Health New Zealand
Te Whatu Ora

Paediatric, Adolescent and Young Adult Palliative Model of Care – Summary Paper for feedback

National Palliative Care Steering Group, March 2025

Have your say at: ThoughtExchange https://tejoin.com/scroll/905162211

The Health Zealand, National Palliative Care Steering Group are now seeking sector, stakeholder and public feedback on potential future national services for tamariki, rangatahi/children, young people and their whānau/families, based on the proposal developed by our Models of Care – Paediatric Working Group.

All feedback will be considered however, we would particularly appreciate thoughts on:
- whether the proposals will meet the needs of tamariki, rangatahi/children, young people and their whānau/families
- the establishment of a national clinical service network and the resources required
- the 3 proposed service configuration options
- the proposed make-up of the interdisciplinary teams
- the practicality of implementing these options
- any potential unintended consequences of change

Feedback is open now until Friday 2nd May 2025 (at the link above)

To send your feedback in writing (e.g. from a group or organisation), email us at **palliativecare@tewhatuora.govt.nz**

We acknowledge the sensitive, and often challenging, nature of palliative care for children and appreciate your willingness to share your feedback.

For further information about the National Palliative Care Work Programme, see our website **National Palliative Care Work Programme – Health New Zealand | Te Whatu Ora**

Overview of this document

This document has 2 parts, the first summarises the recommendations of the National Palliative Care Steering Group (SG) and outlines proposed options for future national service configurations for paediatric, adolescent and young adult (AYA) palliative care in Aotearoa New Zealand. These are based on the proposal developed by the Models of Care – Paediatric Working Group (WG) in 2024, which includes ways to achieve a nationally co-ordinated approach to care that meets the needs of tamariki and whānau across Aotearoa.

The second part includes the full WG report which is appended after page 11 (*Paediatric and Adolescent Young Adult (AYA) Palliative Model of Care)*.

Overall, the model proposes flexible collaboration between all paediatric palliative care (PPC) providers to meet the diverse needs of tamariki and whānau. It also acknowledges care in the community requires support from community social care providers. Using a shared-care approach, specialists would provide timely access to specialist paediatric palliative care for children with complex needs. This approach of seamless transition and flexible collaboration, enables services to deliver culturally responsive, whānau centred care to tamariki with life-limiting illnesses, regardless of where they live.

The National Palliative Care Steering Group are now seeking feedback on this proposal and the service configuration options outlined.

Key recommendations

1. **Establish a national specialist PPC clinical network that:**
    a. holds tamariki (aged up to 24 years) and their whānau at the heart of care
    b. works with existing services and supports to meet tamariki needs
    c. improves equitable access to specialist services and improves health outcomes
    d. is based on the values of; Mana Motuhake (self-determination), Whanaungatanga (meaningful relationships), Aroha (expression of love), Manaakitanga (caring for others), Kotahitanga (unity, togetherness), and Wairuatanga (spirituality); and
    e. is delivered in a nationally co-ordinated way.

    This would include:

    I. Specialist PPC interdisciplinary teams working together as a national service and supporting generalist PPC providers where required
        i. Option One: national clinical service network only
        ii. Option Two: national clinical service network and two hubs
        iii. Option Three: national clinical service network and four hubs
    II. 24/7 after-hours access to specialist PPC for generalist PPC providers
    III. Psychosocial support for tamariki and whānau, including bereavement care
    IV. A national education programme to support generalist PPC providers
    V. Nationally co-ordinated clinical governance, service development, education, quality improvement and research
    VI. Nationally consistent outcomes measures

2. **Interdisciplinary Team:**
    a. A national clinical service network, with or without 2 or 4 hubs, may include an expanded interdisciplinary team to support national 24/7 on-call services, administration and service co-ordination
    b. The interdisciplinary expertise may include Medical Specialists and trainees, Nurse Practitioners, Clinical Nurse Specialists, Registered Nurses, Social Workers, Psychosocial Support, Māori Liaison, and Occupational Therapy.

Overview

Paediatric Palliative Care Explained

Paediatric palliative care (PPC) services care for infants, children and young people with life threatening conditions, life-limiting conditions and terminal illnesses[1]. It encompasses the physical, psychosocial, spiritual and developmental needs of the child and provides support to their whānau. International standards published in 2022 state that all children with life-threatening conditions, life-limiting conditions and terminal illnesses have a right to access palliative care[1].

Globally over 20 million children are eligible for PPC, with prevalence estimates ranging from 63.2 per 10,000 children to 120 per 10,000 in the United Kingdom. Each year in New Zealand, an estimated 274-328 children die from life-threatening or life-limiting conditions[2,3]. In England, deaths and prevalence of children with palliative care needs has risen almost three-fold from 26.7 per 10,000 to 66.4 per 10,000 between 2001 and 2018; a trend that is likely being mirrored in New Zealand[4]. Paediatric palliative care has been shown to improve the quality of life for children[5] and significantly reduce their need for acute health services, including up to a 45% reduction in days spent in hospital (including emergency consultations and inpatient admissions) [6,7].

(More detailed child mortality statistics for Aotearoa 2000-2018 are included in Appendix 1 of the first section.)

There are three levels of delivering PPC:

1. A palliative approach delivered by all healthcare providers
2. Generalised PPC, and
3. Specialist PPC[1].

A palliative approach to care can be delivered by all healthcare providers including primary care and community-based services. Generalist PPC is mostly delivered by secondary paediatric services and specialist PPC is delivered by interdisciplinary specialist PPC teams.

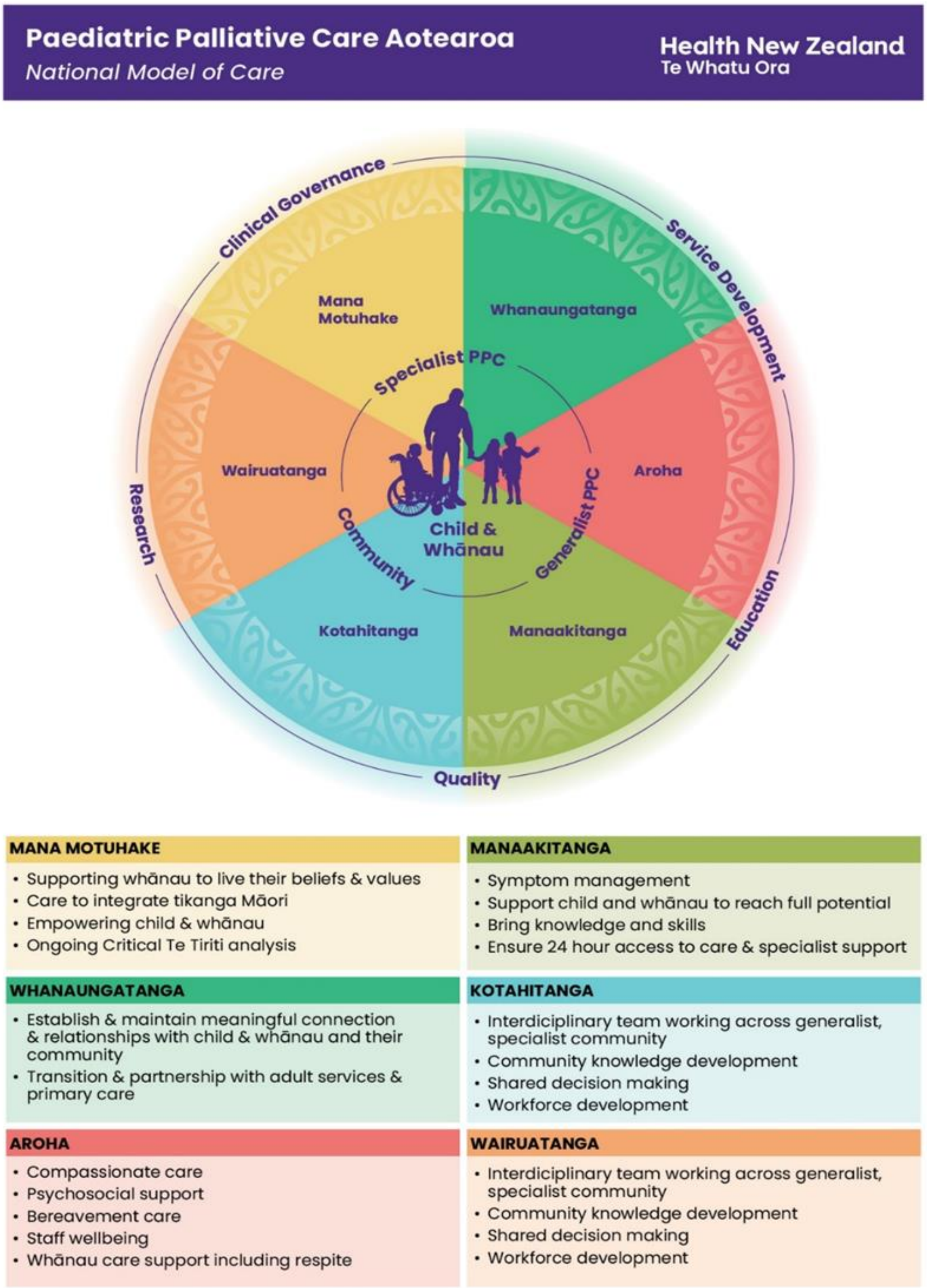
Paediatric Palliative Care Services in Aotearoa

Paediatric palliative care support should be available 24/7 to the child, whānau and clinicians, no matter where the child lives. In New Zealand with current resourcing and personnel, this cannot be accomplished. Specialist PPC, generalist PPC and primary care are under resourced and cannot provide quality symptom management, psychosocial, spiritual, developmental and end-of-life care to patients and their whānau throughout the country to accepted international standards[8].

At present there are 2 wholly Crown funded specialist PPC services in Aotearoa. One is based at Starship Children's Health in Auckland, and the other in Christchurch. There is also a service in Hamilton which receives both Crown and charitable funding for their service. A new specialist PPC service in Wellington, established wholly with philanthropic funding, delivers care to those in the lower North Island (Central Region). Access to specialist PPC varies around the country, as well as the services provided in different locations. At present, the total Crown funded specialist PPC workforce nationally is currently less than 10 FTE (including vacancies). With no funded training positions for any PPC discipline, expertise is held in the hands of a few staff leaving specialist services vulnerable to staffing shortages and capacity constraints in care delivery.

A New Paediatric Palliative Care Approach Proposed

The Models of Care - Paediatric Working Group (WG) developed a Paediatric Palliative Care Aotearoa, National Model of Care (see Figure 1) based on 6 research-based values of care. These values reflect the bicultural heritage of Aotearoa and include mana motuhake, manaakitanga, whanaungatana, kotahitanga, aroha and wairuatanga[9]. Tamariki and whānau are at the centre, supported by generalist and specialist PPC services, as well as their communities. Generalist PPC providers are also supported by specialist PPC. In turn, clinical governance, service development, education, quality and research support service delivery. Further information about this model is available in the full WG report appended after page 11 (*Paediatric and Adolescent Young Adult (AYA) Palliative Model of Care)*.



MANA MOTUHAKE
- Supporting whānau to live their beliefs & values
- Care to integrate tikanga Māori
- Empowering child & whānau
- Ongoing Critical Te Tiriti analysis

MANAAKITANGA
- Symptom management
- Support child and whānau to reach full potential
- Bring knowledge and skills
- Ensure 24 hour access to care & specialist support

WHANAUNGATANGA
- Establish & maintain meaningful connection & relationships with child & whānau and their community
- Transition & partnership with adult services & primary care

KOTAHITANGA
- Interdiciplinary team working across generalist, specialist community
- Community knowledge development
- Shared decision making
- Workforce development

AROHA
- Compassionate care
- Psychosocial support
- Bereavement care
- Staff wellbeing
- Whānau care support including respite

WAIRUATANGA
- Interdiciplinary team working across generalist, specialist community
- Community knowledge development
- Shared decision making
- Workforce development

Figure 1 Paediatric Palliative Care Aotearoa, National Model of Care

Options for Paediatric Palliative Care Service Configuration

Options for the most effective and accessible configuration of services need to be considered. Two options were discussed by the Working Group and a third was added by the Steering Group that builds on existing services. All options include a national clinical network and a shared-care model to support whānau, working closely with their existing health team.

Option 1 – PPC Clinical Service Network

This option focuses on better co-ordination of existing services by joining services together in a national managed specialist PPC clinical service network, with additional funding to provide after-hours clinical support (e.g., via telehealth or similar), administration and a national coordinator. This option supports generalist PPC services to provide 24/7 services to tamariki and whānau as required and is the most feasible and cost-effective option.

