



## THE PAEDIATRIC SOCIETY OF NEW ZEALAND

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### Submission

To Health and Disability Systems Review group  
From: Paediatric Society of New Zealand  
Date 31-05 2019

#### **Introduction:**

This submission is from the Paediatric Society of NZ (PSNZ), a national organisation with a membership of over 500 dedicated child health professionals. The membership includes all professional disciplines across nursing, allied health and medical groups and represents clinicians engaged at the frontline of care, academics and child health leaders, all working for the health and wellbeing of infants, children and youth in Aotearoa NZ.

Other specific area submissions have been made separately by the following Special Interest Groups under the 'umbrella' of PSNZ, and with our support.

We also strongly endorse the submission and recommendations from the Child Poverty Action Group which has been shared for our review.



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1. What are the key values that you would want to underpin our future public health and disability system?

**Infant, child and youth health and wellbeing needs are paramount** and should be prioritised. This principle of paramountcy recognises the need to be cared for and nurtured from the start of the life course as foundational for all of society's well-being. *He taonga te tamaiti (Every child a treasure).*

**Equity of health outcomes and opportunity** is a value that calls for focus on Māori, Pasifika, and economically disadvantaged populations who do not experience the good health outcomes expected for all children. Equity should also be addressed for geographic variations, balancing access to care with need to concentrate certain specialised services.

**Te Tiriti o Waitangi** with its principles of partnership, participation and protection underpins the relationship between Government and Māori. *Te Tiriti* must inform the way of working with Māori throughout healthcare from governance to delivery.

The **patient voice must be sought and listened to**. Specifically children and youth need to be consulted, consistent with UNCROC and furthermore adding value to the systems and providers of healthcare.

**Resources must be used in the best way possible** (efficiency) to achieve the best health outcomes (efficacy). This includes the importance of wise allocation with ongoing attention to evidence base to inform initiation, continuation and discontinuation of health interventions.

***He aha te mea nui o te ao. He tāngata, he tāngata, he tāngata***

What is the most important thing in the world? It is people, it is people, it is people.

Health is about the whole person living in their context of whānau and community. Healthcare is delivered by people. Working with people and for people calls for respect and compassion as foundational values of all that is done in the name of healthcare.



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2. If you imagined the ideal health and disability system for New Zealand in 2030, how would people's experiences differ from today?

Achieving equity: Success would be demonstrated by equity of health outcome for Māori, Pasifika and economically disadvantaged populations. Positive engagement and trust in the NZ healthcare system would then be an international example of turning things around for the better for those currently not doing well. Better health would contribute to improved well-being.

Prevention and early intervention services would be well-funded, and well-supported by public health campaigns.. Resources would be directed to those with the greatest need, e.g. community-based midwifery, trauma informed addictions services and parenting support for pregnant women through the initial few years (at least) of their child's life, Well Child Tamariki Ora providers, immunisation, injury prevention, resiliency-focused health promotion to young people, trauma informed addictions services for pregnant women through the first 3 – 5 years of their infant's life. Prevention for many issues requires persistence for many years and so approaches that have evidence base need to have a long-term commitment beyond the usual NZ political cycles. E.g. healthy weight in childhood has value that really is only seen in the decades to follow. There are opportunities for prevention which have strong evidence base which require national leadership to effectively benefit our population. (1) Fluoridation of reticulated water supplies, to improve oral health. Currently some key areas with poor oral health are missing out due to local council variations. (2) Folate in bread, to prevent Spina Bifida and other spinal developmental abnormalities.

Primary Care: Children and youth up to the age of 18 years would receive free primary care including both acute and preventative care. Primary and community care would have capacity for proactive preventative healthcare and health promotion. Robust and comprehensive primary care systems would provide easily accessible (e.g. 7 days a week) local health services for all members of the family in a way that is able to provide continuity of care, to manage complexity and to access effectively other more specialised services. Primary care service to vulnerable populations requires sufficient capacity matched to need, and capability to deliver high quality 'point of care' services. The principle of strengthening the diagnostic-treatment capabilities at the early points of contact should be tested and applied across the healthcare system as appropriate.

