Submission on the New Zealand
Health and Disability System Review

Due 31 May 2019

To: Heather Simpson, Chair, Expert Review Panel

This submission is from:
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Child Poverty Action Group (CPAG) is an independent charity working to eliminate child poverty in New Zealand through research, education and advocacy. CPAG believes that New Zealand’s high level of child poverty is not the result of economic necessity, but is due to policy neglect and a flawed ideological emphasis on economic incentives. Through research, CPAG highlights the position of tens of thousands of New Zealand children, and promotes public policies that address the underlying causes of the poverty they live in.

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Background

Thank you for this opportunity to have input into this important mahi – ngā mihi nui ki a koutou katoa.

The Health and Disability System Review is of great importance to Child Poverty Action Group (CPAG). Children in poverty, and their families, disproportionately have higher rates of physical and mental illness and disability than those who are not in poverty. They have greater difficulty in accessing and/or affording appropriate management for their health and disability needs.

CPAG submits that the health and disability system needs to contribute to Aotearoa New Zealand being the best place in the world to be a child. The literature is very clear that the effects of childhood reverberate throughout adulthood; and thus, children need prioritisation.

The Expert Advisory Group on Solutions to Child Poverty (2012) defined child poverty as:

Children living in poverty are those who experience deprivation of the material resources and income that is required for them to develop and thrive, leaving such children unable to enjoy their rights, achieve their full potential and participate as full and equal members of New Zealand society.

Designing a health and disability system that upholds children’s rights

New Zealand has ratified the United Nations Convention on the Rights of the Child (UNCROC), undertaking to ensure to the maximum extent possible the survival and development of the child.\(^1\) Under UNCROC, New Zealand must recognise:

- the right of the child to the highest attainable standard of health and to facilities for the treatment of illness and rehabilitation of health (Article 24);
- the right of the disabled child to enjoy a full and decent life, in conditions which ensure dignity, promote self-reliance and facilitate the child’s active participation in the community (Article 23); and
- the right of every child to a standard of living adequate for the child’s physical, mental, spiritual, moral and social development (Article 27).

UNCROC applies to almost all children in Aotearoa New Zealand\(^2\) and is part of New Zealand’s domestic legal framework, via the Children, Young Persons, and Their Families (Oranga Tamariki) Legislation Act 2017, which is to come into effect on 1 July 2019.\(^3\) Strategies for improving children’s wellbeing under the Children’s Act 2014 (the Child and Youth Wellbeing Strategy currently under development) are also intended to help New Zealand meet its international children’s rights obligations.

In accordance with New Zealand’s international obligations, UNCROC principles should underpin the development of all policy and practice affecting children in New Zealand. The Ministry of Social

1 Article 6, regarding survival and development, is a key principle under UNCROC and must be applied across all other rights.

2 New Zealand has entered a reservation to UNCROC which means the government does not have to apply UNCROC to children unlawfully in New Zealand.

3 From 1 July 2019, section 5(1)(b)(i) of the Oranga Tamariki Act 1989 will require any court or person exercising power under the Act to respect and uphold the rights of the child under UNCROC and the United Nations Convention on the Rights of Persons with Disabilities.
Development has developed a Child Impact Assessment Tool\(^4\) that might assist the Health and Disability System Expert Review Panel to identify opportunities to improve the performance, structure and sustainability of the health and disability system for children.

**Children in poverty**

The number of children in poverty and hardship is very high as the following table shows.

**Table: Child poverty rates and numbers for the year 2017/18.**

<table>
<thead>
<tr>
<th>Measure</th>
<th>Rate (%)</th>
<th>Children under 18 years</th>
</tr>
</thead>
<tbody>
<tr>
<td>50% of median household income BHC</td>
<td>16</td>
<td>183,000</td>
</tr>
<tr>
<td>60% of median household income BHC</td>
<td>25</td>
<td>281,000</td>
</tr>
<tr>
<td>40% of median household income AHC</td>
<td>16</td>
<td>174,000</td>
</tr>
<tr>
<td>50% of median household income AHC</td>
<td>23</td>
<td>254,000</td>
</tr>
<tr>
<td>60% of median household income AHC</td>
<td>31</td>
<td>341,000</td>
</tr>
<tr>
<td>Material hardship (6+/17)</td>
<td>13</td>
<td>148,000</td>
</tr>
<tr>
<td>Severe material hardship (8+/17)</td>
<td>6</td>
<td>65,000</td>
</tr>
<tr>
<td>Both under AHC 60 and in MH</td>
<td>9</td>
<td>98,000</td>
</tr>
</tbody>
</table>

BHC = before housing costs, AHC = after housing costs

*Source: Perry, 2019*

Children and their families living in poverty are at additional high risk of experiencing a whole range of physical and social challenges. The Expert Advisory Group on Solutions to Child Poverty (2012b) noted that New Zealand children in poverty suffer health issues to a greater extent than those in wealthier households. Their examples were that children in poverty are:

- “At a 1.4 times higher risk of dying during childhood than children in higher-income households.
- “More likely to die of sudden unexpected death in infancy than their peers.
- “Three times more likely to be sick.
- “At greater risk of contracting infectious diseases, as these spread more easily in overcrowded and difficult household conditions.
- “At least 1.5 times more likely to be hospitalised than their peers.
- “Hospitalised at a 5.6 times higher rate than those in wealthier areas for injuries from assault, neglect or maltreatment.
- “Less likely to have fruit and vegetables than those in wealthier households.
- “More likely to have poor outcomes in adulthood, including higher risk of heart disease, alcohol and drug addiction, and worse oral health at age 26.
- “Children with disabilities are over-represented among poor children, with a disproportionate number living in beneficiary families.”

Poverty disproportionately affects children in sole parent families who are disproportionately in receipt of an income support benefit.

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Poverty also disproportionately affects Māori and Pacific families; in 2015, just under half of the children aged 14 or under living in poverty and hardship were Māori and Pacific, yet Māori comprised only 15% of the total population, and Pacific peoples only 7.4% (Dale 2017).

The Welfare Expert Advisory Group (WEAG), in its far-reaching report (WEAG 2019) – all of which is pertinent to this review, due to the correlation between poverty and health & disability issues – has recommended immediate steps towards adequacy of income, including increases in all main benefits and Working For Families tax credits which, if implemented, would result in reduction in child and family poverty.

