

This submission has been edited in consultation with the author to preserve privacy

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Health and Community Services Committee
Parliament of Queensland
hcsc@parliament.qld.gov.au

Dear Sir/Madam

Thank you for the opportunity to make a submission to this important inquiry. I would welcome the opportunity to address the public hearings and expound on this submission. Please note that, should you wish to make submissions publicly available, I would appreciate the opportunity to de-identify this submission for the sake of my daughter. Please contact me to arrange this as de-identification would require more than crossing out her name given the rarity of her condition.

1. My daughter's medical condition, in summary

My daughter, [REDACTED] is aged four, a happy, affectionate, beautiful little girl who is full of energy and has a wicked sense of humour. She also has multiple life-limiting, life-threatening medical conditions, global developmental delay and a very uncertain future.

[REDACTED] was born [REDACTED], the size of a 27 week baby but born at 34 weeks. Her tiny size (less than 1kg) was a mystery. She spent the first three months of her life at the Mater Mothers Hospital in the intensive care, high dependency and special care units before discharge home [REDACTED] then spent the next four months of her life bouncing in and out of hospital until in February 2009, at age 8 months, she was admitted in what was to be an horrendous, year-long hospital admission.

At the start of 2009 our daughter developed intestinal failure and was placed on long-term Parenteral Nutrition (PN – a complex life support therapy whereby complete nutrition is given intravenously). Because this is only available publicly through the Royal Children's Hospital (RCH), [REDACTED] was transferred from the Mater Children's Hospital to the RCH. PN therapy is associated with high morbidity and mortality, the major risks being life-threatening septicaemia, thrombosis, running out of large veins suitable for PN infusion, and liver failure. [REDACTED] has had two episodes of septicaemia, extensive thrombosis throughout the right side of her body, leaving us only two major veins through which PN can be administered for the remainder of her life, and is in the early stages of liver disease.

The PN therapy that keeps her alive also limits her life expectancy. She may live for many years, some years or only months depending on the complications that might arise. Each day is uncertain and, therefore, precious.

[REDACTED] also has numerous other life-limiting conditions.

Mid-way through 2009 our daughter went into respiratory failure and became dependent on overnight ventilation and spent 6 months in the Paediatric Intensive Care Unit (PICU) while her condition was stabilised such that we could take her home on PN and overnight non-invasive ventilation. She was discharged home from PICU in December 2009 and remained on overnight ventilation until January 2011. She is now considered to be in borderline respiratory failure.

█ also has █ (itself a life-threatening condition if not managed appropriately), █. Her overall condition is █ of a type never before seen by geneticists. She is literally the only child with her condition in the world and we therefore have no clear prognosis.

█ has grade 4 airways, meaning only a highly trained anaesthetist or intensivist would be able to intubate █ in a respiratory emergency. When the Prince Charles Hospital becomes the only paediatric option available on the northside, we will no longer have safe tertiary medical care available on our side of town and will have to hope for timely transport to the Queensland Children’s Hospital in an emergency situation.

2. Impact on my family – very brief summary

█ We relocated to █

█ maintain a 24/7 presence at █ bedside while she was an inpatient in 2009, and so, after discharge, we could safely manage █ multiple weekly appointments and numerous unplanned, emergency trips to the Department of Emergency Medicine.

My husband sold his business and I resigned from a permanent senior officer position in the Queensland Public Service. We have exhausted much of our savings and now rely on intermittent contract work and the carer pension to meet our needs. For three years, my husband has cared for our daughter all night, every night, while I do the “day shift” in meeting our daughter’s care needs. We see very little of each other. We have privately borne as much cost as we possibly can but, being full-time carers for our child, we cannot generate funds for expensive medications, respite support or equipment.

3. Respite and disability support

Despite having global developmental delay, physical disabilities █ severe speech delay, oral motor planning coordination problems, and being tube fed (in addition to the PN), █ was not considered eligible for support through Disability Services Queensland (DSQ) due to her medical complexity.

At the end of 2009, we were discharged home with a child with 24/7, high risk, high complexity care needs without a single hour of respite support. Each night was a nightmare for our daughter with severe abdominal pain, bilious vomits and no sleep for anyone. Each day involved constant vigilance to prevent aspirating vomits, tend to our suffering child and prevent catheter fracture while she was on continuous PN infusions.

After three months, my family was nearly burnt out and hysterical from sleep deprivation. Although we had great support from Xavier Children’s Support Network, we could not use their respite carers

because [REDACTED] care needs were considered too medically complex and high risk for a paraprofessional support worker. We agreed with this assessment. My husband and I could not leave the house at the same time as one of us had to be with [REDACTED] at all times. I investigated all available respite programs, including the home ventilation program, for which our daughter was considered ineligible (despite being on overnight home ventilation).