Option 2 – Clinical Service Network and 2 hubs

As well as adding a clinical service network, the two-hub option proposes additional staffing to set up 2 'new' hubs; a specialist PPC interdisciplinary hub in Auckland/Starship Hospital that serves the Northern (Auckland and above) and Te Manawa Taki (upper North Island) Regions, and a second specialist PPC hub based, for example, in Christchurch Hospital that serves those in the Central (lower North Island) and Te Waipounamu (South Island) Regions. [*Note: the locations have not been confirmed*]. A two-hub model would mirror the proven success of the National Child Cancer Network and support generalist PPC services to deliver palliative care with consultations, advice and guidance from the specialist hubs. This option may require recruitment (over time) of expertise that may not be immediately available in New Zealand.

Option 3 – Clinical Service Network and 4 hubs

As well as adding a clinical service network, the four-hub option proposes additional staffing to set up 'new' specialist PPC multidisciplinary hubs in each of the four regions, based for example, in Christchurch, Wellington, Hamilton and Auckland [*Note: the locations have not been confirmed*], with each serving their region. This option has an emphasis on face-to-face contact between specialist PPC and whānau, requiring staff to travel as needed, and would provide services closer to home for more tamariki and their whānau. This option may also require recruitment (possibly over an extended period of time) of expertise that may not be immediately available in New Zealand.

Clinical Service Network

In Aotearoa's setting, a funded specialist PPC managed clinical service network would coordinate services and care throughout the country. Managed clinical service networks are linked groups of health professionals and organisations from primary, secondary, and tertiary care, working in a coordinated manner that is not constrained by existing organisational or professional boundaries, to ensure equitable provision of high quality, clinically effective care[10]. Children's palliative care managed clinical service networks have been set up in Wales and England and show how geographically separated groups and organisations can work in a coordinated way to provide quality palliative care. In Aotearoa, the National Child Cancer Network has successfully provided high quality cancer care with treatments and outcomes that are the same no matter where the child lives.

With specialist teams working together to share expertise, education, training and an after-hours helpline for clinicians, PPC can be delivered throughout the country.

Hubs:

The proposed hubs would consist of interdisciplinary teams that could include specialist physicians, Clinical Nurse Specialists, a trainee doctor, Nurse Practitioners, Social Workers, child and young adult Psychologists, Occupational Therapists and Māori Liaison staff. The clinicians would be supported by a national coordinator and administration.

The three options have various pros and cons. Some of the main considerations are outlined in Table 2 below.

Table 1 Pros and Cons of Service Configuration Options

	Pros	Cons
Specialist PPC Clinical Service Network	• Improved co-ordination of existing services • More seamless experience for tamariki and their whānau using existing services. • Low-cost option • Supports primary and secondary PPC providers to provide 24/7 care. • Fasted option to implement.	• Will not address current issues regarding access to specialist PPC. • Difficult to ensure access to specialist PPC 24/7 for primary and secondary providers. • Many tamariki and whānau will not be able to access specialist PPC without significant travel. • Pressure on primary and secondary PPC providers to provide 24/7 support. • Will not increase the number of specialist paediatric palliative care clinicians or address service sustainability concerns.
Two Hubs **? Auckland and Christchurch**	• Proven model based on the National Child Cancer Network. • Less expensive to establish and maintain than 4 hubs. • Use of existing paediatric teams to deliver face to face generalist PPC with specialist support • Clinical quality advantage with larger teams and more support • More staff overall will improve service sustainability. • Larger number of patients per centre promoting building of expertise and higher quality training experience. • Fewer specialist PPC clinicians required, therefore easier to staff than 4 hubs. • More locations to train specialist PPC clinicians than we currently have. • Easier to co-ordinate services across two hubs than 4 hubs, promoting consistency of care throughout the country	• Less face-to-face accessibility to whānau (offset by use of telehealth consultations) • Fewer specialist PPC clinicians across New Zealand than 4 hubs. .
Four Hubs **? Auckland, Waikato, Wellington and Christchurch**	• More opportunities for face-to-face consultations with specialist PPC clinicians. • Less travel for whānau to see specialist PPC clinicians (including those traveling between the North and South Island). • Increased opportunities to educate and support colleagues directly. • Most secure option for maintaining specialist PPC capacity to support children long term.	• Larger number of specialist staff required overall. • Cost of PPC staff to travel to whānau • More expensive to establish and maintain. • More opportunity for co-ordination issues between services. • Specialist clinicians more isolated increasing risk of variations in treatment throughout the country.

Next Steps

Services for those facing the end of their life in childhood are an essential part of health care. At present, specialist PPC services vary significantly across Aotearoa, meaning children and their whānau have variable experiences, depending on where they live.

Health New Zealand remains committed to ensuring palliative and end-of-life care meets the needs of all New Zealanders. Your feedback will be used to finalise the proposed model for future national services for tamariki, rangatahi/children, young people and their whānau/families. Thank you for sharing your thoughts with us.

References

---

[1] Benini, F., Papadatou, D., Bernadá, M., Craig, F., De Zen, L., Downing, J., ... & Wolfe, J. (2022). International standards for pediatric palliative care: from IMPaCCT to GO-PPaCS. *Journal of pain and symptom management*, *63*(5), e529-e543

[2] McLeod, H. (2016). The need for palliative care in New Zealand. Technical report prepared for the Ministry of Health

[3] Tunstin K. (2024). Children with a life-limiting or life-threatening condition in Aotearoa. Technical report prepared for the Ministry of Health.

[4] Fraser, L. K., Gibson-Smith, D., Jarvis, S., Norman, P., & Parslow, R. C. (2021). Estimating the current and future prevalence of life-limiting conditions in children in England. *Palliative Medicine*, *35*(9), 1641-1651.

[5] Marcus, K. L., Santos, G., Ciapponi, A., Comandé, D., Bilodeau, M., Wolfe, J., & Dussel, V. (2020). Impact of specialized pediatric palliative care: a systematic review. *Journal of pain and symptom management*, *59*(2), 339-364.

[6] Gans, D., Hadler, M. W., Chen, X., Wu, S. H., Dimand, R., Abramson, J. M., ... & Kominski, G. F. (2016). Cost analysis and policy implications of a pediatric palliative care program. *Journal of pain and symptom management*, *52*(3), 329-335.

[7] Bernadá, M., Notejane, M., González, D., Guillermo, S., & Cavalleri, F. (2019). Description of a palliative care home program during its first year at work. *Archivos de Pediatría del Uruguay*, *90*(3), 28-40.

[8] Aburn, G. E., Gott, M., Moeke-Maxwell, T., & Drake, R. (2024). Paediatric palliative care in Aotearoa New Zealand—current state and future direction. *New Zealand medical journal, 137(1605, 92-97*

[9] Moeke-Maxwell T, Aburn G. (2023) Indigenous and First National Peoples of Australia and New Zealand: Māori people. In: Paediatric palliative care Australia and New Zealand, ed *A practical guide to palliative care in paediatrics* 4th ed. Palliative Care Australia

[10] Baker, C. D., & Lorimer, A. R. (2000). Cardiology: the development of a managed clinical network. *Bmj*, *321*(7269), 1152.

Appendix 1:

Child and Youth Mortality Statistics

There was a total of 4,300 deaths of 0–24-year-olds with a life-limiting or life-threatening condition as the underlying cause of death in Aotearoa during 2000 to 2018, as documented within the National Mortality Collection. There were a further 909 deaths that did not have a life-limiting or life-threatening condition as the underlying cause of death but in which a life-limiting or life-threatening condition was documented as a contributing cause of death.

Table 3 shows the number of deaths of 0–24-year-olds with a life-limiting or life-threatening condition as the underlying cause of death by age group, diagnostic group, ethnic group, DHB of residence, and year of death (University of Otago, Child and Youth Epidemiology Service, 2024, Children with a life-limiting or life-threatening condition in Aotearoa).

*Table **Error! Main Document Only.** Child and Youth Mortality Statistics 2000-2018, New Zealand*

Individuals aged 0–24 years whose deaths were caused by a life-limiting or life-threatening condition, by demographic factor, Aotearoa 2000–2018 Variable				
	Number of deaths	Percent	Rate per 100,000	95% CI
Life-limiting or life-threatening conditions				
Total	4,300	100.0	15.02	14.57–15.48
Age group				
Under 1 year	2,489	57.9	222.61	213.95–231.54
1–4 years	333	7.7	7.38	6.61–8.22
5–9 years	247	5.7	4.32	3.80–4.89
10–14 years	271	6.3	4.69	4.15–5.28
15–19 years	467	10.9	8.03	7.32–8.79
20–24 years	493	11.5	8.67	7.92–9.47
Diagnostic group				
Circulatory	133	3.1	0.46	0.39–0.55
Congenital	1,970	45.8	6.88	6.58–7.19
Gastrointestinal	6	0.1	0.02	0.01–0.05
Genitourinary	<6	s	s	s

Haematology	49	1.1	0.17	0.13–0.23
Metabolic	115	2.7	0.40	0.33–0.48
Neurology	330	7.7	1.15	1.03–1.28
Oncology	1,054	24.5	3.68	3.46–3.91
Perinatal	545	12.7	1.90	1.75–2.07
Respiratory	74	1.7	0.26	0.20–0.32
Other	22	0.5	0.08	0.05–0.12
Ethnic group				
Māori	1,067	24.8	16.09	15.14–17.08
Pasifika	530	12.3	20.66	18.94–22.50
Asian/Indian	398	9.3	11.97	10.82–13.21
MELAA	47	1.1	17.96	13.19–23.88
European/Other	2,253	52.4	14.22	13.64–14.82
Not stated	<6	s	s	s
DHB of residence				
Northland	164	3.8	15.71	13.40–18.30
Waitematā	455	10.6	13.11	11.94–14.38
Auckland	392	9.1	13.71	12.39–15.14
Counties Manukau	607	14.1	17.01	15.68–18.41
Waikato	434	10.1	17.10	15.52–18.78
Lakes	108	2.5	15.15	12.43–18.30
Bay of Plenty	212	4.9	15.97	13.89–18.27
Tairāwhiti Gisborne	57	1.3	16.58	12.56–21.48
Taranaki	108	2.5	15.06	12.35–18.18
Hawke's Bay	165	3.8	15.95	13.61–18.58

MidCentral	166	3.9	14.54	12.42–16.93
Whanganui	59	1.4	14.09	10.72–18.17
Hutt Valley	146	3.4	15.35	12.96–18.05
Capital & Coast	278	6.5	14.87	13.17–16.72
Wairarapa	46	1.1	18.35	13.43–24.48
Nelson Marlborough	90	2.1	11.29	9.08–13.88
Canterbury	442	10.3	14.22	12.92–15.61
South Canterbury	43	1.0	13.34	9.65–17.97
West Coast	29	0.7	15.43	10.33–22.16
Southern	251	5.8	12.79	11.26–14.48
Overseas	48	1.1	N/A	N/A

Acknowledgements

The Health Zealand, National Palliative Care Steering Group would like to thank all members of the Models of Care – Paediatric Working Group for their efforts to improve palliative care services and supports for children and their whānau. This group of lived experience experts, clinicians, and sector representatives was established in December 2023 and worked hard to reimagine how future services could be better configured to provide more consistent and quality experiences of care for those in need.

The Steering Group also acknowledge the efforts of all those in health and social care agencies working to support children, including paediatric, hospital, and community teams who often hold these families in their care for many months or years.

But most importantly, we acknowledge the whānau carers who provide the majority of love, care and support to these tamariki, rangatahi/children, and young people; often needing to take on the additional roles of advocate and navigator to ensure their child has the best quality of life, and death, possible.

Further information about this work and the broader National Palliative Care Work Programme can be found on our website National Palliative Care Work Programme – Health New Zealand | Te Whatu Ora

Paediatric and Adolescent Young Adult (AYA) Palliative Model of Care

Models of Care – Paediatric Working Group

August 2024

Health New Zealand
Te Whatu Ora

Executive Summary:

Specialist Paediatric palliative care (SPPC) in Aotearoa New Zealand currently faces significant disparities in access, quality, and sustainability. Despite the clear need articulated in the 2012 Guidance Document, progress in establishing integrated PPC services has been limited, leaving many children and their whānau without essential support.[1]

This proposal advocates for the development of a National SPPC Service to address these critical gaps. The proposed service will be structured around four specialist regional hubs aligned with Health NZ Te Whatu Ora regions. Each hub will comprise multidisciplinary teams including specialist PPC physicians, senior nursing staff, allied health professionals, and a prioritized Māori workforce. These hubs will support a generalist workforce in smaller regions through PPC kaiwhakarite and partnerships with local palliative care providers.

