Children and Young People's Health Collective Manifesto

CANTEEN
Child cancer FOUNDATION
Heart Kids NZ Tamariki Manawa Māia
Kidney Kids NZ
Make-A-Wish NEW ZEALAND
Ronald McDonald House Charities New Zealand

The Children and Young People's Health Collective at a Glance

VISION/MISSION

To achieve equitable health and wellbeing outcomes for all children and young people, and their whānau

PURPOSE

We exist to represent the needs of children and young people with significant health issues, and their whānau

GUIDING PRINCIPLES

Ensuring core services are available and adequately funded to support equitable health and wellbeing outcomes

Ensuring families and whānau have what they need to provide a stable, safe and healthy environment for their children and young people to successfully support their health.

Ensuring all health-related services are appropriate for developmental and cultural needs of children and young people

Ensuring children and young people receive developmentally appropriate care and their transitions are well managed between healthcare services.

Ensuring policies and services for children and young people are co-designed

Providing forums where the input of young people, their whānau, NGOs, and Māori and Pacific peoples is valued and used to design effective services.

ACTION NEEDED

The Collective calls on the Government to:

Provide equitable financial support for whānau who have children and young people facing significant (acute and chronic) health issues.

Review the National Travel Assistance (NTA) payments and eligibility criteria annually.

Ensure funeral grants are equal across Government agencies.

Ensure there is an appropriate transition to adult health services.

Fund, develop and implement a co-designed national transition programme.

Ensure the workforce is upskilled and has the knowledge to support this transition.

Provide appropriate wellbeing (psychosocial) support.

Undertake a needs assessment of wellbeing services to understand where there are gaps and opportunities.

In partnership with the Children and Young People's Health Collective, develop an action plan with dedicated budget and timeframes in response to the gaps identified in the needs assessment.

Introduction

The Children and Young People's Health Collective is a group of Aotearoa New Zealand charities. These charities provide support to children and young people experiencing significant health issues, along with their whānau. The Collective's vision is to achieve equitable health and wellbeing outcomes for all children and young people, and their whānau, in New Zealand.

Members of the group include Canteen Aotearoa, Kidney Kids NZ, Child Cancer Foundation, Ronald McDonald House Charities NZ, Make-A-Wish Foundation, and Heart Kids NZ. Collectively, we provide a range of essential services that are not currently provided by Te Whatu Ora, and support over 130,000 children and young people each year. **This is over three times the number admitted to hospital.**

The Collective want to see the following outcomes for children and young people:

- Elimination of unacceptable inequities in health outcomes.
- Health services focused on family and whānau wellbeing.
- Culturally and developmentally appropriate services.
- Input from children and young people and their family and whānau in service design.

Building on these priorities for the upcoming 2026 election, the Collective is calling on the Government to provide:

- Equitable financial support for whānau who have children and young people facing significant health issues.
- Appropriate transition to adult health services.
- Wellbeing support for children, Adolescents and Young Adults (AYA), and whānau.

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Context

New Zealand's record on children and young people's health is poor. 30% of children and young people in Aotearoa New Zealand have neither good health nor what they need to thrive. They are predominantly of Māori or Pacific ethnicity and live in socio-economically deprived households.[1]

The Government has acknowledged that children and young people's health is not as good as expected or improving in a comparable manner to that occurring in other OECD countries.[2]

New Zealand youth have poorer wellbeing than those in most OECD member countries. For example, the UNICEF Worlds of Influence Report Card 16 ranked New Zealand 35th of 38 countries on overall child wellbeing outcomes, and with the second highest adolescent suicide rate of 41 developed countries.[3]

The key elements to achieving good health outcomes for children and young people include:

Ensuring family and whānau wellbeing is central to the delivery of services

Good health starts with stability and safety.[4] This is essential for whānau to be able to invest in the health of children and young people.

Key elements that need to be in place include access to financial support and social services, improved wellbeing support for parents, caregivers and siblings and better access to NGOs, advocates and navigators.