OUR RECOMMENDATIONS

Recommendation 1: We recommend that progress towards the following six core principles (to be achieved by 2030) are monitored and assessed over the coming years:

1. The right to universal health coverage
2. Accessing services causes no financial hardship to anyone
3. Equitable uptake of, or access to, and outcomes from these services
4. Greater priority given to public health and primary care, in order to prevent illness and disability and to provide early intervention
5. An effective organisational framework for health services with central leadership
6. Clear links with other systems, child poverty reduction and the Child and Youth Wellbeing Strategy

Recommendation 2: Primary care and pregnancy-related dental care should be available free of charge during the antenatal period and until the 6-weeks postnatal review.

Recommendation 3: Universal free healthcare, including prescriptions, primary care and all vision and hearing care, should be made available to all children and adolescents up to the age of 18 years.

Recommendation 4: Proactive dental and oral health services should be free for children and adolescents up until the age of 18, prioritised within public health and primary care preventive checks.

Recommendation 5: Provide ACC-equivalent support for children with health conditions or disabilities not due to an accident, and for those adults with health conditions or disabilities not due to an accident, who are caregivers of dependent children.

Recommendation 6: Increase focus and resourcing on public health measures to improve the health of poorer children and reduce health inequities.

Examples that we recommend include:

- Increasing vaccination coverage and reducing equity gaps
- Extending schools-based approaches to improving diet and physical activity (eg: banning soft drinks, providing school lunches, extending the food-in-schools programme to reach all hungry children)
- Taxing sugar-sweetened beverages
- Schools-based interventions to prevent uptake of smoking
- Improving the quality of rental and state housing

Recommendation 7: Increase the number of primary and secondary schools offering school-based health and social welfare services, including mental health services specific to early detection, appropriate for the age of the children, noting that the approach to healthcare for adolescents is different for younger children; and school social workers.
Recommendation 8: In terms of equity, we recommend special consideration for these areas:
- Māori
- Pacific
- youth
- lower income parents
- access to oral, vision and hearing care
- mental health services; the high prevalence and acuity of child mental health problems needs an adequate service response
- antenatal care
- maternity care including maternal mental health
- children with disability and/or long term health condition (see Question 6)
- parents with a disability and/or long-term health condition.

Recommendation 9: Starting the National Enrolment Service enrolment as early as possible antenatally and working towards integration of enrolment in all of these: primary care, National Immunisation Register, Well Child / Tamariki Ora and dental health

Recommendation 10: Developing and sharing across all health service providers a universal common assessment plan and pathway for all children starting antenatally

Recommendation 11: Improve access to and the supply of maternal mental health services

Recommendation 12: Fully subsidising contraception for those under 22 years as an immediate first step, and progress to free for everyone by 2030

Recommendation 13: Ongoing and regular evaluation of where are the gaps around the country for access to services, and then active service response steps to reduce these gaps

Recommendation 14: Integrating child and youth mental health services, and providing access to affordable psychological therapies, given the limited primary care provision through public funding

Recommendation 15: Providing reasonable accommodations and support for children with disability to a greater level: extra financial support, extra educational support and better coordination through the system

Recommendation 16: Regular systematic review of universal services around the country and why there is variability in the level of what is offered and accessed, and whether outcomes vary

Recommendation 17: Following the recommendation of WEAG to clarify which disability and health-condition related costs are the responsibility of the Ministry of Health and which are the responsibility of the Ministry of Social Development (WEAG, 2019, p.154). Assess the adequacy of the support available to disabled children and their families across the government as a whole, rather than in agency silos

Recommendation 18: Consideration of the development of streamlined ways for disabled children to qualify for support across government. This includes the sharing of information about support and access needs across government agencies, while respecting people’s privacy

Recommendation 19: A national approach to identification and offering services for all children with rheumatic fever and bronchiectasis

Recommendation 20: Utilising New Zealand databases to automatically offer financial entitlements to low-income families rather than expecting families to understand the system and access their full entitlement

Recommendation 21: Universal common antenatal clinical assessment for all, to identify those who have higher needs, for example physical, psychological, drug and alcohol-related, social (including family violence-related) and financial
Recommendation 22: Offer more intense services based on need. This would include increased access to mental health services, drug and alcohol dependency services, talking therapy, social work and financial advice, mentoring and support, Whānau Ora and Navigator services for those who need them.

Recommendation 23: Identify young adolescents in need of greater support. Extra support to be offered to all schools for adolescents in need of psychological services, counselling, drug and addiction support, social support, mentoring.

Recommendation 24: The Health and Disability System Review should recognise and address the Crown’s Te Tiriti obligations for health.

Recommendation 25: Increase health funding for children to a level that strives to achieve equitable child health outcomes for Māori.

Recommendation 26: Provide culturally appropriate effective antenatal care/maternity services for Māori to ensure all hapū Māori wāhine are enrolled with maternity services as early as possible in their pregnancy, and receive the care to achieve equitable outcomes.

Recommendation 27: Establish whānau-centred health services in kohanga reo, Māori ECE, and kura kaupapa, with sustained government funding.

Recommendation 28: Provide greater access to whānau-centred services and programmes for Māori tamariki in emergency departments, and facilitate the transition of care for Māori tamariki to primary care and Māori health community providers.

Recommendation 29: Ensure the Health and Disability System meets the needs of disabled Māori, including disabled Māori children and their whānau.

Recommendation 30: Appoint Pacific people to leadership positions in the health and disability system.

Recommendation 31: Increase health funding for children to a level that strives to achieve equitable child health outcomes for Pacific children and families.

Recommendation 32: Provide culturally-appropriate, effective antenatal care/maternity services for Pacific women to ensure all are enrolled with maternity services as early as possible in their pregnancy and more equitable outcomes are achieved.

Recommendation 33: Improve income levels, quality housing availability and suitable primary health care so that Pacific people have healthier environments and access to health care.

Recommendation 34: Investigate and address access issues for disabled Pacific children and young people with Disability Support Services.

Recommendation 35: The Health and Disability System Review follows the recommendation of WEAG and clarifies which disability and health-condition related costs are the responsibility of the Ministry of Health and which are the responsibility of the Ministry of Social Development.

