



Feedback to Te Whatu Ora | Health NZ on A Paediatric Adolescent and Young Adult Palliative Model of Care

Who is Skylight Trust?

Skylight Trust provides leadership and services for tamariki, rangatahi and their whānau, who have experienced loss, grief, trauma and tough times.

Our unique offering is a full spectrum of care for tamariki and rangatahi aged 5-24 with mild to moderate mental health concerns.

We provide counselling, programmes and resources. Our work is evidence-based and trauma-informed.

Our main interest in the topic

We are a specialist mental health organisation focused on the mild to moderate mental health needs of tamariki and rangatahi. We provide grief and loss (psychosocial) support - a core element of Specialist Paediatric Palliative Care (SPPC).

Our main interest in the topic is to ensure that all tamariki and rangatahi have equity of access to health care and – in particular – that the mental health of all tamariki, rangatahi and their whānau is enhanced by the operation of public policy and the delivery of health care.

Every year, around 3,000 children and young adults (up to 24 years old) in New Zealand need palliative care. But three in four who die do not receive specialist care they deserve because of the enormous disparity in the delivery of SPPC.

There is currently only one publicly funded paediatric palliative care (PPC) doctor in the country, based in Auckland and two fully Crown funded specialist PPC

services in Aotearoa - Starship Children's Health in Auckland, and Christchurch. As the working party notes, there are charitable NGOs (such as Skylight) "that work across New Zealand which do great work in this space but often work in silos and remain underfunded."

While we do our best to co-ordinate with other NGOs and providers, delivering services and cross referring where we can, we are in no doubt that the current situation leaves most children and families without specialist support, especially in rural regions.

Which model of, and option for, care do we support?

We support the Paediatric Palliative Care Aotearoa, National Model of Care (see Figure 1 in the consultation document) developed by the Models of Care - Paediatric Working Group (WG) based on six research-based values of care.

Tamariki and rangatahi and their whānau should be at the centre of care.

We also therefore **support option 3, a Clinical Service Network and Four Hubs.**

- This model would align with Te Whatu Ora | Health New Zealand's 'four regions' structure.
- It would formalise the informal 'hubs' funded 'privately' to meet the needs of the Midland and Central regions.
- It would create greater equity in service provision – demographically, ethnically, and geographically.
- It would enable the workforce to grow and provide resilience in the system.
- It would reduce overall costs on the health and hospital system – reducing avoidable hospitalisation and emergency department visits, both regionally and nationally.
- It would also reduce the consequential trauma and stress associated with hospitalisation and the effects on the mental health of tamariki, rangatahi and their whānau, for a wider segment of the population.
- It would enable local and timely access to care in the community, enabling care at home, even in rural areas.
- It upholds the articles of Te Tiriti o Waitangi and the UN Convention on the Rights of the Child - equitable healthcare access, and to be free from unnecessary suffering.

We recommend that:

- there is at least one specialist per region, supported by a small interdisciplinary team
- there are strong links to psychosocial support that is also adequately funded for this purpose. Skylight would be happy to provide its services given our track record and expertise.
- there is investment in training and retaining the necessary specialist workforce

We strongly support a dedicated 24/7 on-call service for families and clinicians.

We are not convinced that two hubs can meet the need that exists today, nor will this option meet the need that is likely to be present in the future (based on international comparable trends). Variability in service need not be an issue with regular contact between hubs and with the Clinical Services Network.

The status quo is plainly unfit for purpose, with children dying in pain needlessly and whānau left unsupported, and psychologically traumatised.

Conclusion

It is time to act. We support moving to the four-hub model to produce equal outcomes across the country cost effectively and most importantly, to enable tamariki, rangatahi and their whānau to live (and die) with dignity and with professional support, as close to home as is possible.

Skylight wants to support the mental and physical health of the many tamariki and rangatahi (and their whānau) accessing palliative care. If the four-hub model is not pursued, we favour the two hub model over the status quo.