The proposed model emphasizes a community-led, outreach-driven approach to ensure SPPC is accessible, equitable, and sustainable across the country. It recognizes the unique challenges faced by rural and regional clinicians, proposing a partnership model to enhance end-of-life care through collaboration with local health services.

The implementation of this national service will significantly reduce suffering for children with life-limiting conditions and their families, providing them with consistent, high-quality care regardless of location. The service will also offer crucial psychosocial and bereavement support, minimising long-term harm for those affected.

This proposal aligns with Te Pae Tata's directive to create a nationally consistent palliative care model, ensuring that all children in Aotearoa have access to the care they need.[2] It presents a cost-effective, sustainable solution that adheres to international best practices and fulfils current government priorities.

Contents

Foreword: 3

AJ's story 4

This story is about a gorgeous little boy AJ as told by his Nana, Davina. 4

Section One: 5

- What is Specialist Paediatric Palliative Care? 5

Frankie's story 8

Section two: 9

- Availability of SPPC in NZ 9
- Specialist Paediatric Palliative Care (SPPC): 9
- Generalist PPC: Provision and Gaps: 10
- Adolescent and young adult (AYA) palliative care: 12
- Current grief/loss (psychosocial) Support: Provision and Gaps: 12
- After Hours Provision and Gaps: 13
- Workforce and training gaps: 13
- Evidence of how NZ compares to other countries: 14
- Evidence for harm if SPPC is not funded: 14

James' Story 15

Section three: The Solution 17

- Key Recommendations from the Working Group 17
- Values that Underpin the Model of Care Recommendations: 18
- Potential Stakeholder Partnerships and how SPPC Links Together: 20

Summary: 21

Poppy's Story 22

References: 24

Section Four: Appendices 27

- Appendix One: Guiding documents used in NZ as background of this work: 27
- Appendix Two: Values and how they relate to child/whānau, community and health system: 29
- Appendix Three: Role Descriptions: 33
- Appendix Four: Risks and Mitigations and how this Proposal Removes Barriers: 36

Foreword:

The Te Whatu Ora Health NZ, Model of Care for Paediatrics Working Group was formed in 2023 to develop a proposed model of care for Aotearoa NZ. It is a joint project, led by the Paediatric Society New Zealand Youth Clinical Networks in collaboration with Health NZ, Te Whatu Ora and the palliative care program. It aims to address the urgent gaps in SPPC.

The Working Group is composed of paediatric palliative care specialists, paediatric oncologist, neonatologist, maternal-fetal medicine specialist, nursing, paediatricians, allied health, researchers and individuals with lived experience.

Over six months, a wide range of stakeholders were consulted including clinicians from rural and regional areas, whānau, Adolescent and young adult support workers, clinicians from child cancer, and a wide range of clinicians and specialists across different fields. The working group welcome further feedback from the sector after the report is released as a draft, to ensure this is the best service possible delivered to these vulnerable children.

This initiative builds on a previous proposal submitted to the Minister of Health (2023) by Dr Amanda Evans and Dr Ross Drake. Developed over an 8-month period in 2022, that proposal bought together specialists in the field, researchers, experts in Māori palliative care, leaders in business and finance, systems change experts, and those who have experienced palliative care.

Currently, the provision of paediatric palliative care for most children in NZ is inequitable and inaccessible, with specialist services limited to a single funded agency (Starship) that provides care primarily to the Auckland Region.

This report presents recommendations that, once implemented, will have a significant and cost-effective impact on whānau and children's lives.

Dr Amanda Evans and Dr Nicole Coupe

(Co-Chairs)

AJ’s story

This story is about a gorgeous little boy AJ as told by his Nana, Davina.

AJ is 20 months old and has a hypoxic brain injury. Over the course of the last year, AJ has struggled with dystonia, seizures and frequent respiratory infections. Despite this he is a little boy full of mischief, smiles and an ability to laugh and enjoy time with his whānau. AJ has spent long periods of time in hospital and when at home has been supported by a team of community health professionals.

Communication and whanaungatanga is integral to the care of any child and their whānau. Without this, mistakes can be made and distress caused for both AJ and us as a whānau.

It is essential we can connect and come together as a team – whānau and health professionals as one whānau around the child. We need to bring our baskets of knowledge together – the whānau of being the experts in their child and the health professionals their skills, training and experience. We must work together as a team. When big decisions need to be made, it is important we have trusting relationships with health professionals who are working with us.

“We row this waka [canoe] together as a whānau (family & health professionals). We need to be on the same waka and heading in the same direction”

The most important ways in which whanaungatanga can be established is through taking time to get to know AJ and us as his whānau. Get to know AJ as a little boy, beyond his illness. Get to know us as a whānau – what matters to us, our beliefs and values.

We need health professionals to always respect our culture and acknowledge that just because we are Māori, we don’t all do things the same. Different iwi, different tribes have different perspectives and different ways of doing things. We would love to be cared for by more Māori clinicians. When that’s not possible, engaging with Kaiatawhai (Cultural support team) and Kaumatua (Māori elders) is really important to us and is a huge support in connecting with hospital staff**. We need health professionals to not be judgemental and authentically connect with us, listening to our perspective and our experiences of caring for AJ.**

We know that we won’t always have a health professional that knows AJ or us as a whānau, especially when we have to come to the emergency department in the middle of the night or weekends, but what helps in these situations is communication, hearing what we are saying and health professionals taking the time to connect with us.

Listening is the most important way you can connect. AJ’s voice needs to be heard – in day-to-day care, in decision making always.

“We are his voice – we are speaking for AJ, understand our voice for AJ”

- Davina, AJ’s Nana

Section One:

What is Specialist Paediatric Palliative Care?

Specialist paediatric palliative care (SPPC) is a medical specialty that cares for children with a serious illness who are vulnerable and may die during childhood. Providing palliative care is beneficial from diagnosis through to end of life and bereavement, with a focus on quality of life.[3,4] To help children and their whānau live the best life possible, SPPC provides expertise in bio-psychosocial-spiritual care, regardless of how long the children are expected to live. It is a specialty that truly embodies the Te Whare Tapa Wha model of health, recognising how essential all domains are for children to both live and die well.[5]

Paediatric Palliative Care is Whānau and Community care:

As demonstrated by AJ's story, the majority of care is whānau-driven and supported within the community where they reside. It is the whānau who provide the child with all the day-in and day-out care. They are the voice for the child, and in addition to parenting, they take on roles as 'nurse', 'doctor' and 'administrator/organiser' of equipment, funds, appointments, prescription pick-ups. The job of the clinicians within this space is to provide the expertise to equip the whānau to do what they can for their own child.

Care for a child is never separated from care of the whānau. Evidence is clear that whānau who care for children with palliative care needs experience increased financial, social, emotional burdens.[6–9] Supporting whānau care is always a priority. When whānau feel supported, they are able to continue to provide for their child's increasing needs especially at end of life.

Alongside direct care to children and their whānau, SPPC provides support to the broader community (for example schools) and to other clinicians who are involved in their care. This support goes beyond building capacity and education, as it's acknowledged that caring for children with serious illness or at end of life is extremely challenging emotionally, and can lead to staff distress, high work-force turnover, and burn-out. SPPC provision does not remove the sadness associated with caring for dying children, but provides communities and clinicians tools to cope, and offers support when they need it, so they feel less alone.

Paediatric Palliative Care is Clinical care

In New Zealand PPC can be delivered by two distinct approaches:

1. Generalised paediatric palliative care; This is care provided by clinicians with some training and skills in delivering PPC. This care is often provided by general paediatric teams, subspecialist paediatric teams, primary care and psychosocial support teams and delivered with back up from the specialist PPC workforce.[10]

2. Specialist paediatric palliative care (SPPC); This is care provided by a multidisciplinary team of health professionals who work exclusively in the SPPC setting and have specialist training and skills in the area. SPPC should be available to all children, and in particular to those with the most complex needs.[10] Specialist skills may encompass symptom management, communication and support with decision making, support with advance care planning, preparing children and whānau for end-of-life care and preparing for acute deterioration or crises.[11,12]

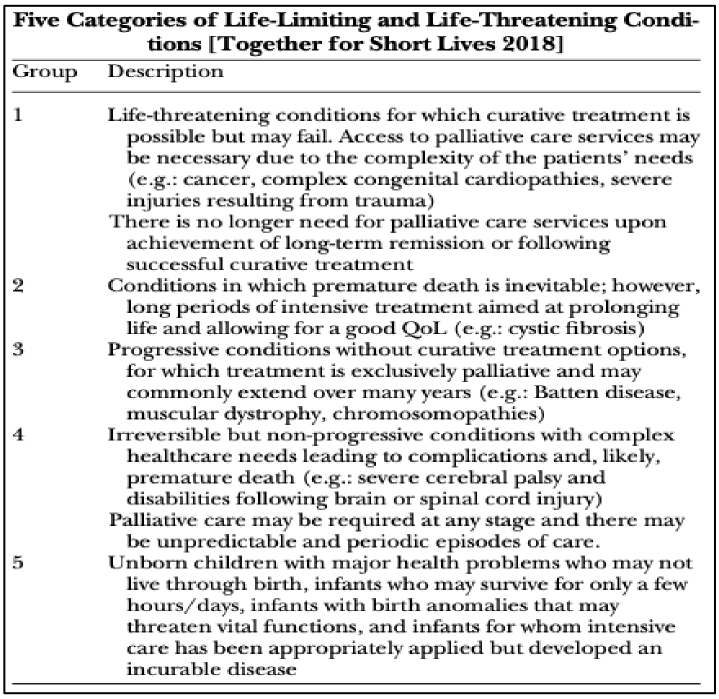
How is Paediatric Palliative Care different to Adult Palliative Care?

Despite sharing similar aims and ethical principles, there are stark differences between paediatric and adult palliative care.[13] Children are not just small adults.[14] They have unique developmental needs that must be recognised in communication, symptom management and all aspects of care delivery. Paediatric care is provided in the context of the philosophy of family centred care, rather than the person-centred approach of adult palliative care.

Traditionally patients referred to adult palliative care are those with life threatening conditions, end-stage cancers, or end-stage respiratory or cardiac failure or advanced dementia. In contrast, children referred to SPPC will predominantly have a non-cancer diagnosis (70 to 80% of children). Common conditions include children with congenital anomalies, neurodisability, metabolic and cardiac conditions. There is high variability in illness trajectory, compared to adults some children will require episodic specialist palliative care input, over many years.[10] All children referred to a specialist SPPC service have complex needs and are medically fragile.

International standards for Paediatric Palliative Care published in 2022 highlighted children that may require SPPC support based on diagnosis. [10,14,15]

Table 1: Categories of Life-limiting and Life threatening conditions that should have access to SPPC services published in International Standards of Paediatric Palliative Care.[10]



Five Categories of Life-Limiting and Life-Threatening Conditions [Together for Short Lives 2018]

Group	Description
1	Life-threatening conditions for which curative treatment is possible but may fail. Access to palliative care services may be necessary due to the complexity of the patients' needs (e.g.: cancer, complex congenital cardiopathies, severe injuries resulting from trauma) There is no longer need for palliative care services upon achievement of long-term remission or following successful curative treatment
2	Conditions in which premature death is inevitable; however, long periods of intensive treatment aimed at prolonging life and allowing for a good QoL (e.g.: cystic fibrosis)
3	Progressive conditions without curative treatment options, for which treatment is exclusively palliative and may commonly extend over many years (e.g.: Batten disease, muscular dystrophy, chromosomopathies)
4	Irreversible but non-progressive conditions with complex healthcare needs leading to complications and, likely, premature death (e.g.: severe cerebral palsy and disabilities following brain or spinal cord injury) Palliative care may be required at any stage and there may be unpredictable and periodic episodes of care.
5	Unborn children with major health problems who may not live through birth, infants who may survive for only a few hours/days, infants with birth anomalies that may threaten vital functions, and infants for whom intensive care has been appropriately applied but developed an incurable disease

SPPC: How big is the problem

There is paucity of data and statistics in SPPC in Aotearoa. Heather McLeod was commissioned by Health NZ, Te Whatu Ora to look at the mortality data for all deaths in NZ in order to explore future need for palliative care. The data is based on 2015 mortality data. They found:

- 328 babies and children up to 19 years of age died with a diagnosis that should have required palliative care.
- Forty eight percent of these were < 1 year of age and a high proportion (70%) were Māori, Pacific, Asian or MELAA ethnicity.
- Many (85%) of those under one died within the first few months.

