by sharing our personal experiences and recommendations we can contribute towards highlighting the need for continued change within the paediatric palliative care and disability landscapes.

Yours Sincerely,

Fiona Engwirda

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Appendices

The Royal Australian and New Zealand College of Psychiatrists, October 2011

Addressing the needs of siblings of children with disability or chronic illness.

Family Demographic:

Mark Engwirda: Building Designer – Blueprint Designs (small business owner)

Fiona Engwirda: Qualified Classroom Teacher and Musician

Married: 12 years

Combined annual income 2011: $75K

Children: James Engwirda (9)
Harrison Engwirda (8) diagnosed Autistic
Kate Engwirda 9.12.08 – 21.5.11

Terms of Reference

The provision of palliative care in Australia, including:

(a) the factors influencing access to and choice of appropriate palliative care that meets the needs of the population, including:

- *(i) people living in rural and regional areas,*
- *(ii) Indigenous people,*
- *(iii) people from culturally and linguistically diverse backgrounds,*
- *(iv) people with disabilities, and*
- *(v) children and adolescents;*

(b) the funding arrangements for palliative care provision, including the manner in which sub-acute funding is provided and spent;

(c) the efficient use of palliative, health and aged care resources;

(d) the effectiveness of a range of palliative care arrangements, including hospital care, residential or community care and aged care facilities;

(e) the composition of the palliative care workforce, including:

- *(i) its ability to meet the needs of the ageing population, and*
- *(ii) the adequacy of workforce education and training arrangements;*

(f) the adequacy of standards that apply to the provision of palliative care and the application of the Standards for Providing Quality Care to All Australians;

(g) advance care planning, including:

- *(i) avenues for individuals and carers to communicate with health care professionals about end-of-life care,*
- *(ii) national consistency in law and policy supporting advance care plans, and*
- *(iii) scope for including advance care plans in personal electronic health records; and*

(h) the availability and funding of research, information and data about palliative care needs in Australia.

Summary of Experience: Paediatric Palliative Care

The Diagnosis of Disability:

Prior to Kate's birth, it was evident from the 19 week scan that she suffered a congenital cardiac defect known as *Tetralogy of Fallow*. Tetralogy of Fallow is rare, but it is the most common form of cyanotic congenital heart disease. Patients with Tetralogy of Fallow are more likely to also have other congenital defects. The cause of most congenital heart defects is unknown. At birth the cardiologists believed that Kate would develop typically but would require open heart surgical repair of her heart defect. Her genetic profile proved to show no abnormalities that could be identified at the time her prognosis looked relatively positive.

Unfortunately this was not the case, as at 12 weeks of age Kate developed seizures and was diagnosed with microcephaly which means small head and brain – as a result she suffered severe epilepsy, respiratory difficulties and regular episodes of apnoea, where she would stop breathing. She also had difficulties feeding and maintaining weight and required nasogastric tube feeding with a continuous flow care pump, as well as continuous oxygen.

Impact of Care Requirements:

Due to Kate's complex medical requirements she required intensive 24 hour care, which was provided by my husband and I, with no outside nursing help and minimal respite funding. The first 18 months of Kate's life was spent bouncing in and out, but mostly in hospital. A significant focus during this time was given not only to her healthcare and stabilisation but to my education. I spent many hours during those hospital admissions in addition to caring for Kate, learning how to medically manage her care. This involved becoming competent in insertion of Nasogastric Tubes, providing oxygen therapy, providing relevant heart rate and oxygen saturation monitoring, trialling feed types and rates of administration through a *flowcare* feed pump, managing seizures, medication regimes, faecal management and use of enema's, and later the management of a *port-o-cath.*

These care requirements had a profound and devastating impact on our family.