Transition of youth with chronic illness and disability would be strongly supported through healthcare right across the gap that is currently experienced between child health and adult services.

Listening to the patient voice, and in particular children and youth, would be a normal part of health systems all the way from design through to delivery. Approaches to achieve this including face to face, paper, and online, formal youth employment opportunities and further and would continue to be refined. Communities would enjoy a sense of involvement and 'ownership' of their healthcare as the systems reassure them that they are being heard. Patients, including children and youth, would be meaningfully involved in their personal health care and goal-setting.

Enabling environments and facilities: Physical design of healthcare, educational and other



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neighbourhood settings would fully enable the participation and opportunities for people with disabilities. Access to equipment that enables would be made much easier and seamless in a way that also delivers equity of opportunity for all. Disability would be addressed in practical and social innovations that enable 'the good life' which includes opportunity for participation. Families carrying the challenge of enabling a child with disability would be well supported with resources – human and material – to achieve good outcomes for their children and young people.

Workforce fit for community served: The workforce would better reflect communities served, and so would specifically include Māori and Pasifika clinicians in all allied health, nursing and medical disciplines. The workforce would be continuing to develop high levels of cultural competence and interpersonal skills to enable excellent delivery of technical expertise. Excellence would be a shared aspiration across the workforce.

Information Systems which enable: On-line tools and interactive information systems will support whānau to partner with clinical teams in their healthcare. The clinical information that supports a person's care would safely but seamlessly 'move' with the patient in a way by which this information is available at the various points of care for them through the healthcare system. The patient/caregiver would have clinically supported access to their own information in ways that enables greater involvement in their own care. The system would promote health literacy development for our whole population. Community level discussions about health would be well informed. A national information system platform would be progressed to support regional and national integrated care. Integrated electronic medical records and information sharing includes medication systems and systematic reconciliation (including paediatrics). For medications a single 'source of truth' updated in real-time would enable safer use and prescription of medication and better informed care.

Dismantle the 'silos': Antenatal, child and youth impact would be considered throughout the system being assessed as a key consideration for service developments as well as at policy and legislation levels. Serious consideration should be given to fully integrate child physical and mental health services. Current separation of mental health services is often counterproductive. Wellbeing would be considered in its broadest sense with partnerships across health, education, housing, justice, United Nations Convention on the Rights of the Child (UNCROC), Treaty of Waitangi and economic development. The approach would drive a health and wellbeing model which integrates across all government sectors. This would enable funding flexibility that responds in an evidence-based way to the need.



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3. What system level changes would you recommend to improve equity of health outcomes and wellbeing? What impact would you expect these changes to make?

**Funding:** A key change towards improving equity is focusing resources on prevention and early intervention. Getting health optimised in the antenatal and early years and focusing on high need populations is critical to reducing the gaps that otherwise only increase over the life course. Funding models require the necessary flexibility to work collaboratively and to effectively engage clinical leadership. Flexibility will increase agility so that investment can shift as population priorities change. There needs to be opportunity for funding to be allocated at regional level to implement effective models of care. Service design should include tools that easily define areas of greatest need on which to focus with culturally appropriate models of delivery.

**Equity focused Quality Improvement:** Monitoring and reporting systems of clinical service and outcome data need to be developed in ways that facilitate quality improvement cycles and ensure equity is consistently sought. This also requires ensuring all health professionals have time for quality and training to use these tools effectively. The aspiration for excellence needs to be enabled with the tools to improve practice. New and existing health programmes and services need to be provided with enough resources to properly evaluate and monitor.

**Workforce:** Workforce development should include training in leadership including skills around facilitation and change management, to strengthen working with communities. Workforce needs to be responsive to priorities identified through an epidemiological evidence-base.

**Information systems and data-sharing:** Further development of appropriate information sharing across health, education, and social (including Oranga Tamariki) services is recommended for recognised professionals involved directly in the care of a child and explicitly for the child's wellbeing. Data sharing approaches need to be balanced against public trust in data collection and Māori data governance as well as ensuring appropriate linkages and privacy settings. Currently information sharing is hampered and cumbersome in ways that limit coordinated support of those most in need.