Recommendation 36: The Health and Disability System Review assesses the adequacy of Ministry of Health and Ministry of Social Development disability-related support and recommends changes to eliminate gaps and unmet costs.

Recommendation 37: The Health and Disability System Review align with the work and outcomes of other current reviews and projects across government, including the Learning Support Update, the Education Conversation: Korero Mātauranga, and the Good Start in Life Project.
QUESTION 1

What are the most important values for our future public health and disability system?

Equity and Justice

The ideal system would be equitably responsive and accessible to all of those who could benefit from its help, based on need and the rights of Māori under Te Tiriti o Waitangi. We know that, currently, access differs along lines of ethnicity, income, gender, sexuality and ability, and that this translates into different (and inferior) outcomes for particular groups of people. A lot of work is already happening to strive to reduce these injustices, and our health system should support this work by valuing justice and striving for more equitable outcomes.

Respect

Respect for the rights and diversity of people who move through our health and disability services. Referring to rights lays the foundation for a health and disability system that is empowering and works with people rather than “doing to” them. In relation to children, it helps position them as active participants in their own healthcare. For people with disabilities it helps promote the idea of “nothing about us without us”.

Whānaungatanga

Concepts of whānaungatanga, whānau, and connection are vital to the health and wellbeing of our peoples. Whānaungatanga could also become an approach to apply to the health and disability system itself, as we continue to integrate services across the board. The same approach would help to create bridges between health and disability services and other government spheres such as welfare, education and housing, enabling people to receive all the support they need.

Kaitiakitanga

A system with an emphasis on health promotion and disease prevention, with a potential flow-on effect of reduced dependence on secondary and tertiary care.

All these values, we believe, would be best manifested together in a system organised on the principle of proportionate universalism (Marmot 2010).

QUESTION 2

Think about how the best health and disability system for New Zealand might look in 2030. How would that be different from the system we use today?

The current health and disability system in NZ

In terms of mitigating the effects of child poverty, current strengths of the system include:

- An overall principle of universal care for all children
- Care is “free” at the point of delivery for many children (zero fees for under-14s in primary care)
- Access to emergency services, out-patient and inpatient hospital services for children is not limited by direct cost
- An appropriate focus on the importance of delivery of services in Primary and Community Care
- A high level of skill and expertise from a committed workforce
Major challenges in the current system include:

- Inequitable access to health services, particularly among Māori, in areas such as childhood immunisation and oral health services
- Precarious funding in many areas with under-resourcing for specific areas. Disability services in general, including those for children, are overstretched, often with unreasonable waiting times for assessment, care, equipment and support
- Lack of coordination between the health and disability system and other sectors on the determinants of health and wellbeing
- Lack of coordination of current digital platforms between different parts of the health sector, and between health and disability and other sectors
- Inadequate support for child health promotion at a national coordinated level
- Multiple structures – Ministry of Health (MOH), District Health Boards (DHBs), Primary Health Organisations (PHOs) and many others including non-governmental organisations (NGOs) – which provide an inefficient platform for equitable and integrated child health service delivery
- Less financial and other support provided by health and disability, and welfare, systems compared with Accident Compensation Corporation (ACC) for the same degree of illness or impairment not caused by an accident (WEAG 2019)
- Inadequate funding support for children with disability, and children in families with parents with disability; this needs urgent attention (WEAG 2019)
- Under-resourcing and under-utilisation of public health, primary care and allied community services. As David Skegg has recently noted “Public health [in New Zealand] is generally compromised by a lack of central leadership and commitment”(Skegg 2019, p. 8). Therefore, only a small proportion of health funding is spent on prevention. There is an urgent need for central leadership over the public health responsibilities that are currently shared amongst the Ministry of Health, DHBs, the regional public health units, PHOS, NGOs and local authorities.

How the best health and disability system for New Zealand might look in 2030

We advocate proportionate universalism as the underpinning principle (Marmot 2010). This means core universal health services and universal access to health services. Then proportionately more services to those who need more than the universal base.

The provision of both universal and targeted health services requires appropriate reasonable accommodations, so that people with disability have equitable access to and outcomes from these services.

Six core facets to achieve by 2030:

7. The right to universal health coverage
8. Accessing services causes no financial hardship to anyone
9. Equitable uptake of, or access to, and outcomes from these services
10. Greater priority given to public health and primary care, in order to prevent illness and disability and to provide early intervention
11. An effective organisational framework for health services with central leadership
12. Clear links with other systems, child poverty reduction and the Child and Youth Wellbeing Strategy

Recommendation 1: We recommend that progress towards these six core principles are monitored and assessed over the coming years.
Universal services

- **Offering free antenatal primary care and dental care services**

  **Recommendation 2:** Primary care and pregnancy-related dental care should be available free of charge during the antenatal period and until the 6-weeks postnatal review.

  In addition, we recommend an integrated maternity care service: coordinated provision by midwifery, “general practice” and community support services.

  Free primary care should include, but not be limited to, a pregnancy-related GP visit in the third trimester. The purpose of this visit is to renew engagement of the mother-to-be with the GP, assess psychosocial issues, discuss family planning, provide whooping cough vaccination, provide vitamin D in the winter months, and pre-enrol the infant-to-be.

  **Current situation:** For antenatal services, currently only maternity-related visits are free. General primary healthcare and dental care in pregnancy is not.

  **Reasoning:** The antenatal period is a crucial time for early childhood development (a large and increasing body of research points to the importance of early brain wiring). For the best health of the child as well as the pregnant person, it is especially important that the health system responds to the following issues, particularly as some of them can be exacerbated by pregnancy: mental health issues (particularly anxious depression); drug and alcohol addiction; oral health; and issues with social support (eg family violence).

- **Free universal healthcare services up to the age of 18 years**

  **Recommendation 3:** Universal free healthcare, including prescriptions, primary care and all vision and hearing care, should be made available to all children and adolescents up to the age of 18 years.

  **Current situation:** Primary care is free for children under the age of 14, but not free for adolescents above that age.

  **Reasoning:** The adolescent years are important for development, and mental and physical illnesses commonly occur in this age group. There is a need for adolescents from backgrounds of socioeconomic deprivation to have no cost barriers to accessing health care.