- Counties Manukau had the most children who died (n = 82) in need of palliative care in NZ followed closely by Canterbury (n = 75).
- Mid-Central had the largest representation of Māori children who died and needed palliative care, exceeding the proportion of Māori children in the region.
- A half (52%) of children and 78% of under 1-year olds died in hospital and approximately 20% spent between 20 days to over 60 days duration in hospital in the last year of life.
- 5% had over 50 visits as an outpatient in the last year of life.
- 25% were admitted to Starship (inpatient and/or outpatient services).

In summary, these statistics show that approximately one child every day dies that needs palliative care, and those that do die have high health care utilisation at end of life with many coming into hospital as an inpatient or outpatient. Although limited data was available it shows that the one funded SPPC only had contact with a quarter of these children.

Many regions in NZ refer to their local hospice for additional support, especially if the child has complex symptoms during the end-of-life period and the paediatrician requires palliative care input (albeit from adult-trained palliative specialists). Hospice NZ* reported that children make up 1% of their yearly referrals. This equates to 150 children per year. A third of these referrals were from Rainbow Place (Hospice Waikato) and a third from Nurse Maude Christchurch, which is not surprising given they have provision for paediatric palliative care nursing support. The rest were distributed across most regions in NZ.

**based on unpublished data from their data commons and used with permission.*

SPPC need is ten times more than the mortality statistics:

Health care economists have made resource and funding predictions based on phases of illness in palliative care.[16,17] For paediatrics it is predicted mortality data represents less than 10% of the referrals to SPPC, 20% - 30% are either unstable or deteriorating (meaning they require high resource intervention and care) or stable 70 - 80%. [18–20]

Extrapolating that to the NZ statistics above means NZ have approximately 350 die that require palliative care, 250 – 350 will have acute needs due to instability and deterioration, international literature suggest all these children and families require SPPC input.

Furthermore, approximately 2000 – 2750 will be living with an illness that will require intermittent involvement from palliative care, described as ‘episodic palliative input’ but are currently stable.

Future numbers:

Studies from the UK have shown the prevalence of children with life limiting conditions has risen significantly, from 25 per 10,000 in 2002 to 66 per 10,000 in 2019 – a threefold increase over 17 years.[21,22] This reflects that children with serious illnesses are living longer, often relying on life-sustaining technologies such as artificial nutrition and non-invasive ventilation. As a result, these children are living longer but with more medically complex needs.

Given the similarities between healthcare systems in NZ and UK, it is expected that a similar rise in prevalence with numbers likely to continue increasing over time. More studies will be needed in this area in order to accurately monitor the numbers.

Frankie’s story

Our lives changed forever in December 2020, when our beautiful three-year-old boy Frankie was diagnosed with a rare and aggressive form of brain cancer. We were devastated to find out there were limited treatment options for him due to the location and type of tumour. After getting through the initial 10 day stay in hospital when he was diagnosed, and six weeks of radiation treatment, we focused on making memories with Frankie and spending precious time together as a family. Wee Frankie passed away at home just 5 months after he was diagnosed.

Being thrown into a world so suddenly that we knew nothing about, with such a poor prognosis was devastating and overwhelming. We were so fortunate to have amazing support from our family, friends and workplaces as well as through the healthcare system and various charities.

We remember so vividly the first time we heard the words ‘’palliative care” and were introduced to the incredible team at Starship. At such an emotional and overwhelming time, all you want is the best for your child and to know that you and the team around you are doing everything you can to care for your child. The approach we experienced was proactive and gentle - with information given to us in a respectful way, at the times we needed it. We always felt that our voices were heard. **We were shocked to understand later that not every child and family in New Zealand has access to support like we had. We now understand the privileged position we were in, living in Auckland at the time with access to Starship, and having the support of a big charity like Child Cancer Foundation behind us.**

The wrap around support from the Starship Oncology and Paediatric Palliative Care teams, as well as the Consult Liaison Child Psychiatry team, our GP, Community Nursing, Child Cancer Foundation, and our family and friends has enabled us to look back on this time knowing that we had the resources and support to do everything we could to support Frankie during this time, as well as his big sister Scarlett, who was five at the time.

Many families choose to care for their child at home during their final weeks and days. It was incredibly important to us that Frankie was at home, surrounded by everyone he loved.

We cannot stress enough how incredibly overwhelming this is. Not only the emotional aspect of it, but the anxiety that comes with understanding the medical aspects of caring for your child, preparing for all the ‘what ifs’ and wanting to do the absolute best for them. Caregivers need sufficient time spent with them to develop a proactive plan and to understand (as much as they can) what the various scenarios might look like to give them the confidence to bring their child home. Outside of normal working hours, they need someone on the end of the phone who they trust and who can make a decision on what is best for their child in that moment.

We cannot stress enough how vital better access to after-hours support is for caregivers.

Three years on now and we miss our boy so much. He is still such a big part of our life, his fire trucks and Paw Patrol toys brighten up our home and we talk about him all the time. Our grief is still raw and certainly not smaller in anyway, but perhaps we are starting to grow around it and slowly figuring out how to live and grieve.

Every child and every family deserve access to support like we had. The additional layers of grief and trauma associated with not getting this right have long lasting impacts on families.

- Michelle & Warrick (Frankie’s mum and dad)

Section two:

Availability of SPPC in NZ

It is unlikely that children who die in NZ have access to SPPC. In NZ most children who have palliative care needs will get this support by their whānau and generalists (those with some training) or those with no training. Generalists include primary care, general paediatric services, adult palliative care clinicians (nurses and doctors who don't have training in paediatrics).

In rural and regional areas, this is often provided as a partnership between clinicians with different skill sets. Psychosocial and bereavement services are scarce and often not available to those who are bereaved. Parents are often left not knowing who to turn to after the death of their child.

"I was given the news two of my children had a rare condition and they won't live past their teens, they are terminal and will continue to decline, then I got in my car to drive home alone with the kids in the car. I wasn't sure I wanted to make it home, all I had for support was google"

- Mum of twins who haven't had access to SPPC in one of NZ's major cities.

Specialist Paediatric Palliative Care (SPPC):

Starship SPPC Service

Starship Palliative Care is the only publicly funded SPPC service in Aotearoa. This service provides SPPC for antenates (24weeks gestation) to adolescent young adults. The Starship SPPC service operates across the Auckland region (Te Hana – Bombay) to provide SPPC and support to children and their whānau wherever the child and whānau are located including home, hospital or community facilities.

The service operates Monday to Friday 0800-1700. The team consists of:

- PPC Specialist (0.6FTE),
- general paediatrician with a special interest in PPC (0.5FTE),
- three Clinical Nurse Specialists (2.1 FTE),
- Senior Social Worker (0.8 FTE),
- Child & Adolescent Psychiatrist (0.1 FTE) and
- Child & Adolescent Psychotherapist (0.3 FTE).

The service works closely alongside community services, Starship subspecialist services and cultural support teams to provide care in partnership with whānau. Funding for this service is provided by Te Toka Tumai Auckland, Te Whatu Ora.

Rei Kōtuku SPPC Service Central Region

A privately donor-funded SPPC health service 'Rei Kōtuku' has been initiated as a 'proof of concept' with temporary funding intended to bridge the gap and provide for the urgent unmet need in the area. Sustainability relies on future funding from private to public funding.

This service provides SPPC for antenates (24weeks gestation) to 20-year-olds in the hospital and community within the Central Region (Hawkes Bay – Wellington – Manawatu- Whanganui). It partners with Non-Government Organisations and governmental services to build teams around the child and whānau to ensure they have the support they need. The specialist team travel to areas around the Central Region to see children in their communities and support the community teams providing the front-line care.

Rei Kōtuku consists of

- PPC Specialist (1.0FTE),
- Clinical nurse specialist (0.7 FTE),
- educational psychologist (0.8 FTE)
- project manager (0.2 FTE) and general manager (0.5 FTE).

Rei Kōtuku also provides a bereavement service to children who have lost their parent or sibling, working closely with the parents and schools.

Rei Kōtuku is currently training an advanced trainee through RACP in partnership with the PPC specialist, paediatricians and adult palliative care service. He is the only current trainee in NZ.

Both specialist services at Starship Children's Health and Rei Kōtuku provide consultative phone advice (during working hours) for other clinicians around Aotearoa.

Generalist PPC: Provision and Gaps:

There are two regions in NZ that offer specialist nursing and allied health support. Currently classified as 'generalist', these regions could easily be classified as 'specialist' with the addition of specialist medical cover.

Canterbury

Canterbury DHB has provided 0.2 FTE for a Paediatric Oncologist with a diploma in palliative care. Nurse Maude Hospice employs 1.6 FTE of PPC Clinical Nurse Specialists who work in community and provide recommendations to hospital clinicians.

They provide palliative and end-of-life care to children and their whānau in the Canterbury region and often support the rest of the South Island where they can.

Hamilton

Hamilton has two non-governmental organisations that work together to provide PPC in the community.

Hospice Waikato/Rainbow Place

Rainbow Place is partially funded to provide a limited number of respite nights through the general Hospice Waikato contract with Health NZ, Te Whatu Ora. The remaining respite days/nights, recreation programme, in-home and community visits, events, counselling, social work support, bereavement support, massage and wellbeing, and staffing resource are funded from donations and Hospice shops.

Rainbow Place staffing includes

- Clinical Nurse Manager (0.9FTE),
- Clinical Nurse Specialist (0.8FTE),
- 4 registered nurses (2.9FTE total),
- 3 health care assistants (1.8FTE total) and
- recreation and activities coordinator (0.6FTE).

True Colours Children’s Health Trust

True Colours is a not-for-profit charitable trust that is fully community funded. It is a nursing and counselling service, for tamariki and rangatahi (from antenates to 18 years) with high health needs, and their whānau.

They provide palliative care in the Waikato NICU Department and children’s ward, although these services are unfunded.

A nurse-led clinic was launched in March 2024 (3 days/week) to provide nursing assessment, care coordination and liaison with other providers caring for tamariki who have chronic or serious health conditions. This clinic was set up to meet a need where were finding it challenging to get in to see their GP in a timely manner.

True Colours provides services to the Waikato region in hospital and community.

The team currently consists of:

- CEO/PPC CNS and has a small clinical case load (1 FTE),
- psychotherapist (1 FTE),
- social worker/therapist (1 FTE),
- 2 counsellors (0.8 FTE)
- 2 x CNS (0.6 FTE, 1 a mental health nurse, 1 a paediatric CNS),
- 1 x registered nurse casual (works 8 - 24 hours/week),
- 1 children’s counsellor casual (8-16 hours/week),
- 1 FTE Operational Manager,
- 1 contracted counsellor (8 hours/week),
- 1 contracted clinical psychologist (8 hours/fortnight).

Other Generalist Provision:

Children outside the four regions above with palliative care needs are cared for by;

- general practitioners,
- general paediatricians, and
- local adult palliative care clinicians.

While it is rare for children to require end-of-life care is rare, when it does occur, it is often resource-intensive, with many paediatricians reporting 1 to 2 cases per year. When it occurs, it often requires significant input from the many clinicians involved, who are often untrained (ie. no specific under or postgraduate training). Due to the lack of FTE allowances for these paediatricians, there is little scope for home visits by these clinicians, and in many regions, no out-of-hours community nursing cover (ie to change syringe drivers over the weekend), often meaning that children and whānau may have limited choice over where they die because of the limitations of the local health service.

Primary care physicians lack training in SPPC and seem to be under-utilised in this space,[23] however NZ lacks data on their involvement.

Adolescent and young adult (AYA) palliative care:

The AYA age group, comprising individuals aged 13 to 24 years is particularly vulnerable as they transition from paediatric to the adult healthcare services. This transition period often exposes them to potential gaps in care. The AYA Cancer Network Action Plan 2020-2025 was developed with input from clinicians working with young people, participants in the AYA Leaders' programme, and a survey of 200 young people. Over the years, AYA survival rates have improved by 4% when comparing data from 2000-2009 and 2008-2017. The current survival rate stands at 84% survival, with ethnic disparities observed: 78% for Māori, 81% for Pacifica and 87% non-Māori, non-Pacific individuals.