We brokered support from highly trained agency nurses, funded temporarily by community agencies who wanted to assist us. During this time, I approached DSQ and Queensland Health (QH) for funding to continue the model of respite we had successfully set up, and which had restored us to sanity.

I was asked to complete one of DSQ's 60 or 80 page (can't remember now) applications for support which, many months later, was deleted without being read (I have the email receipt to prove this). After deliberations between QH and DSQ, it was decided [REDACTED] was too medically complex to come under the auspice of DSQ. QH decided to vary eligibility requirements for the home ventilation respite program and accept [REDACTED] into the program.

It wasn't until the end of 2010 (a year since discharge from PICU) that we had trained home ventilation carers coming to our home to provide respite. Although we are now very happy with the carers, this was a very distressing process for us as we had trusted agency nurses providing respite for many months and did not want to transition to paraprofessional carers when we had developed a safe respite model that worked for us.

I could not even begin to calculate the hours it took for me to lobby and advocate for the respite we now receive. However, the long-term security of this funding is unclear to me and we do not like having to rely on a specific respite program and carers.

Our ideal would be to receive self-directed funding where we could carefully recruit our own carers, train them, and use funding flexibly to meet our respite needs. Given this is accepted best practice and in line with the NDIS recommended model, it is disappointing that models of self-directed funding are not available outside the DSQ system, for children with medically complex care needs.

I should also declare that I worked as a social policy analyst for the Queensland Government for many years, before I ceased work due to [REDACTED] long term hospitalisation in 2009. If I had not been highly skilled in writing submissions, making business cases and, had I not personally know senior executives in the central office of DSQ and QH, I do not believe I would have had our case considered, nor received any kind of timely response. I declared openly that my preference was to approach our case the civilised way, within existing systems and processes, but that I would not hesitate to create a media spectacle if left with no option. I do not believe many other parents would have the skills and contacts I had, which enabled a supportive response.

Of about 13 children on long-term PN, I believe [REDACTED] is the only one to receive respite support.

The modest respite we receive pays huge dividends for our family and the health system. In the six months when [REDACTED] was being nursed in hospital by nurses, she had two episodes of life-threatening septicaemia, secondary to poor nursing of her central venous catheter and PN dependence. Since September 2009, when my husband and I assumed full care of [REDACTED] catheter and PN

administration (while still an inpatient and subsequently at home), [REDACTED] has not had a single episode of septicaemia.

The cost of central line associated septicaemia (bloodstream infections) is very high (average cost \$30-35,000 I believe). By keeping us well enough to nurse our daughter with a high degree of diligence, the public system has saved tens of thousands of dollars in preventable infections and hospital admissions, not to mention the huge quality of life benefit for [REDACTED] and developmental benefits from not being traumatised by preventable hospital admissions.

When [REDACTED] was discharged home, our doctors suggested that elective hospital admission was the only safe respite option available for [REDACTED]. At that time, [REDACTED] could only be nursed in PICU due to her complex care needs, which comes at a cost of \$4,000 per day on average. We considered this option obscene in terms of subjecting a child to unnecessary hospital admission, the high public cost and the stress and guilt for us of doing something so awful to our child simply to have a break. Needless to say, we did not take this option. In contrast, the respite services we receive cost far less than any elective hospital admission (whether in PICU or a ward), is much safer in terms of infection control, and is appropriate in terms of providing a nurturing environment for [REDACTED] at home.

I personally know several burnt-out parents, who did not receive respite, who have presented to hospital with fabricated symptoms in order to get “respite” via a hospital admission for their chronically ill children.

It is not a case of saving public money by not providing respite services: the costs are borne in other, hidden ways such as burnt out parents, family breakdown, preventable hospital admissions and attendant preventable hospital-acquired infections, and compounded trauma and developmental delay for children subjected to preventable hospital admission.

Summary and Recommendation regarding respite for medically complex children

- ***That QH and DSQ develop a model of safe, flexible, respite support for children with high and medically complex care needs. Needs assessment should occur before families are discharged home so supports are in place before they experience the shock of having their child at home. Funding should be guaranteed for as long as the child’s needs remain high and complex so families know they will be supported over the long term and do not have to waste time pursuing short-term funding solutions to a long-term problem.***
- ***I would caution against merging HACC funding with DSQ funding, given the current rigidity of DSQ services and the comparative flexibility of HACC funding.***

4. Paediatric Palliative Care

[REDACTED] came under the care of the Paediatric Palliative Care Service in March 2011. I asked for the referral as [REDACTED] was by then in untreated pain that rated 10/10 on pain scoring scales. At nearly three years of age, she could not sit unsupported, crawl or weight-bear in any way. At that time [REDACTED] was so unwell I realised we might be approaching the need for end-stage care and I wanted this to occur before we reached crisis stage. I began funeral planning for the second time in [REDACTED] life at this time.