- **Free comprehensive dental and oral health services up to the age of 18 years**

  **Recommendation 4:** Proactive dental and oral health services should be free for children and adolescents up until the age of 18, prioritised within public health and primary care preventive checks.

  **Current situation:** While some dental services are free, many children miss out on comprehensive dental care.

  **Reasoning:** Poor dental health in childhood and adolescence can continue to have major consequences throughout a person’s life, impacting not only their teeth but their entire physical, mental and social wellbeing.

- **ACC-equivalent support for those with health conditions or disabilities not due to an accident**

  **Recommendation 5:** Provide ACC-equivalent support for children with health conditions or disabilities not due to an accident, and for those adults with health conditions or disabilities not due to an accident, who are caregivers of dependent children.

  **Current situation:** Parents with health conditions or disabilities, and parents of children with health conditions or disabilities, receive much less generous, means-tested welfare payments
and face more difficulties accessing health services, than those eligible for accident compensation. The amount of financial assistance that people may receive from ACC is usually higher than that provided by MSD for the same level of incapacity.

**Reasoning:** This horizontal inequity offends natural justice. We note WEAG Recommendation 41: “Include in the scope of the New Zealand Health and Disability System Review the relationship between the health and disability system and the accident compensation scheme and how the relationship between these and the welfare system could be changed to improve outcomes for people with health conditions and disabilities and carers” (WEAG 2019).

**Public health**

Alignment of public health goals with the United Nations Sustainable Development Goals 2030 would confirm New Zealand’s intention of leaving no-one behind. Moreover the United Nations Sustainable Development Goals include universal health coverage which means that all people and communities can use the promotive, preventive, curative, rehabilitative and palliative health services they need, of sufficient quality to be effective, while also ensuring that the use of these services does not expose the user to financial hardship. New Zealand is a signatory to these goals.

- **Increased resourcing for, and focus on, public health**

  **Recommendation 6:** Increase focus and resourcing on public health measures to improve the health of poorer children and reduce health inequities.

  Examples that we recommend include:
  - Increasing vaccination coverage and reducing equity gaps
  - Extending schools-based approaches to improving diet and physical activity (e.g. banning soft drinks, providing school lunches, extending the food-in-schools programme to reach all hungry children)
  - Taxing sugar-sweetened beverages
  - Schools-based interventions to prevent uptake of smoking
  - Improving the quality of rental and state housing

  **Reasoning:** Public health interventions such as these are highly cost-effective and sometimes cost-saving (Owen et al. 2010). It is much better to prevent ill health and injury than to deal with the consequences: keep people well rather than having to “make” them well; supporting children and families to continue wellbeing is a better use of resources than waiting until they are at greater risk or are in poorer health before “making them better”.

- **Increasing healthcare and social worker access in schools**

  **Recommendation 7:** Increase the number of primary and secondary schools offering school-based health and social welfare services, including mental health services specific to early detection, appropriate for the age of the children, noting that the approach to healthcare for adolescents is different for younger children; and school social workers.

  **Reasoning:** Time availability (particularly for working parents) and location can be barriers to healthcare access for children; to make it as easy as possible to access healthcare, it is best to provide it where children are mandated to be located 25 hours a week. Moreover children themselves may feel comfortable asking about health issues within the school.

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5 See https://sustainabledevelopment.un.org/?menu=1300

6 https://www.who.int/health_financing/universal_coverage_definition/en/
QUESTION 3

What changes could make our health and disability system more fair and equal for everyone?

All our recommendations above are aimed at making the system fairer and achieving equitable outcomes, and we have further recommendations about making the system fairer for Māori (see Question 4) and Pacific people (see Question 5) below. But policies are only as good as their implementation. Therefore, we need to address fragmented and uncoordinated services, and move more rapidly towards more effective coordination between services.

For example, while access to general practice (GP) services for children has improved significantly in recent years as fully-funded GP visits and pharmaceuticals have gradually been extended to children under the age of 14 years, there is still room for improvement and access to primary care remains a problem for many people, because of cost of access and service fragmentation.

In addition, we agree with the WEAG recommendation to “include in the New Zealand Health and Disability System Review how cost and other barriers can be reduced so people on low incomes can access primary care, dental care, alcohol and other drug services, mental health care, secondary care, and vision and hearing services” (WEAG 2019, p. 154).

Mental health issues and addictions are disproportionately found in families and children living in poverty. Therefore we support the wide-ranging findings and recommendations of He Ara Oranga: Report of the Government Inquiry into Mental Health and Addiction.7

Recommendation 8: In terms of equity, we recommend special consideration for these areas:

- Māori
- Pacific
- youth
- lower income parents
- access to oral, vision and hearing care
- mental health services; the high prevalence and acuity of child mental health problems needs an adequate service response
- antenatal care
- maternity care including maternal mental health
- children with disability and/or long term health condition (see Question 6)
- parents with a disability and/or long-term health condition.

We recommend:

- **Recommendation 9:** Starting the National Enrolment Service enrolment as early as possible antenatally and working towards integration of enrolment in all of these: primary care, National Immunisation Register, Well Child / Tamariki Ora and dental health
- **Recommendation 10:** Developing and sharing across all health service providers a universal common assessment plan and pathway for all children starting antenatally
- **Recommendation 11:** Improve access to and the supply of maternal mental health services

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• **Recommendation 12**: Fully subsidising contraception for those under 22 years as an immediate first step, and progress to free for everyone by 2030

• **Recommendation 13**: Ongoing and regular evaluation of where are the gaps around the country for access to services, and then active service response steps to reduce these gaps

• **Recommendation 14**: Integrating child and youth mental health services, and providing access to affordable psychological therapies, given the limited primary care provision through public funding

• **Recommendation 15**: Providing reasonable accommodations and support for children with disability to a greater level: extra financial support, extra educational support and better coordination through the system

**Equity of access**

Access to psychological therapies, dental services, optometry services and secondary referrals should be equitably available via every DHB and PHO.

There needs to be monitoring of use of services for health and disability, and outcomes. We would like to see linkages of national data bases eg Integrated Data Infrastructure (IDI) developed, to focus on monitoring diseases and conditions associated with poverty such as rheumatic fever, bronchiectasis, and certain disabilities.