Due to the nature of Kate's condition, she was quite unstable and required hospitalisation for treatment almost weekly. The precarious balance between home life and hospital management of a baby so complex was extremely difficult, our other children were experiencing much hardship, particularly Harrison (due to his Autism) who found it difficult to cope with the frequent and quick household changes that occurred without warning. In order to manage life at home for Kate's siblings, (James and Harrison) my husband (who has runs a small business in Building Design) relocated his office to home so he could provide continuity of care to our boys whilst I managed Kate, including her admissions and 24 hour nursing requirements. This move (coupled with the GFC) has had a profound impact on the business' ability to continue to earn income, and we suffered significant financial hardship. *(see financial impact section)*

At this time we were not registered with DSQ (Disability Services Queensland) nor did we have, or were aware of respite funding, what it was, or how we could access it. The hospital system did not distribute information about respite or make an attempt to link us with any service until Kate was 6 months of age – we were granted emergency funding by DSQ as I presented (in tears) to a local DSQ office, obviously stressed, exhausted and overwhelmed with the situation we found ourselves in.

It was through my own research and talking to other parents that I became aware of HACC (Home and Community Care) funding and located a service directory (after many hours of internet searching) online. I proceeded to ring every service provider in our local area, in order to see if they could provide us with funding for respite – after days of phone calls. I had 3 service providers lined up for interviews, after a lengthy and exhaustive process, these interviews translated into a total of 16 hours of in-home assistance per week. Not even 1 night per week. I proceeded to fill in the 70 page application form for Centrelink's disability funding in my spare time. The paperwork and process driven system of obtaining funding on top of the emotional and physical demands of caring were relentless.

Palliation:

The doctors couldn't find a reason why Kate had so many medical problems – it is thought that she has a syndrome so rare it could not yet be identified by genetics. Kate spent 40 weeks and most of the first year of her life, in hospital – Kate underwent countless operations including Open Heart Surgery (aged 9 months). It became evident at 12 months that her heart could not be repaired further and that she had a *Pulmonary Stenosis* (Stenosis occurs when the valve cannot open wide enough allowing less blood to flow to the lungs) and a remaining *Ventricle Septal Defect* (many holes in the wall that separates the right and left ventricles of the heart), both defects could not be surgically repaired.

On her first birthday we were told that unfortunately Kate's heart anatomy was unable to be fully repaired – sadly she was deemed "palliative" and referred to another hospital for palliative care in January 2010. The doctors were uncertain how long her heart would keep working for – her big brothers James and Harrison understood that their sister Kate would not grow up to be big like them, a huge realisation for boys so young.

Our daughter (Kate) experienced care across 2 major children's hospitals in Brisbane. This was a difficult experience for the logistical medical management as different hospitals specialise in different medical conditions.

The next 15 months Kate was lucky to spend mostly at home – with many regular appointments at both hospitals with different specialist teams. Little in-home support or respite was offered to us and despite the fatigue Mark and I cherished each day and provided full-time care to Kate 24 hours, 7 days a week. As parents we devoted much time to sourcing funding for various medical equipment and respite – negotiating a difficult system with limited support. Respite was limited and all funding only available only to be used in the home. We **never** got a full night's sleep - this was a tough gig – one which we endured because of devotion – and out of pure love for Kate.

In a bid to provide our family with respite options, RCH's Paediatric Palliative Care Service referred us to a facility in Sydney that provides end of life care to children at no cost to families. Funds were sourced (approx $600) via *Xavier Children's Support Network* as part of their *HACC funding* for family "breakaway packages" to contribute towards our airfares.

In 2010 we travelled interstate to NSW to visit Bear Cottage a purpose built facility that could provide appropriate paediatric care for children like Kate who were required specialist palliative care -while our family enjoyed some much needed respite. We valued this experience and the full nights of sleep that came with it.

Events surrounding Kate's end of life:

In 2011 we returned for another much needed respite break, as no such facility existed in QLD. Little did we know that on this holiday we would experience firsthand the grace with which end of life care **can** be provided.