The pain management which occurred following involvement of the PPCS literally transformed [REDACTED] life. Within one day she was sitting unsupported, within three she was crawling and pulling herself into standing. At four years of age, she now walks, runs, dances and chases balls in the park. This is due to a combination of pain management in the first instance, followed by outstanding gastro-enteral care at RCH which has improved [REDACTED] gut health and associated symptoms.

The PPCS has provided practical case coordination support and funding for consumables and medications that are beyond our financial reach. The PPCS has referred us for family holidays at Bear Cottage in Sydney, the only palliative care respite facility available for families in Australia. We have had two treasured family holidays there (including trips to Luna Park, the Play School studios, the beach etc) and are planning our third holiday in October. Friends have conducted fund-raising dinners to meet our travel costs.

While this is a fantastic service, the proposed Hummingbird House in Queensland is badly needed. We would dearly love somewhere local that we could get a break from intensive 24/7 nursing care and just be “mum and dad” or possibly even leave [REDACTED] there with her grandparents and have a few days break as a couple (something I can’t quite imagine at this stage!).

There are many other families who would be eligible for PPCS services but probably don’t know it. I suspect some research in this area would highlight a high degree of unmet need and lack of awareness about the definition used for the PPCS (eligible for children with life-threatening, life-limiting conditions where they are unlikely to survive to the age of 18).

I requested our referral to PPCS and only found out about the service from other families in the system. Our daughter’s consultant physicians were unaware that [REDACTED] was eligible for PPCS services as they thought it was only an end-of-life service. The benefit of early referral to PPCS is that it can maximise the quality of life for children before they reach end stage and families have the chance to form trusted relationships before they reach the unthinkable end-stage.

On this, I should note that some of the life-changing things that have occurred for [REDACTED] resulted from “hospital corridor” and “parents room” conversations with other parents (eg referral to the PPCS). Some thought is probably warranted as to how to tap into this to maximise word of mouth and peer support, but in a way that is appropriate to time-poor parents. For example, we are often invited by community organisation to family events, seminars and parents weekends but don’t have the interest, time, energy or respite support to enable us to attend these.

In contrast, an online forum, email group or something similar would be far more valuable and feasible from my point of view. If this could be moderated by QH and DSQ it could be a valuable and low cost peer-support initiative. Discussion groups could evolve around specific conditions, equipment, disabilities etc. Perhaps this exists and I don’t know about it!

Summary and recommendation re palliative care

- ***Research levels of unmet need for the PPCS, expand the service to meet this need, and focus on early intervention as well as referral at end-stage.***

- ***Support the development of Hummingbird House to provide Queensland families with support akin to Bear Cottage in Sydney.***
- ***Consider ways to facilitate electronic peer-support and information provision for time-poor parents.***

5. Conclusion

A summary of the past four years would highlight the following strengths of the system:

- Many dedicated clinicians who provide outstanding and compassionate care for children
- A high quality public health system that spares no expense in valuing and saving children's lives
- An excellent Paediatric Palliative Care Service
- Community based organisations that are responsive to individual need and flexible in their approach (eg Xavier Children's Support Network, which has provided us untold support which I have not had time to outline in this submission)
- The informal parent support network

On the downside, I would highlight the following limitations:

- Despite excellent acute care, there is no commensurate investment or thought about how to support parents who take their medically complex children home from hospital with high and complex care needs. It seems foolish to invest so much in high cost acute care and not then follow through with far more modest investment to help keep children well and safe in their homes, and keep families intact and healthy.
- A disability system that is so constrained it seems more intent on finding ways to render families ineligible for services, rather than supporting them. Of the eight very medically complex children I know, five of whom are palliative, I cannot name a single one that has received a cent of disability support from DSQ packages. Although all the children have complex medical needs, they all have multiple and serious disabilities – how they can be kept outside the disability support system is beyond me.
- An overall system that is completely un navigable for anyone without skills in submission writing, lobbying and advocacy, research and investigation.

There are many other issues I would like to address but my respite carer leaves in fifteen minutes so this will have to do! If you would like to discuss this further at the public hearings, please give as much notice as possible so I can organise care arrangements for my daughter.

Yours sincerely

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