All low-income families should have automatic access to their financial entitlements (WEAG 2019). This includes the Community Services Card (CSC), but not all those who are entitled actually have a CSC. It is a similar story with Child Disability Allowance and Disability Allowance, and other financial entitlements with the welfare system. Currently many people are not aware of their entitlements and how to fully access them. These solutions would be of value:

• **Recommendation 16**: Regular systematic review of universal services around the country and why there is variability in the level of what is offered and accessed, and whether outcomes vary

• **Recommendation 17**: Following the recommendation of WEAG to clarify which disability and health-condition related costs are the responsibility of the Ministry of Health and which are the responsibility of the Ministry of Social Development (WEAG, 2019, p.154). Assess the adequacy of the support available to disabled children and their families across the government as a whole, rather than in agency silos

• **Recommendation 18**: Consideration of the development of streamlined ways for disabled children to qualify for support across government. This includes the sharing of information about support and access needs across government agencies, while respecting people’s privacy

• **Recommendation 19**: A national approach to identification and offering services for all children with rheumatic fever and bronchiectasis

• **Recommendation 20**: Utilising New Zealand databases to automatically offer financial entitlements to low-income families rather than expecting families to understand the system and access their full entitlement

**Greater service provision for those who have greater needs**

There needs to be greater investment in identifying and offering intensive wrap-around services to those children with higher needs.

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8 Appointments at Family Planning are free for people aged under 22 years but contraceptive treatments still incur charges.
Recommendation 21: Universal common antenatal clinical assessment for all, to identify those who have higher needs, for example physical, psychological, drug and alcohol-related, social (including family violence-related) and financial

Recommendation 22: Offer more intense services based on need. This would include increased access to mental health services, drug and alcohol dependency services, talking therapy, social work and financial advice, mentoring and support, Whānau Ora and Navigator services for those who need them.

Recommendation 23: Identify young adolescents in need of greater support. Extra support to be offered to all schools for adolescents in need of psychological services, counselling, drug and addiction support, social support, mentoring.

QUESTION 4

What changes could most improve health for Māori?

Context

In addition to the attainment of health equity as a moral imperative, tamariki Māori as tangata whenua have the right to experience equitable health affirmed by Te Tiriti o Waitangi (1840), the United Nations Convention on the Rights of the Child (United Nations 1989), the United Nation’s Declaration on the Rights of Indigenous Peoples (United Nations 2007), and within the broader frameworks of international human rights pertaining to indigenous peoples. However, such protection generally does not occur and Māori children disproportionately experience poor health outcomes (Robson & Harris 2007) and youth suicides (Ministry of Health 2017a). To contribute to improving Māori child health outcomes and addressing inequities, substantive actions are recommended, including those mentioned below.

Recommendation 24: Address Te Tiriti o Waitangi obligations in the health sector

The health sector plays an important role in acknowledging Te Tiriti o Waitangi and therefore the status and rights of Māori to achieve equitable health outcomes. In response, some Crown agents such as DHBs have taken steps to implement Te Tiriti principles of partnership, protection and participation, and responding to Te Tiriti obligations is now a section in DHB Annual Plans 2019/20 (DHB 2019/20). However, the principles alone are a limited view of Te Tiriti, and the Health and Disability System Review should recognise the four articles of Te Tiriti and the associated obligations for the health sector to facilitate Māori health gain and reduce inequities (Berghan G et al. 2017, Came H et al. 2018). These articles are:

Article 1 – Kāwanatanga (governance) is equated to health systems governance and performance. This includes establishing structural and other mechanisms to ensure partnerships with Tangata Whenua at a governance level.

Article 2 – Tino Rangatiratanga requires that Māori can exercise self-determination which is concerned with opportunities for Māori leadership, engagement, decision-making and service delivery of health sector activities.

Article 3 – Oritetanga (equity) is concerned with achieving health equity, and therefore with reducing systematic inequities in determinants of health, access to health, and health outcomes

Article 4 – Te Ritenga (right to beliefs and values) provides Māori with the right to practice their own spiritual beliefs, rites and tikanga. The health system has a Te Tiriti obligation to honour the beliefs, values and aspirations of Māori patients, staff and communities across all activities.
Thus, the Health and Disability System Review should recognise and address the Crown’s Te Tiriti obligations for health based on the four articles.

**Recommendation 25: Increase funding for programmes that prioritise Māori child health**

Recent data indicate very high rates of some preventable diseases such as acute rheumatic fever in Māori children (Duncanson M et al. 2018). Adverse effects start from pregnancy onwards, with Māori mothers more likely than non-Māori to have stillbirths, pre-term births and newborn deaths. Māori babies are more likely to be exposed to risk during the antenatal period. The proportion of Māori babies born to mothers without a Lead Maternity Carer (LMC) at the time of delivery, and the proportion of mothers of Māori babies smoking at time of first LMC contact are significantly higher than for non-Māori (Ministry of Health 2009). Many potentially avoidable hospital admissions for poverty-related infectious diseases such as serious skin infections, respiratory infections such as bronchiectasis (chronic lung damage), influenza, pneumonia and gastroenteritis are higher for Māori children. The gaps have continued over the last two decades as Figure 1 clearly demonstrates.

From 2000 to 2012, admissions for injuries from assault, neglect or maltreatment of children aged 0 to 14 years were higher for Māori children than for non-Māori children (Turner N & Asher I 2014). Poverty plays a key role in child abuse and preventable diseases, and key underlying factors for poverty can be changed by policy (Wynd 2013). The racism which underpins the lack of progress in many areas in the determinants of health and the health care system perpetuates this profound disadvantage. The association between racism and poorer health outcomes can be altered if we have the will to challenge and address institutional and other forms of racism in our health and disability system (Jones R, 2014) an all our other state systems.

![Figure 1. All-cause hospitalisation rates, 0-14 year olds, by category and ethnicity 2000-2017. Source Duncanson M et al 2018.](image)

Thus, health funding for children needs to be increased to a level that strives to achieve equitable child health outcomes for Māori.

**Recommendation 26: Increase access to effective antenatal care for hapū māmā**

As recommended above for all pregnant people, early engagement in pregnancy with health providers is likely to lead to better maternal and child health outcomes (Expert Advisory Group 2012). Early engagement can enable providers to:

- Offer regular antenatal care
• Inform and support pregnant women in regards to important issues such as better antenatal nutrition and discontinuation of smoking and alcohol use
• Identify important health and social needs such as mental health concerns, poor housing, family violence and other social concerns.