Unexpectedly and tragically whilst on holiday on 21st May 2011, Kate suffered sudden cardiac arrest. Luckily we were surrounded by the beautiful staff and surroundings of a place that specialised in Paediatric Palliative Care.

How different it would have been if Kate had died in her home state of Qld?

Qld has no such paediatric palliative care facilities, the options for your child are to either die in hospital and not be guaranteed of a private setting, or die at home. Neither of these options were appealing to us for differing reasons.

Bear Cottage (in NSW) has trained staff and purpose built facilities that cater to children and their families when a child dies and also when they are experiencing long term palliative care. Whilst Kate's death was sudden and somewhat unexpected, the staff showed professionalism, care and compassion. The facilities allowed us to have Kate located posthumously in a 'cool room' which was decorated and furnished beautifully like a child's bedroom. As we had to organise funeral directors and make arrangements for repatriation, Kate was kept here for just under 3 days. This gave our family valuable time to do, and say all that we needed to, and was a valuable start to our grieving process. On the day that the funeral director came to take Kate, Mark and I, lovingly tucked her into her small white coffin with only the gentle touch of love that parents can give. This was an opportunity not afforded to many and one for which I am forever grateful.

Kate chose to close her eyes for the last time in the knowledge that her and her family were in the best of care. Having this experience has made the journey of loosing Kate that little bit easier for both Mark and I and our boys James and Harrison. Our hope is that Queensland families have the opportunity to choose care like this if they desire.

Financial Impacts:

Due to the care requirements, my husband Mark needed to relocate our small Building Designs business office to the home, in order to provide continuity of care to our other children. This move not only cost us financially, but also put the business in a position of being outside the marketplace, which has had implications for the propensity to earn income.

In addition, I was forced to close down my small business as a music teacher in order to become a full time carer to Kate. Whilst we did receive carer allowance payment, this is in no way subsidised the cost of caring for Kate, our loss of income or even covered her weekly medication costs.

Example/ breakdown of expenditure:

In the final year of Kate’s life, our private health fund (Teachers Union Health) paid out $189K toward the costs of hospitalisation, therapy, medication and the other related costs.

Our personal out of pocket cost was $30K, which was paid for after tax dollars, and only 10% was rebated under Medicare.

These costs were for services such as:

Specialist doctors GAPs
Speech Therapy/Occupational Therapy/Physiotherapy
Medication not covered by PBS
Medical Equipment (hire and purchase)
Wheelchair
Medical consumables not provided for in-home nursing
Hospital parking and hospital generated expenses

Respite costs and respite provider services fees

This figure does not include funeral costs, repatriation expenses, burial costs or other associated expenses generated as a result of Kate's death which totalled $12K.

As a family, the financial cost to us (out of pocket) for the treatment of both our children's disabilities is in excess of $300K (of after tax dollars). We are in a situation where financially we can no longer sustain this, and if the situation does not improve, we may be forced to sell our home. This is yet another strain on our family and stress on our marriage and another loss and hardship to our family, as if losing a child isn't enough.

Equipment funding and Sourcing:

During Kate's life she required many various different medical aids and equipment that allowed her care to be given in the home and for her to be able to access the community. Some equipment was sourced and loaned from the both Mater Children's Hospital and the Royal Children's Hospital, other equipment was loaned by community care organisations and some purchased by us personally due to unavailability.

A lack of transparency exists within this process and communication between government and non government organisation is nonexistent. Leaving parents in a position where they are required to articulate and advocated their child's needs whilst managing their child's care. This is very difficult to maintain long term sustainability when experiencing the stressful nature of caring for your child who is experiencing acute and serious medical complications.