**Governance relationships:** At both government nationally and community locally the relationship between health and other sectors (e.g. housing, education, social, industry) needs to be strengthened in such a way that determinants of health and wellbeing can actually be addressed. Two serious examples of this are Rheumatic Fever and Bronchiectasis which continue to occur at unacceptable rates amongst Pasifika, Māori and economically disadvantaged children/youth. We need to see a much stronger accountability across other sectors to address a condition for which health caught addressing the downstream consequences of poor housing, overcrowding and the multiple adverse impacts of poverty. A strong and meaningful governance relationship between health boards and local authorities would be demonstrated through making neighbourhoods and environments health promoting (e.g. encouraging healthy activity, healthy eating,) and preventative (e.g. reducing injury,) with pervasive and long term social benefit. Similarly strengthening the relationship between the Ministries of Health and Education, to oversee a positive working relationship between DHBs and schools, would be demonstrated by schools and early childhood services having the resources to manage and adequately support children and young people with health conditions and disabilities.



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Involving Communities in their Health: Approaches to actively involve communities and individuals in service co-design processes require focus with service users (and non-users) from populations who are currently disadvantaged and experience poor outcomes. This is an important step toward achieving equity.

4. What system level changes would have the most impact on improving health outcomes for Māori?

Leadership: Māori leadership at all levels; include Māori on boards and in other leadership roles.

Culturally competent sector: Continue training right through the workforce (currently training as well as existing) towards excellence in cultural competency. This includes administrative staff.

Governance that engages Māori: Ensure feedback is meaningfully obtained from Māori with systems of governance that ensure response.

Measure Māori outcomes: Continue to measure outcomes as well as underlying process indicators in ways that feedback and inform progress towards equity for Māori.

Māori worldview informing design: Ensure service changes designed by Māori can be delivered using a Māori worldview and receive funding to implement and evaluate health outcome improvement. Our healthcare sector needs to ask Māori what they need and enable them as a way forward. This will require investment in community driven services, with organisational scaffolding to achieve progress.

5. What system level changes would have the most impact on improving health outcomes for Pasifika peoples?

Leadership: Pasifika leadership at all levels; include Pasifika on boards and in other leadership roles.

Cultural competency: Continue training right through the workforce (currently training as well as existing) towards excellence in cultural competency. This includes administrative staff.

Governance that engages Pasifika: Ensure feedback is meaningfully obtained from Pasifika peoples with systems of governance that ensure response.

Measure Pasifika outcomes: Continue to measure outcomes as well as underlying process indicators in ways that feedback and inform progress towards equity for Pasifika.

Pasifika worldviews informing design: Ensure service changes designed by Pasifika can be delivered using Pasifika worldviews and receive funding to implement and evaluate health outcome improvement. Our healthcare sector needs to ask Pasifika what they need and enable them as a way forward. This will require investment in community driven services, with organisational scaffolding to achieve progress.



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6. What system level changes would have the most impact on ensuring that disabled people have equal opportunities to achieve their goals and aspirations?

Leadership: Include people with disability (and caregivers) in leadership at all levels; include on boards and in other leadership roles.

Competency of workforce: Continue training right through the workforce (currently training as well as existing) towards excellence in competency working with people with disability. This includes administrative staff.

Governance that engages people with disability: Ensure feedback is meaningfully obtained from people with disability (and caregivers) with systems of governance that ensure response.

Measure outcomes for people with disability: Continue to measure outcomes as well as underlying process indicators in ways that feedback and inform progress towards equity for people with disability (and caregivers).

Address funding disparities: there exists a significant disparity of funding for people with disability under Health and Disability Services funding compared to those under ACC funding. This is an issue that must be addressed to improve the situation for those currently less adequately supported under general disability funding.

Equity of access: There are geographic differences in access to support that need to be addressed towards achieving equity.