Currently pregnant people from backgrounds of poverty, and particularly Māori women, often present late in pregnancy and receive limited antenatal care. Data from 2010 indicates that nearly one sixth of Māori women were not attended at all by an LMC (midwife, general practitioner or obstetrician) during their pregnancy (Expert Advisory Group, 2012). Early engagement with maternity services can be a greater challenge for women living in disadvantaged neighbourhoods, and greater resourcing is required. Effective engagement strategies could include increasing the Māori midwifery workforce and access to whānau-centred kaupapa Māori antenatal services so that Māori wāhine are engaged early in pregnancy.

Thus, effective antenatal care/maternity services need to be provided for Māori to ensure all hapū Māori wāhine are enrolled with maternity services as early as possible in their pregnancy.

**Recommendation 27: Increase access to health services in kauapapa Māori domains and settings**

There is significant unmet need and inequalities in child health outcomes particularly among Māori. Māori children consistently have higher Ambulatory Sensitive Admissions for respiratory conditions and infectious diseases compared with non-Māori/non-Pacific, and rates of acute rheumatic fever and rheumatic heart disease continue to be extremely high, exceeded only by rates in Pacific people. Socio-economic determinants are driving these high rates, and barriers to accessing effective primary health care remain (Ellison-Loschmann & Pearce 2006, Bidwell 2013).

In response, programmes such as nurse-led school-based clinics (eg ‘ManaKidz’) have been implemented across primary and intermediate schools since 2012 (Anderson et al 2016). Programmes such as ‘Mana Kidz’ utilise nurses and whānau support workers to deliver primary healthcare services including treatment of throat and skin infections in a school-based setting. An evaluation of programmes such as ‘Mana Kidz’ shows early indications of intended effectiveness (Anderson et al 2016, Lennon et al 2016).

However, there are few similar programmes offered in kura kaupapa and early childhood education (ECE) settings for Māori. To improve access to culturally responsive healthcare services and address unmet health need among tamariki Māori, additional preventative and primary care services delivered in kura kaupapa and early childhood settings is recommended. Engaging kura kaupapa, kohanga reo and other Māori ECE centres would provide an opportunity to engage with whānau, marae, and the wider community. Increasing health literacy among the Māori education workforce, and Te Reo development opportunities among the health workforce may also arise because of working in Māori education domains.

Thus, whānau-centred health services need to be established in kohanga reo, Māori ECE, and kura kaupapa, with sustained government funding.

**Recommendation 28: Increase care coordination and integration between secondary care and primary/community services for Māori**

A significant proportion of Māori children present to secondary-care emergency departments (ED), often out of hours, and many of these presentations may be preventable (Barker et al 2016, Lyndon 2019).

The reasons for the high utilisation of EDs by Māori are not well-established, but are likely to be multiple and complex. International research suggests such factors as barriers to accessing primary care; preference for the ED over primary care services; socio-economic factors; proximity to the hospital; being a single parent; parental anxiety; and parents believing their child’s condition is serious all contribute to ED presentations (Duncan et al. 2013, Gnani et al. 2016)
A proportion of ED presentations are potentially preventable with the use of culturally appropriate and accessible local community and primary health care services, and better transition pathways back to these services (Duncan et al. 2013). Strategies may include investment in whānau support workers in children’s emergency departments to provide whānau-centred services and programmes, and increasing care coordination and integration with Māori community health providers and primary care services. Greater primary care service provision in settings such as community pharmacies, by telemedicine, or co-located in ED departments could also be considered.

Thus, greater access to whanau-centred services and programmes for Māori tamariki needs to be provided in EDs, and the transition of care for Māori tamariki to primary care and Māori health community providers needs to be facilitated.

Disability and Māori

Māori are more likely to have a disability and are increasingly using disability-related support. This means it is all the more important that the Health and Disability System considers and meets their needs.

In the 2013 Disability Survey, Māori children had a higher disability rate than other ethnic groups. 15% of Māori children aged 0 to 14 had a disability, compared to 11% of all children. In 2016, Māori made up 20% of all young people and children aged under 19 who were using Ministry of Health Disability Support Services (Ministry of Health, 2017b, p.10). Over the last decade, the percentage of Māori caregivers receiving the Child Disability Allowance has steadily grown. Twenty-four percent of caregivers receiving the Child Disability Allowance are now Māori.

**SUMMARY: RECOMMENDATIONS TO IMPROVE HEALTH FOR MĀORI**

- **Recommendation 24**: The Health and Disability System Review should recognise and address the Crown’s Te Tiriti obligations for health.
- **Recommendation 25**: Increase health funding for children to a level that strives to achieve equitable child health outcomes for Māori.
- **Recommendation 26**: Provide culturally appropriate effective antenatal care/maternity services for Māori to ensure all hapū Māori wāhine are enrolled with maternity services as early as possible in their pregnancy, and receive the care to achieve equitable outcomes.
- **Recommendation 27**: Establish whānau-centred health services in kohanga reo, Māori ECE, and kura kaupapa, with sustained government funding.
Recommendation 28: Provide greater access to whānau-centred services and programmes for Māori tamariki in emergency departments, and facilitate the transition of care for Māori tamariki to primary care and Māori health community providers.

Recommendation 29: Ensure the Health and Disability System meets the needs of disabled Māori, including disabled Māori children and their whānau.

QUESTION 5
What changes could most improve health for Pacific peoples?

Potentially preventable diseases

Pacific children, more than children from any other ethnic group suffer the highest rates of many potentially preventable diseases and poor health outcomes. For hospital admissions this is clear in Figure 1 above.

Rheumatic fever and bronchiectasis are two preventable diseases causing lasting damage to people’s hearts (rheumatic fever) and lungs (bronchiectasis); these diseases afflict Pacific people at shockingly high rates compared with non-Pacific people. Pacific children and young adults are nearly 70 times more likely that NZ European children and more than twice as likely as Māori children to be admitted to hospital with acute rheumatic fever and rheumatic heart disease (Simpson et al 2016). Bronchiectasis (lung damage) often starts in early childhood. In 2017, the incidence of bronchiectasis in children under 15 years was highest in Pacific children at 28.0 per 100,000, compared with 17.7 in Māori, 4.6 in Asian children, and 8.8 in all non-Māori and Pacific children (Telfar Barnard L & Zhang J, 2018). The combination of preventable poverty, unhealthy housing and crowding, and inadequate basic health care underpin these shocking figures (Salesa 2017).