To follow is a break down the equipment and the source that indicates the complex nature of securing equipment within the hospital and community context. Securing funding and obtaining this equipment depended largely on my skill to advocate within the system and required much of my time in discussing our needs with various specialists and organisations

***Table:** Demonstrates the complex nature of securing equipment within the hospital and community context.*

Equipment	Community Organisation/Funding Body	Referral Process
Oxygen tanks for in-home and portable use	MASS (Medical Aids Subsidy Scheme) Paediatric face masks supplied. Tubing not supplied Low flow paediatric oximeter not supplied rent = $15 per month	3 monthly referral from Paediatric Respiratory Specialist.
Nutricia – Feed pump	Mater Children's Hospital	Mater Children's Hospital - Dietician Team
Nutricia – Feed pump supplies	Homeward HENS program Mater Children's Hospital (external tender to Nutrica)	Mater Children's Hospital - Dietician Team (3 monthly script)
Medication Pole – for feed pump	Xavier Children's Support Network (equipment loan pool)	Occupational Therapist Xavier Children's Support Network
Suction Unit	In home unit – Mater Children's Hospital Portable unit – Royal Children's Hospital	Mater Children's Hospital – Complex Care Team via Paediatrician
Therapy Equipment	Vision Australia	Self referred
Specialised Sleeping Support System	Purpose made by Royal Children's Hospital Rehabilitation Department.	Royal Children's Hospital – Palliative Care Team Dr Anthony Herbert
Tumbleform Seating System	Xavier Children's Support Network (equipment loan pool)	Occupational Therapist Xavier Children's Support Network
Oxygen and Heart Rate Monitor	Private Purchase = $1200	Self Sourced due to unavailability
Apnoea Monitor (first 12 months)	Mater Children's Hospital	Mater Children's Hospital - Cardiologist
Wheelchair = $11K	Partially funded by: Disability Services Qld Commonwealth Care Respite Services FSG Australia (emergency funding) Parent Contributions $3K	Supported by Disability Services Qld & Xavier Children's Support Network Occupational Therapist referred.

Sibling Support Services:

Our eldest boy James was lucky to access a sibling support program run once a month by *Xavier Children's Support Network*. He was happy to attend this program and looked forward to the regular interaction with other siblings and was supported by this process.

Unfortunately when Kate died, we were told (due to funding restrictions) James was no longer eligible to attend this service, as Kate was no longer a client due to her death. Despite approaching the service to offer to provide a user pays contribution option we were unable to secure his attendance. Unfortunately when James most needed support it was not available to him. In Queensland, child grief and bereavement services are not readily available in the community. As an example of service inequity, if Kate had died of cancer, James would be able to access support and counselling through the Red Kite organisation. No such options are available to non-oncology patient siblings.

After 9 months of searching for an appropriate service provider who specialises in paediatric grief and loss, we have found a service, thus we continue to pay privately for his weekly 1:1 sessions. To date we have not been able to locate an appropriate group peer sibling program that can assist our boys in adjusting to the loss of their sister or addressing the issues that having a disabled sibling brings.

James unfortunately is the eldest of two siblings with a disability, not only has he experienced more of life's hardships than most of his peers; he experiences daily what it is like to have siblings with a disability. He will one day become his brother's carer. Evidence based research noted in the report detailed below, suggests these siblings are 'at risk' and that early intervention and support is critical for siblings.

[1] *"Inspite of the obvious need, siblings continue to be overlooked and services remain inadequate. At an immediate level, siblings are not good advocated for themselves; they are rarely 'a squeaky wheel', as they often feel guilty or disloyal if they discuss their concerns. Of course, parents are often so stretched emotionally and physically that it is difficult for them to always address the issues or advocate for more sibling support. However there are a number of systemic gaps that contribute significantly to the inadequacy of services for siblings."*

Bereavement Support Services:

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[1] The Royal Australian and New Zealand College of Psychiatrists, October 2011

Addressing the needs of siblings of children with disability or chronic illness.

Grief and loss following the death of a child is significant and a very difficult experience for families and couples, exacerbating the usual stress on marriage and families. In our experience, no free counselling has been offered by any services providers. Very few service providers are experienced in assisting parents with the grief and loss of their child.

