



Proactive Release

Submissions on the Child and Youth Wellbeing Strategy

August 2019

The Department of the Prime Minister and Cabinet has released the following submission received during its public consultation on the child and youth wellbeing strategy.

Some of the information contained within this release is considered to not be appropriate to release and, if requested, would be withheld under the Official Information Act 1982 (the Act).

- Where this is the case, the information has been withheld, and the relevant section of the Act that would apply, has been identified.
- Where information has been withheld, no public interest has been identified that would outweigh the reasons for withholding it.

Key to redaction codes and their reference to sections of the Act:

- **9(2)a** – Section 9(2)(a): to protect the privacy of natural persons, including deceased people.

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Child and Youth Wellbeing Strategy – Submission Template

This document is intended for individuals or groups who wish to make a formal submission on the child and youth wellbeing strategy.

Please complete this template and email it to: childandyouthwellbeing@dpmc.govt.nz

A guide to making a submission is available on the DPMC website <https://dpmc.govt.nz/our-programmes/child-and-youth-wellbeing-strategy>

Submissions will close on **Wednesday 5 December**.

Please provide details for a contact person in case we have some follow up questions.

Contact Name:	Cynthia Ward
Email Address:	cynthia@truecolours.org.nz
Phone Number:	9(2) (a)
Organisation Name:	True Colours Children's Health Trust
Organisation description: (tell us about your organisation – i.e. who do you represent? How many members do you have? Are you a local or national organisation?)	<p>True Colours is a child health organisation that cares for children and young people with serious illness and their families. It is a nursing and counselling service that works collaboratively with other providers in the Waikato region.</p> <p>Predominantly True Colours provides care to the child with serious illness, their siblings and parents inclusive of extended whanau. Care and support are provided from the time of a child's diagnosis through to bereavement support if the child or young person dies.</p> <p>True Colours is governed by a Trust Board and has a team of five full time staff (two counsellors, one psychotherapist, one nurse specialist with the dual role of CEO, one executive communications assistant, and another nurse commencing in January 2019. Contracted to the organisation is two clinical psychologists, and one counsellor).</p>

Executive Summary:

(Please provide a short summary of the key points of your Submission - 200 words)

True Colours Children's Health Trust welcomes the opportunity to contribute to the voices of other child health providers as the Government develops a strategy to ensure that children and young people in New Zealand have what they need to have improved lives.

Medically fragile babies/children, often technology dependent are cared for at home in the community by their families. Predominately, parents are responsible for this care, at times experiencing burden, with little resource or support.

The impact on families is vast, relationally, financially, emotionally, physically and socially. Therefore, children who have the illness and their healthy siblings experience the long term effect on their family unit.

While much is known about the complexity of children's illnesses, less is known about what parents/families need to sustain themselves, particularly through the extended years of a child's disease trajectory to safely care for their children.

There is the need to provide appropriate support and resources that will equip children to be cared for safely by their families at home. Care packages that include funding along with skilled caregivers to provide respite will contribute to the child's safety and quality of life. This challenge needs to be addressed for the benefit of the child and their entire family unit.

Submission Content

The Child and Youth Wellbeing Strategy is welcomed as significant development for all children and young people in Aotearoa New Zealand, and for our society as a whole. To have opportunity to hear children and young people's voices heard at a national level is an exciting move in going forward. While as a nation, we have talked the talk of having children at the forefront of their care in health, at times this has not been the case. The Child and Youth Wellbeing Strategy is a way to include children and young people's voices to write policy and deliver key services that specifically meet their needs.

The child wellbeing strategy wellbeing proposed focus areas includes children and young people with disability. However, currently children who are medically fragile or living with chronic illness are not currently acknowledged in this document. Therefore, True Colours proposes the terminology include children who live with chronic illness and medical fragility be included in the documentation.

While the 16 desired outcomes in the proposed framework may include all children, and young people it is essential to ensure those with high health needs do not get overlooked in the preparation and delivery of the strategy.

Medically fragile children who once would not have survived prematurity or their diseases now have better opportunity to live. However their conditions are often complex and intensive in the care required. These children are often reliant on technology to survive, such as feeding pumps and respiratory equipment.

A decade ago, these children and young people would be in hospital settings for long periods of time, now health providers expect families, predominantly parents to provide this high level of care at home. Evidence depicts families are burdened with the responsibility of care, along with suffering exhaustion, being sleep deprived and stretched to capacity. The long reaching impact of the child's high health needs touches every aspect of family life. Stressor on finances, relationships, physical health, mental health and family dynamics touch into areas already of concern in NZ such as poverty, domestic violence and mental health concerns.

There is considerable focus on aged care with resources and funding allocated for a population group living longer, however often with compromised lives. Yet, there is less focus on babies surviving extreme prematurity (23 weeks) due to advanced medical technology and knowledge, yet living with often very compromised lives and dependent on their families and caregivers for as long as they live.

To ensure these children and young people in New Zealand have their needs met, where they are seen heard and understood, it is paramount that they are included and acknowledged in the Child, Youth Wellbeing Strategy. .

True Colours endorses and agrees with the submissions made by the Paediatric Society and organisations such as CPAG,.

Please note that your submission will become official information. This means that the Department of the Prime Minister and Cabinet may be required to release all or part of the information contained in your submission in response to a request under the Official Information Act 1982.

The Department of the Prime Minister and Cabinet may withhold all or parts of your submission if it is necessary to protect your privacy or if it has been supplied subject to an obligation of confidence.

Please tell us if you don't want all or specific parts of your submission released, and the reasons why. Your views will be taken into account in deciding whether to withhold or release any information requested under the Official Information Act and in deciding if, and how, to refer to your submission in any possible subsequent paper prepared by the Department.