The fact that East Asian and Indian children have been relatively protected from these preventable diseases illustrates that high rates of disease are not inevitable for non-European children in New Zealand, and that a lot more needs to be done to achieve equitable outcomes for Pacific people.

Disabilities

Disabled Pacific people and their families are more likely to choose family-based support options but the system does not fund these options as well as it does residential options. Residential services mean a family member can no longer live with their family, but are also better funded than family-based support options and typically mean the family no longer has to contribute to support cost.

The lower level of support for family-based options is likely to increase poverty rates among Pacific families who have a family member with a disability. Pacific people who use disability support services are the mostly likely cultural group to live in deprived areas. For the last year that deprivation decile data is available, 53% of Pacific people who use Ministry of Health disability supports are in deprivation deciles 9 or 10 (Ministry of Health, 2015, p. 14). The ongoing lack of resourcing for family-based and community-based options is forcing disabled Pacific people and their families into unfair choices and further driving inequality. There needs to be fair resourcing across different settings. This means increased resourcing for family and community-based options.

There is also evidence suggesting that there may be a significant access problem for Pacific children and young people vis-à-vis Disability Support Services (DSS), in that Pacific children and young people make up a lower percentage of children and young people receiving DSS than receiving assistance from the Ministry of Education’s Ongoing Resourcing Scheme (ORS). As the ORS is for students with high and very high needs, it might be expected that the ORS and DSS percentages would be similar; however, in 2016, Pacific children and young people aged 5 to 19 made up 10.5%
of all children receiving ORS, compared to 7.1% of children and young people aged 5 to 19 receiving DSS (Indicators & Reporting Team, Ministry of Education, 2018; Ministry of Health, 2017). If we take ORS proportions as a baseline, we could reasonably expect 1250 Pacific children to be receiving DSS support; instead, the number is 400 fewer, at 850 Pacific children.

Thus, the following are needed:

- **Recommendation 30**: Appoint Pacific people to leadership positions in the health and disability system.
- **Recommendation 31**: Increase health funding for children to a level that strives to achieve equitable child health outcomes for Pacific children and families.
- **Recommendation 32**: Provide culturally-appropriate, effective antenatal care/maternity services for Pacific women to ensure all are enrolled with maternity services as early as possible in their pregnancy and more equitable outcomes are achieved.
- **Recommendation 33**: Improve income levels, quality housing availability and suitable primary health care so that Pacific people have healthier environments and access to health care.
- **Recommendation 34**: Investigate and address access issues for disabled Pacific children and young people with Disability Support Services.

**QUESTION 6**

What changes could make sure that disabled people have equal opportunities to achieve their goals and the life they want?

People with disability need greater support to enable equality of outcomes (ie achieve equity); equal opportunities are not sufficient.

Disabled children and their whānau are diverse and have many strengths. Yet they face large systematic barriers. Disabled children are more likely to live in low-income households and experience serious discrimination and barriers in access to health, education and other services. These barriers include the accessibility of services, buildings, transport, information and infrastructure as well as negative attitudes from the public and professionals.

These barriers have been compounded by a tendency to treat the health and disability system as separate from other systems (such as welfare and housing), including disability-related income support and allowances. This has resulted in inconsistencies, gaps, unmet costs, and unmet needs for disabled people and their families. WEAG recognised this and recommended that the Ministry of Social Development and the Ministry of Health should work out who is responsible for covering disability and health condition related costs. This information should be made transparent to the public and disability community (WEAG 2019 p 154). This is long overdue and should be a key part of the Health and Disability System Review, which should clarify which Ministry is responsible for which disability and health-condition related costs. The Review should then assess the adequacy of the current disability-related support of both agencies, and recommend changes to eliminate gaps and unmet costs.

The education system also provides supports for children with disability and inclusive education is an essential to their wellbeing. The Good Start in Life Project under the Disability Action Plan9 aims to improve government supports for parents, family and whānau with disabled children aged 0-8 years.

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The project aims to address a number of known issues that are also relevant to the Health and Disability System Review. These include:

- parents, family and whānau being valued and having choice and control
- more timely identification/recognition of need
- more timely access (capacity, eligibility criteria, geographical coverage)
- increased access – not targeted only to very high need
- easier access – good information, less complexity, fewer hoops
- continuity of access over time and when people shift
- services and supports strengths-based and aligned with good practice
- more consistent, coherent and better integrated supports and services.

We recommend:

- **Recommendation 35:** The Health and Disability System Review follows the recommendation of WEAG and clarifies which disability and health-condition related costs are the responsibility of the Ministry of Health and which are the responsibility of the Ministry of Social Development.
- **Recommendation 36:** The Health and Disability System Review assesses the adequacy of Ministry of Health and Ministry of Social Development disability-related support and recommends changes to eliminate gaps and unmet costs.
- **Recommendation 37:** The Health and Disability System Review align with the work and outcomes of other current reviews and projects across government, including the Learning Support Update, the Education Conversation: Korero Mātauranga, and the Good Start in Life Project.

**QUESTION 7**

What existing or previous actions have worked well in New Zealand or overseas? Why did they work, and how might they make things even better in the future?

Strategies and actions that have been effective, both in New Zealand and overseas, have certain characteristics in common that have been vital to their success:

- clearly defining the critical systems issues and opportunities
- developing clear aims able to achieve broad consensus
- effective leadership that gives strong support for all levels of the system. In many of the following examples, there was strong political and professional support, creating national, regional and local engagement.
- supporting effective integration and innovation by ensuring adequate time and funding for all participants in the service, regular evaluation, feedback loops and support for review and incremental change.