The survey revealed that 32% of young people currently undergoing treatment expressed a desire to discuss what would happen if their treatment was unsuccessful but had not been given the opportunity. The Action Plan recommends early access to palliative care services when needed, delivered by a skilled workforce trained in communicating with young people.[24]

In addition to cancer patients, there are AYAs with non-cancer conditions, such as congenital, neurological, metabolic and cardiac conditions who also require palliative care and the subsequent transition to adult services. Heather McLeod's Trajectory of Palliative Care report noted that 15.4% (n=93) of all congenital deaths occurred in individuals over 20 years of age. These young adults are likely to need transition and care from the Adult Palliative Care Service. Although these numbers are small compared to the 36,000 adult deaths annually, it is important to remember that these young adults have experienced a lifetime of serious illness, often requiring intensive 24/7 care from their whānau. The burden on these young people and their families is substantial.

The transition process involves more than just a transfer of care; it requires transfer of equipment loans, changes in funding, and the shift from child disability allowances to living with disability support. Moreover, their care needs often change and intensify during puberty and beyond.

Starship SPPC have developed a guideline for transitioning AYA to adult services which can help ensure a seamless transfer of care. Rainbow Place also uses transition programme, and because it is part of Hospice Waikato, this process is likely more streamlined than in other regions.

Current grief/loss (psychosocial) Support: Provision and Gaps:

Grief and loss/emotional support Is a core element of SPPC. There are charitable NGO's (such as Kenzie's Gift, Skylight, SANDS, CanTeen, and Grief Centre) that provide bereavement services across NZ which do great work in this space but often work in silos and remain underfunded. Parents consulted for this report commented that it is "difficult to know what services are out there" and because of the challenge of finding someone, end up not having any support. As previously stated, statistics are limited to what the need is. A NZ study in those children who die after a bone marrow transplant found only 50% had follow up post bereavement and this is after a long intensive relationship with medical professionals.[25] Another recent study exploring antenatal diagnosis of congenital cardiac conditions in regards to equity and racial bias, found the healthcare system under-resourced to provide equitable support for grieving parents and recommended those families facing perinatal death have a culturally-informed coping strategies.[26]

If a child dies in hospital (NICU or ICU) it would be usual practice in NZ for the parents to receive a follow up phone call by the service in question. The parents are usually invited to return to the unit to discuss medical events that occurred or bring unanswered questions. For children dying under

SPPC or from Hamilton or Canterbury it would be usual practice for the service to visit whānau at home post death and continue to support their needs as long as they require it.

Emotional support and bereavement support is essential to whānau who have children who need palliative care before, during and (if they die) after their child dies, as this has a long-lasting detrimental ripple effect on siblings, parents, whānau, schools and communities. It is well accepted in the literature that the risks to bereaved who aren't supported are seen both short, and long term and include physical, social, learning, behavioural and emotional effects.[27–35]

As demonstrated in the background documents to this report and from many bereaved parents consulted NZ bereavement services lack funding, cohesion, visibility and accessibility.

"Despite having a great team around me when my child died, I felt abandoned in bereavement" – Parent of teenager

After Hours Provision and Gaps:

There is no after-hours cover for SPPC in NZ. If a child with palliative care or end of life needs at home requires assistance over the weekend the whānau bring their children into hospital or call 111 for paramedic support.

"We cannot get anyone in weekends, it's like they think his condition just disappears outside on the normal working week, ED can't help, he is too complex" – parent of a child who requires palliative care but doesn't receive it, in a major city in NZ.

Workforce and training gaps:

In NZ there are currently two NZ trained PPC specialists – one based at Starship at 0.6 FTE and 1 FTE in Wellington. Specialist training through the Royal Australasian College of Physicians (RACP) requires a minimum of 36 months of basic paediatric training, attainment of the paediatric written and clinical exams which is then followed by 36 months of advanced training. There is currently one RACP accredited training site for paediatric palliative care in NZ with no funding to take on trainees.

As mentioned above there is currently one RACP PPC Advanced Trainee who is trained with a partnership approach between the Wellington PPC Specialist, Hamilton Adult palliative care specialists and paediatric specialists.

A sustainable, future proofed service requires succession planning and can only be done with funding a SPPC service.

PPC education in undergraduate health programmes is not consistent. The University of Auckland pre-registration nursing programmes have a long established PPC programme in Year 3, while Massey University has just incorporated a session on PPC. Further work needs to be done to develop education programmes for undergraduate medical and allied health programmes.

Evidence of how NZ compares to other countries:

Internationally, SPPC is an essential service which is on offer in many specialist children's hospitals. Unfortunately, this hasn't been the case in NZ with SPPC being under funded and integrated into only one of NZ children's hospitals (Starship).

International standards have been agreed upon about service provision and what should be available for children with palliative care needs. The funded services in NZ would not meet those standards, in fact NZ was previously well regarded[36] and it is likely if reviewed again would be thought of as having the same provision as a developing country.[37]

When comparing with the investment made in SPPC in Australia, NZ is falling behind with our government providing approximately $900,000 annually to SPPC in comparison to millions provided to Australian children which has made a significant difference to their care delivery especially in regional and remote communities.

Evidence for harm if SPPC is not funded:

If funding for SPPC doesn't increase, there's a risk that it may not be able to operate in the future. There are only two paediatric palliative care specialists and limited accredited training sites, therefore limited access for future trainee specialists (meaning that we will not be able to train our own specialists). There is also a risk that without funding the Rei Kōtuku Central Region specialist service will close within the year as it doesn't have sustainable funding, meaning that those children will no longer have access to SPPC and NZ will lose its only full-time specialist. Leaving one specialist 0.6FTE for the whole country. This would lead to more inequities and suffering for children without access to these needed experts in the field.

It will also mean that NZ will lose that expertise SPPC knowledge that will help grow generalist PPC services, therefore even if generalist services are better resourced, they simply won't have the personnel to train them.

As one bereaved parent says, "**it's like asking your GP to give a child chemo, we wouldn't expect that – no offence, but it is scary to think that GP's and paediatricians will be expected to provide the level of experience that I received from my specialist PPC service**".

James’ Story

Paediatric Palliative care in New Zealand…….. or rather the lack of it.

November 2012 our son James was born, by all accounts a healthy full-term baby. He had two older brothers excited to meet their younger brother. May 2018 James passed away at home in the lounge, in his mother’s arms.

James developed a rare neurological and neuromuscular condition that began aged 2.5yrs, within 6 months he was in a wheelchair, he had a Mickey and was 100% tube feed and medicated through this. As his condition progressed, his medical team scrambled to try and work out what was going on for him, medicines were trialled, genetic testing complete with a variety of continuing tests throughout his 3-year battle.

To date he is undiagnosed which in NZ brings a whole raft of battles in terms of therapy and support but add in the term ‘Palliative’ to his file and BAM! Doors close all over the place.

Our child was STILL ALIVE yet he’s being treated like he was already dead! The label had been placed on our child, we were informed his condition appears to be terminal, he would now be under palliative care, but what did that actually mean?

Our experience was harrowing to say the least, there was little to no explanation of what it meant to now be ‘Palliative’, that getting anything that could enhance his life would now be almost impossible “because he is dying”, this is true, but he still had life to live! Did this Palliative label mean there could be support for us to navigate this journey, to help parent his siblings through this journey?

The simple answer is no, it did not open support doors**, there was no one there to walk along-side us and help us navigate the unknown journey of parenting a child who now fell into the hands of Palliative care.** Was there counselling when we needed it? No, was there child led support for siblings, no, was there support for James who was NOT cognitively impaired with his condition to help him understand what was happening to him, no.

As James’ condition progressed and he lost more and more abilities (note: his condition is likened to Motor Neurone Disease & SMA type 1), as we neared his final months was there wrap around support for us, no.

I was the 24/7 nurse, I was an expert in James’ condition, I was handed responsibility to medicate my child appropriately at home, something I had been doing for the entire 3 years he was with us with this unknown condition. Something I was happy to do because this was my child**, but imagine the weight on a mothers’ shoulders doing this 24/7 with no respite, with no support, with two other children who needed support as they watched their loved brother decline in front of their eyes.** We tried desperately to do whatever we could to help him be as comfortable as possible, to still live his best life until the end. James was on monitors at home all night, there was no sleep for my myself and very little for my husband. He had to work so it was essential he got some sleep, but who gets quality sleep when your child is terminally ill beside you.

What does Palliative mean to us? It triggers PTSD because when two people were sent to us from hospice we welcomed them into our home, to see us and James, but we heard the words…

“Oh, he is a child, he is under 16 we don’t do children”. What was that we actually heard!!! So, because James is a child, because he isn’t an adult, we don’t get support?

What does this mean? **This meant we were in this on our own. We had to navigate what it means when your child dies, the process, who do we call, what do we say, how do we prepare his brothers, how will we cope, is there anything we should know, what will happen to him in the dying process, should I hold him or will that hurt him, but if I don't hold him then …….he will feel alone, I need to hold him, but when he takes his last breath will his body go stiff?**

Do we have to keep monitors on him or can he be free from them, I mean surely it's obvious when he's taken his last breath?

Where is someone to help us through this?

What should we make sure we do BEFORE he dies? Artworks, photos, memories, who can guide us, suggest things we might not think about but really want down the track after he has died.

It is important to note that the medical team James had was exceptional, his local GP and Nurse took over a lot of the support that we simple didn't get once he was Palliative.

Where the MASSIVE gap was, was in the Palliative care, for us it was non-existent, there was so much stress and trauma that could have been avoided if there had been a proper model of Palliative care operating.

James deserved to be supported by a proper Paediatric Palliative team, just as much as my Husband and I did and our older two children.

No family should have to journey this Palliative trip with their child alone.

- Nicola (James' mum)

Section three: The Solution

Key Recommendations from the Working Group

1. A Fully Funded National SPPC Service – that's integrated and works with partners across Aotearoa.

   This National Service will provide care based on the values below: Mana Motuhake, Whanaungatanga, Aroha, Manaakitanga, Kotahitanga, and Wairuatanga.

2. Tamariki are always at the centre of the service development and care plans with their whānau which means service delivery based on family centred care.

3. Equitable Care:

   - Based on the Te Tiriti
   - A) Toitu Te Tiriti with Māori
   - B) Toitu Te Tiriri with everyone

   - Non-discriminatory Care; no discrimination according to Age (antenatal to AYA), or geography. AYA palliative care must be funded as part of the National Service.

4. Accessible Care

   - 4 specialist hubs that include medical, nursing, allied health, Māori/Pacific health. Northern, Te Manawa Taki, Central Region and Te Wai Pounamu.
   - These hubs have outreach to 14 regional centres, where they will travel to if children require specialist input.
   - Partner with clinicians including primary care, community led health providers, NGO's.
   - Funded generalist workforce based in regions – kaiwhakarite.

5. Funded Afterhours Service

6. Funded Bereavement Care

7. Clinical Network – Kaitiaki to oversee national service with adequate administrative support to ensure sustainability.

8. Agreed outcome measures used by all specialist sites.

9. Education/Training

Values that Underpin the Model of Care Recommendations:

The working group designed the graphic below in order to demonstrate the six core values that underpin care delivery, service development, research and education in SPPC across Aotearoa. As well as encompassing Te Tiriti principles, these values are additionally informed by matauranga Māori and described by whānau who have previously cared for a loved one who has died as a result of a serious illness. [38] They were originally adapted for the paediatric setting by Moeke-Maxwell & Aburn (2023)[39] with peer review and additional input from the working group.