Until recently in Brisbane, there were no services that provided support by trained professionals to grieving parents (the previous service closed due to funding cutbacks). Royal Children's Hospital is currently running a pilot program which provides a monthly opportunity for couples to engage in discussion about their experiences of grief and loss with other couples. Interestingly, many more females than males attend and the opportunity for private couple therapy does not currently exist. However in another example of service inequity, if we were experiencing the loss of a child due to cancer, we could access counselling. Due to the financial hardship we are experiencing we are not attending regular private 1:1 counselling sessions.

Recently with assistance of fundraising money, my husband and I had the opportunity to go to Sydney and return to Bear Cottage where Kate died. Bear Cottage utilises a fantastic bereavement model and host a 'Back to Bear Cottage BBQ' for families experiencing the grief and loss of a child. We felt it was imperative to go and the experience was both healing and worthwhile. Grief is not something you can quantify and just 'get over' - it is an ongoing and difficult process.

Paediatric palliative care is about supporting families during *and after* the patient/child has died. As a family we felt abandoned by service providers, as those who did support us could no longer afford to continue to support us during the bereavement phase post death, as funding dollars are scarce and many children wait for such services. Service providers are forced to put their funding where the perceived need is greatest, with little thought to the long lasting effects a child's death has on a family.

Response to the following Terms of Reference:

(a) the factors influencing access to and choice of appropriate palliative care that meets the needs of the population, including:

- Currently there is only one state wide specialist paediatric palliative care service. Two children's hospitals service the paediatric needs of children in Queensland. The lack of centralised paediatric palliative care services means that families with children whom have many complex medical issues are required to split care between facilities which makes medical management very difficult.
- Equity issues for accessing support services – accessing support services and the success of, largely depends on the ability of the parent to advocate and their level of education, cultural heritage
- Support services are more readily available for non oncology patients.
- Lack of <u>access</u> to appropriate respite facilities = no equitable <u>option</u> for care due to the fact that Queensland has no paediatric respite facility or children's hospice.
- Lack of appropriate children and adolescent support services for Grief and Loss, and limited services only available for couples, families and siblings.
- Siblings and families do not appear to be considered a priority in the equation of palliative care service provision and receive little or no funding as a consequence.

Recommendations:

- Increase funding to the current state wide specialist paediatric service to provide specialist representation in both children's hospitals – and increased service provision and access for rural and remote areas.
- Provide funding for training opportunities to educate parents about the system and their advocacy rights. This must be offered at the point of diagnosis to ensure early intervention for families learning to negotiate care and advocacy in the early stages.
- Ensure equitable distribution of funding for both oncology and non oncology services, taking into account the monies allocated and generated by high profile charities such as cancer.
- Address the inequitable of options for respite and end of life choices, by funding a paediatric respite facility which specialises in end of life care.
- Acknowledge that siblings and families are a valuable part of paediatric palliative care and require increase support. Provide funding for increased support services for grief and loss issues for couples, families and siblings.

(iv) people with disabilities,

Issues surrounding respite services for paediatric patients/high care disability with life limiting illness:

- no children's respite facility in QLD
- no children's hospice in QLD
- difficulties accessing sufficient in home support via HACC
- strain on families to provide 24/7 care
- implications of more lengthy time frames for paediatric palliative care = carer fatigue

Recommendations:

- Provide initial funding to build a children's hospice in Queensland. Ensure sustainability of that service by providing a commitment to ongoing annual funding.
- Acknowledge the difference that lengthy time frames of paediatric palliative care have on families. Address the difficulties and lack of transparency in accessing respite funding from services such HACC.
- Address carer fatigue by providing a significant increase to the number of respite hours that are available to families providing 24/7 care to medically complex children in palliative care.