Ensuring all services are appropriate for developmental and cultural needs

The needs of children and young people change as they grow and mature, and their healthcare services need to reflect this.[5]

Children and young people with significant conditions transition between primary, secondary and tertiary services, between hospitals, between specialisations, and between young people and adult services. Effective transition is essential to ensuring young people remain engaged with services, are adherent to their treatment and ensuring improvement in their health outcomes.

Ensuring service design is co-designed with children and young people, and their whānau

It is essential that children and young people, and their family/whānau, are included in the design and delivery of health services. Evidence shows that co-design results in more effective and efficient services.

Consultation and co-design with iwi and Māori health providers are key to delivering services that ensure equitable outcomes, are culturally appropriate and accessible to whānau Māori.[6] The same is true of the differing needs of the Pacific community and health providers.

NGOs, such as members of the Collective can also contribute their expertise and knowledge and can act as a trusted conduit between health services and children and young people, and their whānau.

[1] Child Health Collective. (2021). He oranga ake, he oranga ānamata, Better Health-Brighter Futures Report, Auckland
[2] New Zealand Government. (November 2024). Child and Youth Strategy.
[3] Fleming T., Ball J., Bavin L., Rivera-Rodriguez C., Peiris-John R., Crengle S., Sutcliffe K., Lewycka S., Archer D & C. Clark T et al (2021). Mixed progress in adolescent health and wellbeing in Aotearoa New Zealand 2001–2019: a population overview from the Youth2000 survey series, Journal of the Royal Society of New Zealand
[4] New Zealand Government. (November 2024). Child and Youth Strategy.
[5] Ibid
[6] Mana Mokopuna, Children& Young People's Commission (March 2024). Without Racism Aotearoa Would Be Better.

Call to Action: ONE

Equitable financial support for whānau who have children and young people facing significant (acute and chronic) health issues

One of the hardest journeys a family will ever go through is when their child or young person is experiencing significant health issues. On top of this, there are additional financial burdens that families face. These financial barriers frequently reduce a family's ability to access the services they need to enable good health and wellbeing outcomes.[7]

In many instances it is not uncommon for one or both parents to take leave from employment during a child's illness. These situations add financial pressure to an already stressful situation.

There are often significant costs associated with accessing health services.
The National Travel Assistance Scheme was set up to support patients who needed to travel to access services. The transport and accommodation payment was increased in 2024, after nearly 20 years. Prior to this the scheme was outdated and fell well short of need. The scheme needs to be **reviewed and adjusted every year** to keep up with inflation. Important policy work is taking place within Te Whatu Ora/ Health NZ to update the NTA eligibility criteria to meet current needs. A regular process is needed to check the eligibility criteria over time to ensure it continues to meet changing needs of patients and the health system.

There is little provision for earning parents to be able to take the time off in a palliative situation.
Financial support is provided via 'gifted' extended leave. This is currently at an employer's discretion.

Families that lose a child face the additional financial burden of funeral costs.
Families from lower socio-economic groups may be unable to meet these costs.

The average cost of a funeral for a child is between **$6,000 and $8,000**. For illness, WINZ fund a maximum funeral grant payment of up to $2,616.12[8] which is also asset-tested. **The ability of some families to pay for funeral expenses is significantly compromised.** In contrast, if a child dies from an accident or a treatment injury ACC can fund a grant of up to $7,990.30.[9]

ACTION NEEDED

The Collective calls on the Government to:

Review the National Travel Assistance (NTA) payments annually.

The NTA payments and eligibility criteria need to be reviewed (and adjusted as needed) annually to reflect changes in the Consumer Price Index and changing needs of patients over time.

Ensure funeral grants are equal across Government agencies.

Increasing the funeral grant paid by WINZ for death by illness to match the funeral grant paid by ACC for a death by an accident.

[7] Dr Timmings A (2025). Quantifying the social and economic burden of childhood cancer on New Zealand families and the impact of location, ethnicity and cancer type

[8] Work and Income website 2025 www.workandincome.govt.nz/products/a-z-benefits/funeral-grant.html

[9] ACC website 2025 https://www.acc.co.nz/im-injured/financial-support/financial-support-after-death#one-off-payment-for- partners-children-and-other-dependants

Call to Action: TWO

Appropriate transition to adult health services

Children and young people often need to transition to adult services and between hospitals e.g. from Starship to regional hospitals. **Getting these transitions right is critical.**

The needs of children and young people change as they grow and mature, and their healthcare services need to reflect this. They are often expected to fit into services and models of care designed for adults[10] and placed in unsuitable ward situations with much older people.