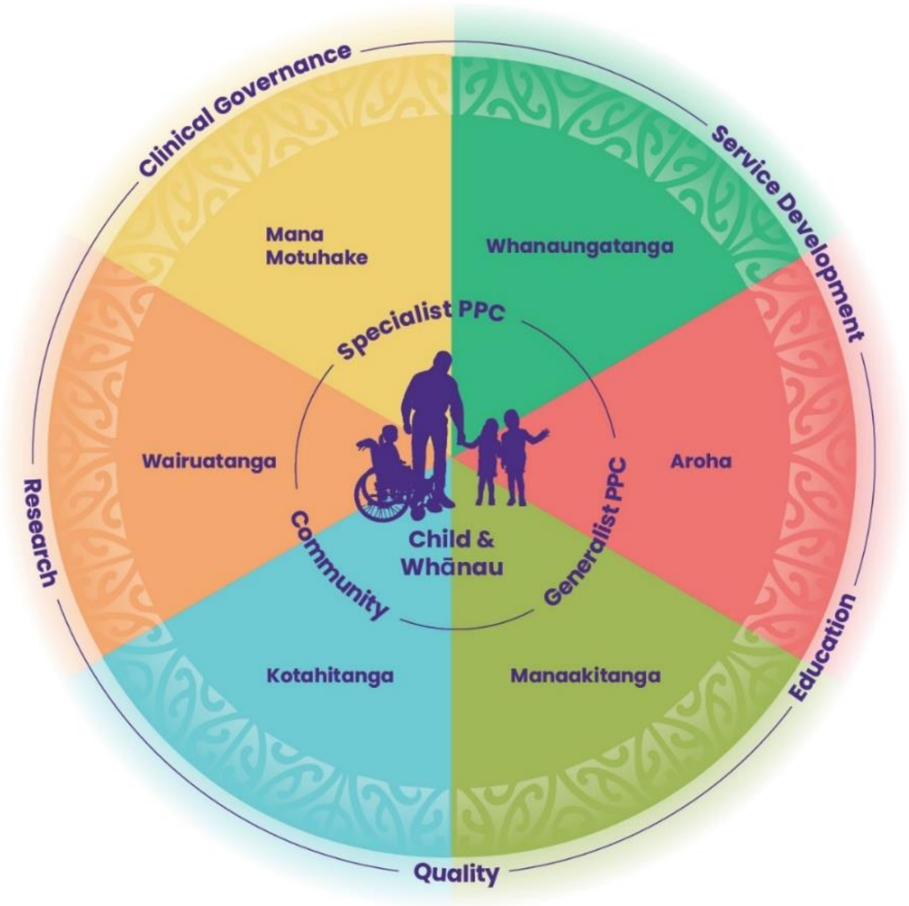
It is important to recognise that these values are woven together to ensure quality care for all children and their whānau. These values will be core elements of the services and each will have quality indicators linked with each value, meaning we are able to demonstrate and be accountable to children and whānau what we are delivering. Measurement of these values will also be reviewed by utilising the child's voice through additional assessment tools ensure the child and whānau voice is heard and recognised in development of services and quality improvement.

Across all values, it is necessary to consider the child and whānau, community and health systems perspectives and responsibility. How these relate to the core values is represented in APPENDIX TWO.

Paediatric Palliative Care Aotearoa

National Model of Care

Health New Zealand
Te Whatu Ora



MANA MOTUHAKE

- Supporting whānau to live their beliefs & values
- Care to integrate tikanga Māori
- Empowering child & whānau
- Ongoing Critical Te Tiriti analysis

MANAAKITANGA

- Symptom management
- Support child and whānau to reach full potential
- Bring knowledge and skills
- Ensure 24 hour access to care & specialist support

WHANAUNGATANGA

- Establish & maintain meaningful connection & relationships with child & whānau and their community
- Transition & partnership with adult services & primary care

KOTAHITANGA

- Interdiciplinary team working across generalist, specialist community
- Community knowledge development
- Shared decision making
- Workforce development

AROHA

- Compassionate care
- Psychosocial support
- Bereavement care
- Staff wellbeing
- Whānau care support including respite

WAIRUATANGA

- Interdiciplinary team working across generalist, specialist community
- Community knowledge development
- Shared decision making
- Workforce development

Potential Stakeholder Partnerships and how SPPC Links Together:

Partners	*Specialists*	*How we link together*
Māori Health Providers	• Local iwi • Māori Liaisons in hospitals • Māori Liaisons • Kaumātua Hospice NZ • Whānau First Start contractors in communities eg Kikikiriroa family services trust.	The Kaitaki will include Māori health leaders/clinicians.
Umbrella organisations and societies	• Palliative Care Collaborative Aotearoa • Hospice NZ • ANZSPM • Palliative Care Nurses Association • Nurse Practitioner Association • Hospital Palliative Care Organisation • Paediatric Society of NZ PPC Clinical Reference Group • Paediatric Palliative Care Australia and NZ • Maternal Fetal Medicine Operations Network • Adolescent/Young Adult Palliative Care Cancer Network • Te Aho ō te Kahu	Representation of a NZ SPPC service on key organisations to maintain visibility of PPC needs Representatives will update the national service of meeting outcomes at regular combined team meetings.
Hospitals	• General Paediatricians • Oncologists and other Medical Specialist Paediatricians • Paediatric Surgical Services • Paediatric Intensivists • Neonatologists • Maternal Fetal Medicine Specialists and • Midwives • Community paediatric nurses • Adult palliative care teams • Paediatric Allied Health i.e. Social Work, Psychology, Occupational Therapy, Play Therapy, Physiotherapy, Pharmacists, etc • Whānau/Māori liaison • Pasifika Liaison • Registered Nurses working in advanced practice roles	SPPC Service clinician involvement at key paediatric hospital service meetings to increase visibility of palliative care in tertiary centres. Service level agreements between regional SPPC service and local hospitals 'Pop-up' Education to the regional centres which will be arranged by the Kaiwhakarite. District nurse services who hold the syringe driver contracts in the community for the regions will partner with the specialist team and provide this service to children who require it. The expectation is they will be trained and supported by the specialist team and kaiwhakarite to work within the paediatric setting with joint visits.
Hospices	• Palliative care specialists • Palliative care nurse specialists • Allied health • Bereavement Teams	Develop hospice 'champions' within hospices to provide and lead PPC for those who require hospice input. 'Pop-up' Education
Primary Health Care	• General Practitioners • Nurse Practitioners • Practice Nurses • Community primary nurses	Partnership in PPC and bereavement care 'Pop-up' Education
External psychosocial services	• CanTeen • Kenzies Gift • Skylight • VCA • Sands	Partner with external agencies who provide support during a child's palliative care or grief and bereavement support

	• Swans Nest • Heart Kids • Cloud workshop • Blood and leukaemia • Child cancer foundation • Growing with grief • Grief centre • Healing Hearts • Effies wish	
Schools	• Early childhood centres • Primary schools • Secondary schools • Schools for the disabled	Partner with teachers, teacher aides, and guidance counsellors to support the children with diagnosis, as well as bereaved children.

Summary:

There is an **urgent** need for NZ to improve SPPC service delivery to attend to long standing, unaddressed issues with access to care, inequity in care, and lack of sustainability. It is a child's right to have access to PPC care wherever they live. No child should be dying in pain without the specialist support they need any longer.

This proposal outlines the need for the service, who the service is for, why it is urgent, as well as offering cost effective solutions resourcing both a specialist and generalist PPC service that are easily achievable, deliverable and measurable.

The authors look forward to continuing to work with Health NZ, Te Whatu Ora, as well as the ministry to ensure our children are getting what they need during their life as well as the end of their life.

Poppy’s Story

When you have a child with a disability or even a complex medical condition most parents are handed a copy of the poem ‘Welcome to Holland’ very early on.

It's pretty clear you get more than you bargained for when a superhero enters into your whanau. Just like the poem says you still become a parent but it looks different, feels different and the journey will be, well, different.

Very quickly, the poem tells you the important thing about this journey or destination of parenting is that it’s not horrible, you just need to learn a new language, buy some new books and meet a bunch of people you wouldn’t have met otherwise. Translated into new mum speak this means you are new to parenting, you are going to be tired, expected to learn a new language, attend a multitude of appointments and quickly come to the realisation disability is expensive. Whilst being reminded it’s not horrible just different. **Many people in the first year said, “at least she survived”, “focus on what she can do, not everything she can’t”. These statements to a mum are society saying do not grieve, be happy with what you have and get on with it.**

The poem then states that after you've been there for a while and you catch your breath, you look around.... and you begin to notice that Holland has windmills....and Holland has tulips. Holland even has Rembrandts. Yes, my journey with Poppy is beautiful, we live every moment, make every memory, fundraise and work for her to be included every single day. I vowed beside her cot in NICU I would give her every opportunity that was given to her twin. But believe me, you will never catch your breath, the anxiety of what next, the fear of asking for accommodations so she can be included and the pain when fences are erected around the windmills, tulips and Rembrandts remain.

The poem goes on to discuss how those around you will continue to brag about coming and going from Italy (parenting the way you dreamed), and how you will continue to think that’s where I was meant to be, that’s what my child should be doing. Yes, maybe to an extent however most friends who had children around the same time as you or that knew you prior to being a mum are gone, either through self-preservation and fear of something happening to my child or that the accommodations of having us in their lives are simply too hard.

Where the poem actually addresses the real part of parenting a superhero is the pain. The pain of that will never go away. Yes, the author is correct in saying the loss of what you dreamed for is painful, but then quickly moves on social norms of downplaying the need to mourn the fact your journey is different, feels different and will most likely have very different outcomes.

Personally, as a mum of a very complex wee girl, I hate the poem Welcome to Holland. **Every day is a fight, each fight comes at a cost. Standing up for access to school, clubs, sports, playgrounds, the cost is time, energy and branding.** You become that mum, the mum that speaks up, goes against accepting that this is how it is. Some look at you like you are ungrateful for wanting more, yet ‘more’ will always be less than what those who are well and able have access to. **There are plenty of fights like these, access to unfunded medication, equipment, caregivers, respite, help and support for both parents and siblings who have huge undiscussed PTSD and anxiety.**

Then there is the fight that we have fought every day since 18 weeks pregnant. The fight to survive. The fight for Poppy to survive. The fight for our marriage to survive. The fight for us to all come out the other end of this knowing we gave this little girl everything we had.

I have learnt the language, I have read the books, I know the maps of this journey inside and out. I give 110% and will always give no matter how tired, how burnt out or how defeated. I will continue to break down barriers, help other parents and give my little girl every single opportunity and experience I can. We know the statistics, they are stacked up against parents of sick and disabled children, the burn out is real, the heart attack percentages are scary, and the systems are not built in our favour.

I wasn't chosen for this journey, Poppy didn't come to me because a higher power knew I could handle it, a parent isn't only 'given what they can deal with'. What you see when you get to know Poppy and our family is a group of girls who will not give up, who will fight, who will work, who will always give just a little bit more, even if it only means we get one more memory, one more day or one more cuddle.

Every single 'one more' has been earnt.

- Hayley Harrison

References:

1. Ministry of Health. *Guidance for Integrated Paediatric Palliative Care Services in New Zealand*.; 2012.
2. Te Whatu Ora, Te Aka Whai Ora. *Te Pae Tata. Interim New Zealand Health Plan*.; 2022. https://www.tewhatuora.govt.nz/about-us/publications/te-pae-tata-interim-new-zealand-health-plan-2022/
3. Himelstein BP. Palliative care for infants, children, adolescents, and their families. *J Palliat Med*. 2006;9(1):163-181. doi:10.1089/jpm.2006.9.163
4. Liben S, Papadatou D, Wolfe J. Paediatric palliative care: challenges and emerging ideas. *Lancet*. 2008;371(9615):852-864. doi:10.1016/S0140-6736(07)61203-3
5. Durie MH. A Maori perspective of health. *Soc Sci Med*. 1985;20(5):483-486. doi:10.1016/0277-9536(85)90363-6
6. Roser K, Erdmann F, Michel G, Winther JF. The impact of childhood cancer on parents ' socio - economic situation — A systematic review. *Psychooncology*. 2019;(March):1-20. doi:10.1002/pon.5088
7. Donohue PK, Williams EP, Wright-Sexton L, Boss RD. "It's Relentless": Providers' Experience of Pediatric Chronic Critical Illness. *J Palliat Med*. 2018;XX(Xx):jpm.2017.0397. doi:10.1089/jpm.2017.0397
8. Lazzarin P, Schiavon B, Brugnaro L, Benini F. Parents spend an average of nine hours a day providing palliative care for children at home and need to maintain an average of five life-saving devices. *Acta Paediatr Int J Paediatr*. 2018;107(2):289-293. doi:10.1111/apa.14098
9. Pelletier W, Bona K. Assessment of financial burden as a standard of care in pediatric oncology. *Pediatr Blood Cancer*. 2015;62:S619-S631. doi:10.1002/pbc
10. Benini F, Papadatou D, Bernadá M, et al. International Standards for Pediatric Palliative Care: From IMPaCCT to GO-PPaCS. *J Pain Symptom Manage*. 2022;63(5):e529-e543. doi:10.1016/j.jpainsymman.2021.12.031
11. Klick JC, Hauer J. Pediatric palliative care. *Curr Probl Pediatr Adolesc Health Care*. 2010;40(6):120-151. doi:10.1016/j.cppeds.2010.05.001
12. Moresco B, Moore D. Pediatric Palliative Care. *Hosp Pract*. 2021;49(sup1):422-430. doi:10.1080/21548331.2021.1964867
13. Chelazzi C, Villa G, Lanini I, Romagnoli S, Latronico N. The adult and pediatric palliative care: differences and shared issues. *J Anesth Analg Crit Care*. 2023;3(1):1-8. doi:10.1186/s44158-023-00085-8
14. Feudtner C, Kang TI, Hexem KR, et al. Pediatric palliative care patients: A prospective multicenter cohort study. *Pediatrics*. 2011;127(6):1094-1101. doi:10.1542/peds.2010-3225
15. Chang E, MacLeod R, Drake R. Characteristics influencing location of death for children with life-limiting illness. *Arch Dis Child*. 2013;98(6):419-424.
16. Hughes-Hallet T, Craft A, Davies C. *Palliative Care Funding Review: Funding the Right Care and Support for Everyone.*; 2011.
17. Clapham S, Holloway A. *Palliative Care Outcomes Collaboration Clinical Manual*.; 2014.
18. Jarvis S, Parslow RC, Carragher P, Beresford B, Fraser LK. *How Many Children and Young People with Life-Limiting Conditions Are Clinically Unstable? A National Data Linkage Study*. Vol 102.; 2017. doi:10.1136/archdischild-2016-310800
19. Fraser L, Jarvis S, Carragher P, Beresford B, Parslow R. *P246 Children in Scotland Requiring Palliative Care: Identifying Numbers and Needs (The ChiSP Study)*. Vol 52.; 2016. doi:10.1016/j.jpainsymman.2016.10.292
20. Lorna Fraser A, Bedendo A, Jarvis S. *Children with a Life-Limiting or Life-Threatening Condition in Wales: Trends in Prevalence and Complexity. Research Report.*; 2023.
21. Fraser LK, Miller M, Hain R, et al. Rising National Prevalence of Life-Limiting Conditions in Children in England. *Pediatrics*. 2012;129(4):e923-3929. doi:10.1542/peds.2011-2846

22. Fraser LK, Gibson-Smith D, Jarvis S, Norman P, Parslow RC. *Making Every Child Count. Estimating Current and Future Prevalence of Children and Young People with Life-Limiting Conditions in the UK.*; 2020.