Examples include:

- **Strong focus on primary care delivery, as improved health outcomes are linked to effectiveness of primary care (Starfield et al 2005)**

  Evidence of the health-promoting influence of primary care has been accumulating ever since researchers have been able to distinguish primary care from other aspects of the health services delivery system. The declaration of Alma Ata in 1978 began a period of primary care development which has shown very clearly that countries placing a strong focus on primary care such as the UK and latterly New Zealand deliver much better
outcomes than other comparable OECD counties. The evidence also shows that primary care (in contrast to specialty care) is associated with a more equitable distribution of health in populations, a finding that holds in both cross-national and within-national studies. The US healthcare system is the most potent comparator illustrating repeatedly how a relatively low priority on organised primary care delivers a system that is corrosive in terms of efficiency and equity.

- **Child Friendly and Youth Services (Hetrick et al. 2017)**
  Child-friendly services recognise that interventions should focus not only on managing the child’s health condition, but also on their physical and/or social environment, thus avoiding the medicalisation of social problems. It includes addressing environmental issues (air and water quality, sanitation), socio-economic problems (poverty, social exclusion, poor housing and nutrition), access to education, or parental issues (parenting skills, parents’ mental health, domestic violence or substance abuse). For vulnerable and disadvantaged children and families, there is evidence that such integrated services offer long-term gains in health, wellbeing and life chances. (eg Council of Europe https://rm.coe.int/168046ccef)

- **Patient-centred care delivered outside conventional health settings, such as school clinics, Youth One Stop Shop (YOSS), NGO youth services.**
  For effectiveness, efficiency and equity, many health services, including many child-friendly services, are most appropriately delivered outside of traditional health settings. Young people require services that are accessible, affordable and appropriate.

- **Prevention and early intervention with childhood social and psychological problems**
  Increasing awareness of the importance of the “early years” (pre-conception, ante natal and postnatal health and the under-fives) in terms of neural and behavioural development has led to innovation and focus on supporting resilience and promoting early intervention for childhood behavioural and social issues and problems. Evidence for prioritising preventive and early intervention is found at a broad and global level, where action is seen as imperative to reduce the burden of mental health problems in future generations and to allow for the full development of vulnerable children and adolescents (Kieling et al. 2011)
  There is also evidence for the effectiveness of these approaches for specific mental health problems such as anxiety (Neil and Christensen 2009), conduct disorder and substance use problems (Webster-Stratton et al. 2001).

- **Child immunisation strategies, based on a systems approach and primary care engagement**
  Child immunisation rates have dramatically improved over the last 12 years, due to a whole of system approach. The Increased Immunisation Health Target Champion is Dr Pat Tuohy of the Ministry of Health10 who has agreed to be contacted for further information.
  The key five elements leading to success are:
  1. Development of the National Immunisation Register which is able to identify those who have been immunised, and those who have not, including their GP details.
  2. Outreach reaching individual families to reduce inequalities by ethnicity and deprivation level. Partnership with Māori and Pacific providers.

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10 [https://www.health.govt.nz/new-zealand-health-system/health-targets/about-health-targets/health-targets-increased-immunisation](https://www.health.govt.nz/new-zealand-health-system/health-targets/about-health-targets/health-targets-increased-immunisation)
iii. Whole of system - talked to families and to every group of people in places where immunisations could be enabled or occur. Linkages were made between every part of the system and immunisation is recognised as a key part of everyone’s work.

iv. Research to find where obstacles occurred and why, and remedy them – a continuous improvement process.

v. Government made increasing immunisation rates a target, and then-Minister of Health Tony Ryall took an active interest in progress, himself an “immunisation champion.”


There is an artificial separation between different health sector activities, which becomes problematic when matched with the need to take a ‘life course’ approach for many issues. This is particularly true for the separation between childhood and adolescence and the transition for many into adult life. Integrated care is about joining things up in order to meet health needs, and in ways that make sense to children and families. The needs of children with long-term problems are pressing in this regard. Planned care for children with long-term conditions often takes second place, and management of children with long-term conditions is suboptimal, leading to reduced quality of life and increased costs as these young people move into adulthood.

**QUESTION 8**

What are the most important changes that would make the biggest difference to New Zealanders?

1. Address socioeconomic determinants of health and disability, and provide adequate financial and other support (implement the recommendations of the WEAG Report)
2. Take a proportionate universalism approach with antenatal identification for all, followed by baseline universal services and targeted extra support and services for identified higher need.
3. Increase preventive public health strategies
4. Strong focus on primary care delivery to improve health outcomes
5. Improve Māori health outcomes by
   i. Recognising and addressing the Crown’s Te Tiriti obligations for health
   ii. Increasing health funding for children to a level that strives to achieve equitable child health outcomes for Māori
   iii. Providing culturally appropriate effective antenatal care/maternity services for Māori
   iv. Establishing whānau-centred health services in kohanga reo, Māori ECE, and kura kaupapa, with sustained government funding
   v. Providing greater access to whānau-centred services and programmes for Māori tamariki in emergency departments, and facilitating the transition of care for Māori tamariki to primary care and Māori health community providers
   vi. Ensuring the Health and Disability System meets the needs of disabled Māori, including disabled Māori children and their whānau.
6. Improve outcomes for Pacific people by
   i. Appointing Pacific people to leadership positions in the health and disability system.
ii. Increasing health funding for children to a level that strives to achieve equitable child health outcomes for Pacific children and families

iii. Providing culturally-appropriate, effective antenatal care/maternity services for Pacific women

iv. Improving income levels, quality housing availability and suitable primary health care

v. Investigate and address access issues for disabled Pacific children and young people with Disability Support Services.

7. Improve outcomes for disabled children by increasing financial and other support.
8. Provide ACC-equivalent support for parents of children with health conditions or disabilities not due to an accident.

QUESTION 9

Is there anything else you wish to add?

We further recommend that the Review seek out child health expertise, including by consulting with children and young people themselves.

This review of Health and Disability System does not appear to have a representative of the disability community among the members of the Review panel. Therefore it will be less well-equipped to make a comprehensive review from the point of view of disabled people. We recommend that a representative of the disability community be co-opted to the Review.

Summary

Children in poverty and their families disproportionately have higher rates of physical and mental illness and disability than those who are not in poverty. They have greater difficulty in accessing and/or affording appropriate management for their health and disability needs.

The Health and Disability System has important contributions to make to the health and wellbeing of children and families in poverty. CPAG’s recommendations for improvements are found in our responses above.
REFERENCES


United Nation’s Declaration on the Rights of Indigenous Peoples.