Paediatric services are multidisciplinary and family-focused, offering comprehensive wraparound support, including referrals to specialist NGOs. In contrast, adult services are often siloed, relying on the individual to access support and information.[11]

When transitioning between paediatric and adult care they are at risk of disengaging with services and dropping out of care. **Substandard transition can result in reliance on emergency health services, increased hospital admissions, poor long-term clinical outcomes, and disrupted psychological wellbeing.[12]**

ACTION NEEDED

The Collective calls on the Government to:

Fund, develop and implement a co-designed national transition programme.

Including:

- Mandated national standards for the transfer of care with clear assessments, care plans policies and measures and reporting.
- Joint protocols for all hospitals to ensure consistent care planning.
- Models of care that are culturally appropriate for Māori and Pacific peoples.
- Models of care that are developmentally suitable.

Ensure the workforce is upskilled and has the knowledge to support this transition.

To ensure the health workforce:

- Provides consistent care regardless of region.
- Understands developmental milestones.
- Understands all standards, guidelines, policies affecting care for children and young people as they move between services.
- Is culturally competent and culturally safe

[10] Child Health Collective. (2021). He oranga ake, he oranga ānamata, Better Health-Brighter Futures Report, Auckland
[11] Yattheesh T.; Langridge.; Gordon I.; Russell J.;Muir C.; Hamm LM.; (2022) Strategies and tools to aid the transition between paediatric and adult health services for young adults with neurodevelopmental disorders: a scoping review protocol, BMJ Open
[12] Ibid

Call to Action: THREE

The provision of appropriate wellbeing (psychosocial) support

In New Zealand, **when a child or young person is significantly unwell, whānau often do not receive adequate wellbeing (emotional, practical and financial) support.** This includes parents and siblings.[13]

Without appropriate support families experience distress and are often traumatised.[14] Alongside managing the health of their child, families are often separated due to the need to travel for treatment. Parents are without their usual support networks including extended whānau. They need to take extended periods of time off work resulting in significant financial burden.[15]

When children and young people need treatment, evidence consistently shows that when their family and whānau are well supported, health outcomes for children and young people are improved.[16] **For a child's treatment to be effective and adhered to it is essential parents are involved and there is social support and whānau cohesion.**[17]

NGOs are currently managing the burden of providing wellbeing support in the absence of this being delivered nationally in a hospital or community setting.

ACTION NEEDED

The Collective calls on the Government to:

Undertake a needs assessment of wellbeing services to understand where there are gaps and opportunities

This will require consultation with:

- Children and young people, and their whānau.
- The NGOs that are part of this Collective.
- Iwi and Māori health providers.
- Pacific peoples' health providers.

In partnership with the Children and Young People's Health Collective, develop an action plan with dedicated budget and timeframes in response to the gaps identified in the needs assessment

[13] AYA Cancer Network Aotearoa. (2021). New Zealand Adolescent and Young Adult Cancer Action Plan 2020 to 2025 Mahere Tautapa Mate Pukupuku Taiohi. Auckland. Retrieved from https://ayacancernetwork.org.nz/aya-cancer-action-plan-2020-2025/

[14] Child Cancer Foundation (2025) What is Trauma Informed Care in Paediatric Oncology? Volume 2

[15] Dr Timmings A (2025). Quantifying the social and economic burden of childhood cancer on New Zealand families and the impact of location, ethnicity and cancer type

[16] AYA Cancer Network Aotearoa. (2021). New Zealand Adolescent and Young Adult Cancer Action Plan 2020 to 2025 Mahere Tautapa Mate Pukupuku Taiohi. Auckland. Retrieved from https://ayacancernetwork.org.nz/aya-cancer-action-plan-2020-2025/

[17] Denny, S., de Silva, M., Fleming, T., Clark, T., Merry, S., & Ameratunga, S. et al. (2014). The Prevalence of Chronic Health Conditions Impacting on Daily Functioning and the Association With Emotional Well-Being Among a National Sample of High School Students. Journal Of Adolescent Health

Summary

This manifesto for the Children and Young People's Health Collective has been produced to highlight critical issues faced by children, young people and their whānau affected by significant health issues covered by members represented in the Collective.