23. Jarvis S, Parslow RC, Hewitt C, Mitchell S, Fraser LK. GPs' role in caring for children and young people with life-limiting conditions: A retrospective cohort study. *Br J Gen Pract*. 2020;70(693):E221-E229. doi:10.3399/bjgp20X708233

24. AYA Cancer Network Aotearoa. *New Zealand Adolescent and Young Adult Cancer Action Plan 2020 to 2025.*; 2020.

25. Evans AM, Thabrew H, Arroll B, Cole N, Drake R. Audit of psychosocial and palliative care support for children having allogeneic stem cell transplants at the New Zealand national allogeneic transplant centre. *Children*. 2021;8(5). doi:10.3390/children8050356

26. Watkins S, Ward K, Brown R, et al. Parent and healthcare professional experiences of critical congenital heart disease in New Zealand to advance health equity. *BMC Health Serv Res*. 2024;24(1):1-12. doi:10.1186/s12913-024-11410-4

27. Nelson CA, Scott RD, Bhutta ZA, Harris NB, Danese A, Samara M. Adversity in childhood is linked to mental and physical health throughout life. *BMJ*. 2020;371:1-10. doi:10.1136/bmj.m3048

28. Carton ER, Hupcey JE. The Forgotten Mourners. *J Hosp Palliat Nurs*. 2014;16(5):291-303 13p. doi:10.1097/NJH.0000000000000067

29. Mclaughlin C, Lytje M, Holliday C. *Consequences of Childhood Bereavement in the Context of the British School System*.; 2019.

30. DeCinque N, Monterosso L, Dadd G, Sidhu R, Lucas R. Bereavement support for families following the death of a child from cancer: Practice characteristics of Australian and New Zealand paediatric oncology units. *J Paediatr Child Health*. 2004;40(3):131-135. doi:10.1111/j.1440-1754.2004.00313.x

31. Albuquerque S, Pereira M, Narciso I. Couple's Relationship After the Death of a Child: A Systematic Review. *J Child Fam Stud*. 2016;25(1):30-53. doi:10.1007/s10826-015-0219-2

32. Stikkelbroek Y, Bodden DHM, Reitz E, Vollebergh WAM, van Baar AL. Mental health of adolescents before and after the death of a parent or sibling. *Eur Child Adolesc Psychiatry*. 2016;25(1):49-59. doi:10.1007/s00787-015-0695-3

33. Wiener L, Rosenberg AR, Lichtenthal WG, Tager J, Weaver MS. Personalized and yet standardized: An informed approach to the integration of bereavement care in pediatric oncology settings. *Palliat Support Care*. 2018;16(6):706-711. doi:10.1017/S1478951517001249

34. Baldwin JR, Caspi A, Meehan AJ, et al. Population vs Individual Prediction of Poor Health from Results of Adverse Childhood Experiences Screening. *JAMA Pediatr*. 2021;175(4):385-393. doi:10.1001/jamapediatrics.2020.5602

35. Bourassa KJ, Moffitt TE, Harrington HL, et al. Lower Cardiovascular Reactivity Is Associated With More Childhood Adversity and Poorer Midlife Health: Replicated Findings From the Dunedin and MIDUS Cohorts. *Clin Psychol Sci*. 2021;9(5):961-978. doi:10.1177/2167702621993900

36. Knapp C, Woodworth L, Wright M, et al. Pediatric palliative care provision around the world: A systematic review. *Pediatr Blood Cancer*. 2011;57(3):361-368. doi:10.1002/pbc.23100

37. Clelland D, van Steijn D, Macdonald ME, Connor S, Centeno C, Clark D. Global development of children's palliative care: An international survey of in-nation expert perceptions in 2017. *Wellcome Open Res*. 2020;5:1-29. doi:10.12688/wellcomeopenres.15815.3

38. Moeke-Maxwell T, Nikora LW, Mason K, Carey M. Te Whakatara! – Tangihanga and bereavement COVID-19. *Ethnogr Edge*. 2020;4. doi:10.15663/tee.v4i.77

39. Moeke-Maxwell T, Aburn G. Indigenous and First National Peoples of Australia and New Zealand: Maaori people. In: Paediatric Palliative Care Australia and New Zealand, ed. *A Practical Guide to Palliative Care in Paediatrics*. 4th ed. Palliative Care Australia; 2023.

40. Mherekumombe MF, Frost J, Hanson S, Shepherd E, Collins J. Pop Up: A new model of paediatric palliative care. *J Paediatr Child Health*. 2016;52(11):979-982. doi:10.1111/jpc.13276

41. Slater PJ, Osborne CJ, Herbert AR. Ongoing value and practice improvement outcomes from pediatric palliative care education: The quality of care collaborative australia. *Adv Med Educ Pract*. 2021;12(October):1189-1198. doi:10.2147/AMEP.S334872

42. Palliative Care Australia. *Paediatric Addendum - Palliative Care Service Development Guidelines*.; 2018. https://palliativecare.org.au/wp-content/uploads/dlm_uploads/2018/12/PalliativeCare-Paediatricaddendum-2018_web.pdf

43. Government of Western Australia Department of Health. *Western Australian Australian Paediatric Paediatric Strategy Strategy for for End-of-Life and and Palliative Palliative Care Care 2021-2028*.; 2021.

44. Government of Western Australia Department of Health. *Western Australian Optimal Paediatric End-of-Life and Palliative Care Pathway*.; 2021.

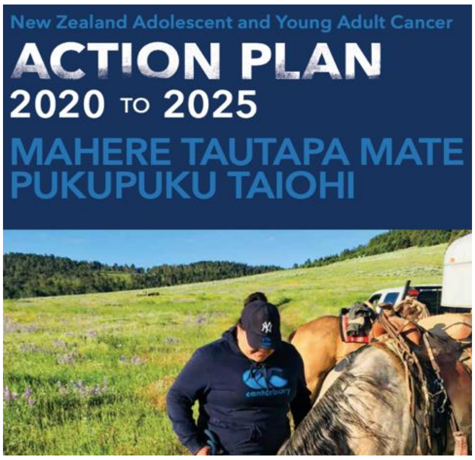
Section Four: Appendices

Appendix One: Guiding documents used in NZ as background of this work:

GUIDANCE FOR INTEGRATED
PAEDIATRIC PALLIATIVE CARE
SERVICES IN NEW ZEALAND

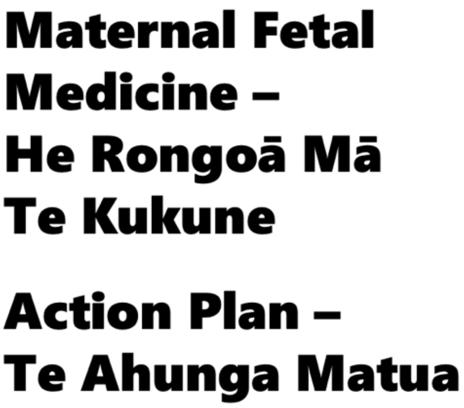
September 2012

A national review of Paediatric Palliative Care commissioned by the Ministry of Health and published in 2012, highlighted the need to improve integration of palliative care service delivery to children with serious illness and their whānau. This document proposed Starship Palliative Care remain the national specialist service with national consultative and service development responsibilities. A lead paediatrician and nurse coordinator were to be appointed in each region to lead service development and link local providers with the national specialist service. Unfortunately, there has been no progress made on these recommendations or further investment in Paediatric Palliative Care.



New Zealand Adolescent and Young Adult Cancer
ACTION PLAN
2020 TO 2025
MAHERE TAUTAPA MATE
PUKUPUKU TAIOHI

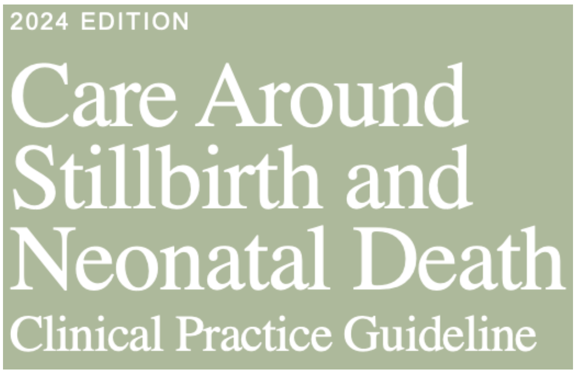
The AYA cancer action plan was developed by consumers and clinicians. Their priorities include palliative care that is delivered by those who know how to work with and communicate with rangatahi. It also prioritised earlier palliative care referrals to the service. Due to this Action Plan the NZ Cancer Network commissioned a working group in order to create resources for AYA with palliative care needs, as well as commitment to training adult services in how to communicate with rangatahi.



Maternal Fetal
Medicine –
He Rongoā Mā
Te Kukune

Action Plan –
Te Ahunga Matua

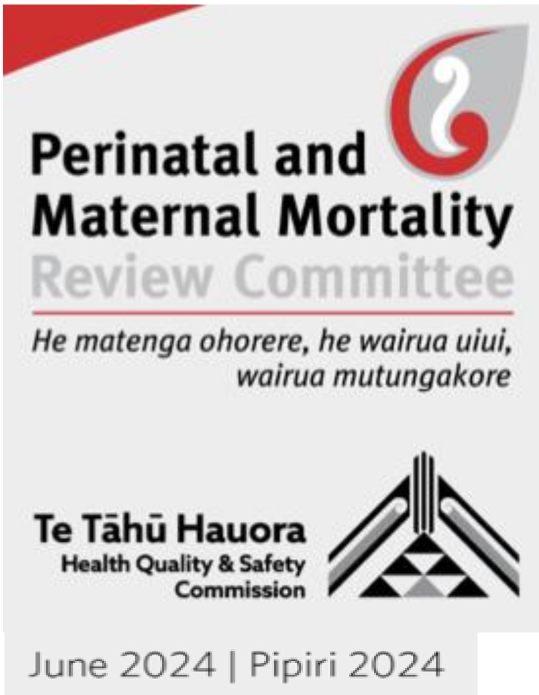
A Maternal Fetal Medicine Action Plan published by MOH proposed the MFM network and working group with specific priorities. This has included consideration for perinatal palliative care in guidelines and consumer pamphlets which shows a need and commitment to include perinatal palliative care in the current obstetric/MFM models.


2024 EDITION
Care Around Stillbirth and Neonatal Death
Clinical Practice Guideline

Perinatal Society Australia and New Zealand (PSANZ) have recently released this document emphasising the need for structured and collaborative bereavement services**.**


Perinatal Bereavement Support Environmental Scan
28 March 2023

Whakarongorau Aotearoa and Te Whatu Ora released a joint environmental scan report. This report included stakeholder and consumer feedback and reinforced the need for streamlined bereavement services in the perinatal and neonatal space. The report recommended the need for perinatal palliative care services**.**


Perinatal and Maternal Mortality Review Committee
He matenga ohorere, he wairua uiui, wairua mutungakore
Te Tāhū Hauora
Health Quality & Safety Commission
June 2024 | Pipiri 2024

This review states that perinatal mortality has not improved over the years and strongly recommends action from the government to design and fund perinatal bereavement services.