Sufficient support: Community supports need to be strengthened for young people with disability moving into adulthood. Support for all disability needs to be longitudinal which includes ensuring financial viability of our NGO sector

Child Development Services and Systems: We recommend this HD&S review closely examine the recent report, "Stocktake and Needs Analysis of Child Development Services in New Zealand" (Widdowson, et al, 2015) to inform redevelopment. The report notes suboptimal collaboration and coordination between Child Developmental Services (CDS), education, Needs Assessment and Coordination Services (NASC) and social services such as Oranga Tamariki. There are differing eligibility criteria, variable focus, and limited systems for communication. The report discusses workforces shortages in many areas including psychology, and speech language therapy. The report also talks about the significant lack of resources for those with mild to moderate needs, those with communication difficulties, Fetal Alcohol Spectrum Disorder (FASD) and sensory issues, with minimal to no early intervention in many of these areas.

This CDS stocktake needs to be considered alongside the Mental Health inquiry with consideration of how we remove the artificial silos between Infant maternal health, child and youth mental health and child developmental and paediatric services. We need to develop a true single point of assessment for our children where early in-depth development and behaviour assessment and support may be given. Too often our children are given a simplistic level diagnosis such as ADHD when much broader attention is required to consider attachment, family function, cognitive function and other diagnoses such as FASD. The cost of not 'understanding' our children is too great at every level of societal 'cost'. Serious consideration needs to be given to broadening the NASC criteria for disability, a common example is FASD with borderline intellectual functioning, where support is clearly needed but not accessible under current criteria.



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7. What existing or previous initiatives have best delivered improved and equitable health outcomes and wellbeing in New Zealand or overseas? Why have these approaches worked, and what is their potential to deliver further improvement?

Quality Epidemiology data and analysis: For children and youth there has been systematic regular (annual) and robust reporting of the equity gap through the NZ Child and Youth Epidemiology Service (NZCYES), with helpful data separations by ethnicity and socioeconomic status (NZDep). This has been very informative for DHBs and other services to appreciate the current gaps in health outcome. For example, comparative data has been used by many DHBs to improve outcomes for Māori, such as using Ambulatory Sensitive Hospitalisations (ASH) as an indicator for Māori children. Similarly the data has clearly informed the development of approaches to reduce Māori Sudden Unexpected Death in Infants (SUDI). The NZCYES should be extended to cover outpatient services in order to assess needs in relation to conditions such as eczema and food allergies.

Innovations of healthcare delivery: e.g.

- Before School Checks (B4SC) and Incredible Years delivered in Hawkes Bay as an intersectoral partnership has greatly improved the performance of these programmes, and ensured high equity of access and outcome for both programmes.
- Partnering of Well Child Tamariki Ora nurses with NGO social workers has been demonstrating significantly improved outcomes for whānau.
- Plunket buses in South Auckland, employing staff from many language backgrounds, greatly improved access to and outcomes from this service
- Providing primary care from marae similarly improved access and outcomes.
- Youth One Stop Shops (YOSS) and school based health services have improved access and outcomes for young people, such as reduced teen pregnancy and earlier treatment of Sexually Transmitted Infections.
- Opportunistic immunisation and provision of Nicotine Replacement Therapy to parents on children's wards increased availability and engagement.
- Violence Intervention Programme and Oranga Tamariki social workers in DHBS has improved liaison between sectors and care for specific children at risk of abuse and neglect. Co-location has been very helpful.

Culturally informed models: Whānau ora is a great model which, where working, is bringing additional coordination and navigation at the Whānau level with improved outcomes for children, for Māori and for all people with complex social and health challenges.

Hapu Wananga, antenatal education based on connection, identify, hope and aspiration embedded with SUDI prevention programs and evidenced based community intervention and co-design.

System level approaches: Child Friendly Cities (e.g. Leeds, UK) is an example of a framework which leverages across government, business, health, education and social services to create great environments and communities that nurture children and young people



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- 8 What are the top priorities for system level change that would make the biggest difference to New Zealanders?

Funding for the early years (from conception): Significant additional funding (for services and workforce) into the early years (from conception) focused on addressing equity from the start and preventing the long life-course shadow caused by preventable chronic and life-limiting diseases, e.g. Bronchiectasis, Rheumatic Fever.