Continuity and dissemination of critical information:

- The sector demonstrates a lack of integration of services delivery. There is generally a lack of communication between both government and non-government service providers which translates to inconsistent information distribution and ignorance. In practical terms families often miss out on important information that may be crucial to assisting them and their needs.
- Critical information about the availability of services and referral to such services are often overlooked.
- Lack of consistent dissemination of information regarding entitlements and services for carers.
- This critical 'pathway' of information sharing for families such as ours, are paramount to link families from long term hospitalisation into care in the home/community.
- Families are put 'at risk' if this pathway is not rectified.

Recommendations:

- Provide funding for implementation of programs which explore communication and information sharing with service providers, in both government and non-government organisations.
- Identify the pathway from which families get information about services and referrals at the point of diagnosis.
- Devise a cohesive strategy that ensures families receive all the relevant information about disability and palliation. For use in hospital and by community organisations distributed by medical professionals, social workers, government and non-government departments - ensuring provision of this valuable information with continuity.

(v) children and adolescents;

Many children experiencing life limiting illness/palliative care require intensive treatment and care for many years. It is not simply a diagnosis that lasts three months. This significantly impacts families in many ways;

Financial Impact on families;

- Inability for carer providing 24/7 care to remain in workforce.
- Impacts on family income, due to being reduced to a single income.
- Further financial impact to the self employed or small business owners.
- Those with private health insurance are not benefited in the health system when it comes to complex care arrangement of disabled patient/often disadvantaged financially to cover out of pocket gap etc
- Our private health fund paid out $189K the last year of Kate's life.
- Our *out of pocket* cost that year was $30K - this was paid with "after tax dollars"... and only 10% is rebated under Medicare.
- Inability/difficulties to access funding for equipment, often experienced lengthy wait times – stress of negotiating Govt Dept such as *Disability Services Queensland* in addition to carer requirements.

Recommendations:

- A review of the current % of Medicare Tax Rebate – families whom are providing such care should not be financially disadvantaged to the degree that they currently are.
- If a family is providing palliative care to a child, expenses relating to this care should be claimable with "before tax dollars".
- Increased financial support to small business owners experiencing hardship due to the care requirements of caring for a family member in palliative care.
- Financial remuneration or cash payment to carers whom exit the workforce in order to provide 24/7 care to their child who is experiencing palliative care.
- Revise the process of provision of funding and equipment to ensure that those experiencing palliative care are given both as a matter of priority.

Respite Availability and Funding:

Implications for the lengthy time frame of children being in palliative care has far reaching impacts on need for respite on families, due to carer fatigue and carer burnout.

- There is currently a lack of transparency of funding sources which contributes to difficulty for carers to locate relevant services.
- More funding is required for an increase in respite hours for carers providing 24/7 care to their children in the home.
- A specialised Paediatric Palliative Care Hospice is required to provide carers with the option of 'out of home' respite.
- Flexibility of funding (need for a self directed funding model) is required in order to give families the equity and flexibility to use funding how they see the need. One model does not fit all.
- Carers often have difficulty in sourcing and obtaining funding for much needed disability equipment, this is often a very lengthy process which is stressful when a child is palliative –the requirement of equipment is paramount to quality of life, absence of such equipment may be considered discriminatory.

Recommendations:

- Provide transparency articulating funding sources which will enable carers to locate relevant services more easily.
- Implement more flexibility of funding with the inclusion of a self directed funding model for respite funding, which can be used by all service providers.
- Build a children's hospice in Queensland which is sustainably funded.

(h) the availability and funding of research, information and data about palliative care needs in Australia.

- Currently there are only limited statistics or data related to palliative care service delivery via programs such as Palliative Care Outcomes Collaborative (PCOC).
- The sector experiences a lack of funding for research in palliative care and particularly Paediatrics.
- Funding is required for research to gather information and data about *where, how and why children die,* in order to establish data which identifies the areas of need and to ensure advocacy and ultimately equitable distribution of services and funding.
- Further development of policy change requires research data.

Recommendations:

- Consult peak advocacy bodies and key stakeholders to ascertain if the current research and data available is appropriate for use.
- Provide funding for any subsequent research required.