The working group agree with this and believe that if our recommendations are followed and funding is received these gaps will no longer be major areas of concern.

Appendix Two: Values and how they relate to child/whānau, community and health system:

Whānaungatanga establishing and maintaining meaningful relationships with both child and whānau. This includes getting to know the child and whānau beyond the child's illness, developing an awareness of whanau beliefs and values.

Child & Whānau

Establish & maintain meaningful connection & relationships with child & whānau.

Community

Establish & maintain meaningful connection & relationships with community around the child & whānau.

Health system

Transition & partnership with primary care & adult services.

Wairuatanga is a belief in spirituality, which is practiced in many ways and includes traditional Māori spiritual tikanga (customs) and kawa (ceremonies), christian faiths and other religions. This is a critical component of care provision, and for Māori is a crucial part of who they are; living includes relationships with all manner of things including the land, the water, the natural elements and ancestors and the spiritual homeland. Tikanga include karakia (prayers, chants and incantations), waiata (song/singing) and the sharing of kai (food). Māori draw on these customs to whakanoa (spiritually cleanse) and whakawaatea (spiritually clear) energies, through drawing upon their tikanga. Māori have diverse spiritual beliefs however, there is a commonality in wairua (spirit) and the spirit traveling to be with the Creator and tīpuna (ancestors) following it leaving the body.

Child & Whānau

Empowered to integrate spiritual beliefs and practices into their child's care.

Community

Acknowledge and support spiritual beliefs & practices.

Health system

Advance Care Planning.

Provide space and time for spiritual practices as part of routine care.

Manaakitanga is built on the terms of 'mana' and 'manaaki'. 'Mana' meaning prestige, control, authority, status, and spiritual power - it is a supernatural force in people and objects. To 'manaaki' means to take care of tamariki and whānau, ensuring they can reach their full potential by supporting them and by showing them respect. Manaakitanga is the process of actively caring for tamariki and their whānau through providing hospitality and showing kindness and generosity.

Child & Whānau

Child & whānau supported to reach their full potential, within their community.

Community

Community are supported to have the knowledge & skills to compassionately support children with palliative care needs and their whānau.

Health system

Quality symptom management provision for all children with serious illness.

Workforce development is prioritised to ensure succession planning and sustainability of both a generalist and specialist workforce in paediatric palliative care across nursing, medical and allied health.

Provide support to child & whānau, ensuring 24/7 access to care and advice.

Aroha the expression of love, empathy, affection and compassion in all care provided. Aroha is present in gentle expressions of caring and affection which produce a healing energy that fortifies and sustains whānau to care for pēpi and tamariki. At other times aroha can be seen in emotional eruptions as whānau struggle to navigate and adapt to the stresses of having an unwell tamariki.

Child & Whānau

Whānau feel supported to love and care for their child no matter where they are in their illness trajectory.

Whānau have the practical and emotional support including provision of respite care to ensure their child is surrounded by aroha and manaaki at all times.

Whānau are supported both during the child's illness and in bereavement by their community and professionals with appropriate skills to support them in navigating grief and bereavement.

Community

Community are empowered with skills and knowledge to support children with palliative care needs and their whānau through illness and into bereavement.

Compassionate communities are established to support children and whānau within their own environment.

Health system

Psychosocial care of children and whānau is integrated into routine care of a child with serious illness and their whānau.

Staff wellbeing and resilience is prioritised as a health systems issue, ensuring the environment enables staff to thrive at work and provide the best possible palliative care to children and whānau.

Kotahitanga a process where whānau come together as a collective and make unified decisions. This includes consideration of the child and their developmental needs, ensuring information and engagement is provided in a developmentally appropriate way. When tamariki, whānau and health professionals are all aligned and on the same page, a powerful partnership and team can be developed. This approach ensures the child remains at the centre of decision making and the very best care can be provided to child and whānau.

Child & Whānau

Child & whānau have a strong voice and are able to be active partners in decision making and care.

Community

Interdisciplinary working across community including consideration of education, child & whānau wellbeing, practical supports and physical care needs.

Communities are supported to develop knowledge of paediatric palliative care, to reduce stigma and challenges for whānau navigating palliative care for their child and a community is empowered with the knowledge to provide support to the child & whānau.

Health system

Interdisciplinary working across generalist and specialist paediatric palliative care providers. This includes integration with primary care, general and subspecialist paediatric services and specialist paediatric palliative care services, ensuring the child & whānau have the best possible support to acheive comfort and quality of life.

Mana Motuhake Enabling the right for Māori whānau to be Māori (Māori self-determination); to exercise their authority over their own lives, according to their philosophies, worldviews, values and practices including tikanga Māori. This recognises the mana of whānau in making decisions for their tamariki.

Child & Whānau

Children and whānau are able to live their beliefs and values and be themselves.

Child & whānau feel empowered to have a voice and express what is most important to them, their hopes, wishes and choices.

Community

Child & Whānau to be supported within their community, to integrate their own cultural beliefs and values.

Health system

All care to integrate tikanga Māori, recognising Māori as tangata whenua and Te Āo Māori as integral to the culture of Aotearoa.

Critical te tiriti analysis to be regularly carried out to ensure services are accessible and meet the needs of whānau Māori and all New Zealanders.

Appendix Three: Role Descriptions:

PPC Specialist:

A trained physician through RACP that has a fellowship in paediatrics and palliative care.

The aim is to have 1 – 2 FTE of specialist time in each specialist hub, this is to ensure cover for annual leave, and a workable after-hours roster.

PPC Clinical Nurse Specialist:

An expert senior nursing role which is focused on care delivery providing specialist nursing care and expertise, both in direct care delivery and in support to other staff in the management of children with specialist palliative care needs. These nurses will have extensive experience within child health nursing and have minimum of a Masters of Advanced Nursing.

PPC Kaiwhakarite:

This role can be carried out by a clinician in a local region who has a special interest in PPC. Kaiwhakarite will be expected to be local leaders and have regular communication and partnership with their designated regional specialist PPC hubs. They need to be great communicators, and collaborators as they may coordinate the generalist wrap around team that supports the child in their region. They also need to demonstrate their ability to build relationships with members of their community in order to hold that local knowledge. Recommendation is for 0.2 FTE minimum.

Bereavement/psychosocial clinicians:

All PPC professionals should be equipped to provide emotional support for their tamariki and whānau and this is integrated into daily practice. However, it is all essential that every specialist hub has emotional support workers (counsellors/psychologists/psychotherapists) who will support children and whānau from diagnosis through to bereavement.

Nationally there will be bereavement clinicians who will lead the psychosocial support from diagnosis, coordinate bereavement care (if needed), work with local and national external agencies.

There are many NGO's and clinicians working in the emotional support/bereavement space, but not necessarily working together. The aim of the bereavement coordinator is to bring everyone together and share resources to ensure each region (no matter where tamariki die) will have equitable access to psychosocial/bereavement services.

It is also recognised that some of the most effective care in bereavement is parent-to-parent support, there is strong evidence this is helpful if organised well and is not resource-intensive to provide. The bereavement coordinator will collaborate with NGO's in NZ to ensure collaboration.

Dr Trainee/Fellow/Registrar:

This will help develop future specialist medical workforce, there will be one position per year, which can be split into six-month rotations depending on the applicants. It will be expected the trainees can get experience within the different regions, if they are able to travel.

This position allows other trainees from different specialties to have the opportunity to learn about SPPC to then upskill others and incorporate it into their practice. These particular trainees will have the opportunity to do the palliative care diploma as part of their training for recognition with the Royal College of Physicians.

Māori Liaison and Māori Leadership Team:

Obligations to Te Tiriti ō Waitangi articles and principles are a priority recommendation.

These roles will be supported and appointed by the Kaitiaki. This role will be expected to travel and work with iwi and hapū in rural and regional communities as well as local Māori providers. The Māori liaisons provide leadership in service provision, and work with local kaumātua across Aotearoa to ensure we are providing care that is culturally appropriate, and what is wanted and needed in the community where the tamariki and whānau reside.

Māori liaison will be someone promoted from within their community, as most of the role will be building and maintaining relationships with iwi and hapū. There will also be the opportunity with those from the community to work in this capacity as kaitakawaenga role. We will also prioritise development of a Māori workforce in all clinical areas and prioritise Māori in all roles across the National Service.

PPC Nurse Practitioners:

As part of building a sustainable workforce at least two more nurse practitioner (NP) roles across NZ will be developed. There may also be scope for a neonatal intensive care (NICU) nurse practitioner to help build relationships between palliative care and NICU units across NZ. Increasing NP numbers is an important part of PPC sustainable workforce and aligns with Health NZ, Te Whatu Ora’s goals.

Nurse practitioners are valued members of the specialist teams and can help develop future nursing leaders. Nurse Practitioners can also contribute to the after-hours roster in the same way that registrars would with SMO supervision.

Pop-Up Support and Education:

The foundation of this proposal is whānaungatanga and partnership and is the key to sustainability of the National Service. ‘Pop-ups’ occur surrounding a particular child and whānau individual needs.

Funding for ‘Pop-up’ PPC Education[40,41] [42–44] will allow specialist PPC to provide direct face-to-face support within the regions to build capacity, support and empower local services in the care of children and their whānau. This ‘Pop up’ education can be provided as a home visit to the rural regional area and then build teams around the child and whānau to continue the palliative care that is required.

The Pop-up model has been shown to work well in the Australian setting as well as in the Central Region currently and is an easy solution to increasing equity and accesibility for children in NZ.

School Liaisons:

Work with schools is essential for building the community around the child. It is expected the psychosocial teams will work with and within the school system, and work alongside Ministry of Education, principals, teachers and school counsellors to enable the child to get the most out of their school experience. This will be based within the specialist hubs so it is expected other regions incorporate this into their daily workload and the School Liaison will share resources them.

It is also expected the clinicians will be able to support teachers through the child’s palliative, end of life and bereavement care, and work with pastoral care at schools to provide resources and education so fellow students are supported at the time of the child’s illness and into bereavement.

It may be possible to receive additional funding through Ministry of Education for this particular role.

Appendix Four: Risks and Mitigations and how this Proposal Removes Barriers:

Barriers	How this proposal removes barriers
Lack of governance, funding and under-resourcing in Te Whatu Ora, Te Aka Whai Ora and in the Ministry of Health.	1. Funding and resourcing is increased. 2. Provides framework for ongoing work with colleagues in Palliative Care Collaborative Aotearoa (PCCA) to lobby for governance and representation.
Clinicians' recognition of those who can benefit from SPPC	1. Emphasis on relationships and capacity building through Pop-up's and after-hours provision will demonstrate to clinicians benefit through actions. 2. Build understanding of palliative care in paediatric context, and the advantages to child/whānau of early introduction will occur through greater service prevalence in the country.
Lack of education – under/postgraduate and across disciplines.	1. The education lead will continue to lobby for this and work with palliative care sector to partner in under/post grad qualifications. 2. The 2 - 4 localities allow opportunity for workforce training for future specialist doctors, nurses, and allied health. 3. The trainee post will also be open to those from other specialties such as PICU/ Cardiology/ Oncology and General paediatric further increasing our relationships and training across specialties. 4. Planning for training of 2 further nurse practitioners.
Current uni-or-bi-discipline approach without full multi-discipline team.	1. Two to Four regions that work together will mean further workforce training for MDT. It is estimated to take five years for skilled workforce of all positions across NZ. It also means wider collaboration across communities in Aotearoa rather than silos.
Reliance on inappropriately trained clinicians. Having appropriately trained clinicians without resourced time.	1. Pop-up's with home visits will mean the team can develop anticipatory plans for the children, whānau and health professionals, saving them time. Each Pop-up builds capacity of local community services. 2. PPC team will ensure there is an advice line that clinicians/parents can reach out to after hours. 3. PPC kaiwhakarite will mean a whole workforce of generalists are trained and have access to specialist staff at all times. There will be benefits for the specialists as well, learning about what is available locally and learning from the kaiwhakarite themselves with what knowledge and experience they bring.
Resourcing Service development currently conducted out of hours and without pay.	1. Time for service development has been included in the budget– and includes a small working group for planning and implementation.