The Health and Disability System must be committed to a much more equitable health investment with a reallocation to earlier life course spending. We support the concept that waiting times for diagnosis, assessment and treatment in health care should be matched to a life course model. It is unethical for waiting lists for children to be measured in similar timeframes to adults when this represents a much greater window of lost or reduced opportunity. We believe that strategic investment should be prioritised to populations of core interest to Oranga Tamariki, Māori and Pasifika. The focus on getting it right from the start should include aspirational antenatal care, such as traditional Hapu Wananga programs. This also includes an urgent national focus on reducing foetal alcohol exposure and harm through a range of individual and population wide interventions with a need for strong Māori led championing. There needs to be definite investment into Trauma informed addiction services and parenting support for pregnant women through to the first few years, at least. There is also a need for further incorporation of trauma informed support for fathers. We strongly support a Proportionate Universal approach to funding models which, while including all children, really focuses attention and resource on those with greatest risk of poor outcomes.

Effective governance relationships across sectors: There is a need for a much stronger functional relationship between health and education. This is required to effectively invest and coordinate support for children with learning disabilities. Better systems are required to identify earlier before school which children are having difficulty or are disadvantaged. Then this should be effectively followed through, with continuity of support for these children identified as requiring support. Linkage with health systems and relevant alerts would improve the support particularly for highly transient children. Linkage across health and education is needed for trauma informed support of children exposed to adverse life experiences. Too often our children are perceived as 'naughty' or 'difficult' with their complex behaviours and high rates of adverse childhood experiences. We need to move the focus away from 'behaviour' and towards the unsolved problems the young person is facing. Increased investment in school-based services to support children in their health and learning is a particularly important equity driver.

Focus on maternal wellbeing and the healthy pregnancy: Pregnancy is a key opportunity to change trajectories for the better. Protection of the unborn child from the negative impact of smoking, alcohol, drugs, domestic violence etc. through effective support of the mother and whānau antenatally should be a major focus of the health system. There are so many ways where reducing/removing these adverse factors and attending to maternal health (e.g. oral health, mental health) will multiply benefit for the next generation. Hapu Waananga and traditional connection, identify and aspiration Māori based antenatal care are showing promise.

Early identification: The Well Child Tamariki Ora system is currently ill equipped to identify and support learning and behavioural difficulties. The PEDS tool is ineffective in areas



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where delayed skills are normalised. The onus on the B4SC to ready the child for school is too late in the life course model as the program currently stands. (We are aware that the Well Child Tamariki Ora review is also underway which should take this into consideration.)

Addressing child poverty: No child should grow up in poverty. The focus on eliminating child poverty needs to be maintained through to achievement of equity. Child and whānau poverty is the major determinant for much of child illness that is currently seen in Aotearoa NZ. This will require attention to welfare and social supports {ref: WEAG report}, living wage for low income employees, appropriate funding of early childhood education, healthy housing, quality nutrition, and improved maternity and antenatal care. A substantial support for parents, particularly those disadvantaged currently, is required to support their irreplaceable role in good child development. Families facing multiple adversity should receive culturally and socially appropriate supports for quality parenting and education, including a focus on literacy.

Disability systems – key opportunity for improvement: The need to better understand and support the high levels of unmet disability within our most vulnerable populations. High rates of disability with the populations of core interest to Oranga Tamariki leads to a cycle of failure and repeat referrals back to the statutory space. Contracted support is often short term, a particular understanding around the need to identify disability and provide lifelong packages of support.

Another area of huge unmet need is parents with disabilities parenting children. The NASC funding is often only limited to the parents' needs, with statutory services often involved for the 'children'. The current funding models make it incredibly difficult to fund support for the parents with intellectual disability to support their parenting. This often leads to repeated cycles of being 'in' and then 'out' of statutory care, with consequent significant trauma for our tamariki.

9. Is there anything else you wish to add?

We cannot ignore the current reality of burgeoning acute demand in adult medicine and surgery, and the \$500m collective DHB deficit. These pressures act together to severely constrain the health system's ability to attend to the early years, to be effective in prevention, to innovate and to share and implement innovations from others. Until these issues are addressed system change is unlikely to significantly change care on the ground.