The Collective calls on the Government to affect change in three key priority areas to improve health, wellbeing and outcomes.

The Collective also recognises that action must be taken on wider issues to ensure optimal health outcomes for children and young people.

We support other advocacy initiatives committed to seeking improvements in these areas:

- Bolstering and upskilling the health workforce
- Improving medicines access
- Widening clinical trials access

CHILDREN AND YOUNG PEOPLE'S HEALTH COLLECTIVE

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Organisation Overviews



Canteen Aotearoa is the only national organisation dedicated to supporting rangatahi aged approximately 12–24 who are impacted by cancer, either through their own diagnosis or that of a family member. Its purpose is to ensure that young people do not face cancer alone by providing free, evidence-based psychosocial support. This includes counselling, peer support, camps and personal development programmes designed to support emotional wellbeing, resilience and connection.

CANTEEN



Child Cancer Foundation is the only charity in Aotearoa offering support to every child diagnosed with cancer aged 0-12, and their whānau, from diagnosis, through treatment, and beyond. Its purpose is to ensure that no family faces childhood cancer alone, providing one-to-one emotional, psychosocial, practical and financial support tailored to each family's needs. This includes access to a dedicated Family Support Coordinator, community and support groups, and opportunities for connection and respite. The organisation focuses on the wellbeing of the whole whānau, helping families navigate all the complex challenges that come with a childhood cancer journey.

Child cancer FOUNDATION



Every week in New Zealand, around 12 babies are born with a heart defect, with a congenital heart condition the most common birth defect. A diagnosis can bring overwhelming uncertainty. There is currently no cure, and many heart children face multiple surgeries, ongoing medical care, and lifelong health challenges. For families, the journey can be emotionally, financially, and physically demanding, often beginning before their child is even born. Heart Kids NZ is there, every step of the way, providing nationwide, vital practical information, advocacy, emotional support, and connection with others who are similarly impacted. Most of all by helping families navigate the challenges of diagnosis, treatment, recovery, and life beyond, Heart Kids NZ ensures no heart family has to face their journey alone.

Heart Kids NZ
Tamariki Manawa Māia



Kidney Kids NZ is the only national organisation dedicated to providing care and support for children and their families living with kidney and urinary conditions. Without this support kidney kids and their whānau would face this journey alone. Kidney disease doesn't just affect the child - it turns an entire family's world upside down. Kidney Kids NZ provides support and education, including direct face-to-face support, hospital support, patient advocacy, core information on the various kidney related conditions, as well as wellness and wellbeing. As kidney disease is known as the “hidden disease”, to alleviate this isolation, Kidney Kids NZ create a community of support for all families. It is important to remember that kids want to be kids, so Kidney Kids NZ provide the opportunity to enjoy a national camp that these children may otherwise not be able to experience with their conditions, ensuring they can have fun when they are well enough to do so.

Kidney
Kids
NZ



For 40 years, Make-A-Wish New Zealand has created life-changing wishes for children living with critical illnesses. Every year, hundreds of Kiwi children face prolonged treatment, uncertainty, and disruption to childhood. A wish gives them something often lost during illness: choice, control, and hope. Research shows wishes can improve emotional wellbeing, build resilience, strengthen family connections, and create positive memories during difficult times. More than a moment of joy, a wish helps children look beyond their diagnosis and focus on what is possible. We believe wishes are an essential complement to medical care, improving the journey for children and their whānau.

Make-A-Wish
NEW ZEALAND



Ronald McDonald House Charities New Zealand provides accommodation and practical support for families who must travel away from home so their child can receive hospital treatment. Its purpose is to keep families together by removing stress related to travel, accommodation and daily living costs. Through its Houses and Family Rooms located near hospitals, the organisation offers a home-like environment where families can stay close to their child and focus on their care.

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