child & youth wellbeing

DEPARTMENT OF THE PRIME MINISTER AND CABINET
TE TARI O TE PIRIMIA ME TE KOMITI MATUA

Child and Youth Wellbeing Strategy – Submission Template

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

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

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

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

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

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Organisation Name:	New Zealand Paediatric Sleep Medicine Clinical Network, Paediatric Society of New Zealand
Organisation description: (tell us about your organisation – i.e. who do you represent? How many members do you have? Are you a local or national organisation?)	This submission is from the NZ Paediatric Sleep Medicine Clinical Network which is supported by a relationship that the Ministry of Health has with the Paediatric Society of New Zealand. We are a multidiscplinary team of health professionals from around New Zealand with expertise in the care of children with sleep disorders. Since 2015, the aim of the CN has been to provide clinical leadership in services nationally for sleep medicine in children, aiming to at least meet basic international benchmark standards. Clinical Network Clinical Reference Group membership and profiles: • Elizabeth Edwards (Chair), Paediatrician, Respiratory & Sleep Medicine, Starship Children's Hospital • Rachel Sayers (Facilitator), Assistant Research Fellow, Department of Women's and Children's Health, University of Otago and Lecturer, School of Nursing, Otago Polytechnic • Alex Bartle, Director of the Sleep Well Clinic • Angela Campbell, Manager, Well Sleep Centre, University of Otago • Sarah Currie, General Paediatrician, Hawkes Bay DHB • Dawn Elder (Prof) HOD Department of Paediatrics & Child Health, University of Otago Wellington; Paediatric Sleep Physician • Marie-Francoise Jean-Louis, Paediatric Otolaryngologist, Health Waikato • Barbara Galland, Research Assoc Prof, University of Otago • Nikki Mills Paediatric Otolaryngologist, Auckland DHB • Karen Munro, General Paediatrician Waitemata DHB

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Executive Summary: (Please provide a short summary of the key points of your Submission - 200 words)	• Good quality sleep of an adequate duration is vital for a child's health and well-being. • Ignoring sleep in the Child and Youth Wellbeing Strategy is ignoring 50-60% of children's lives. • ALL children's sleep should be regularly assessed as part of routine health consultations. • There is NZ and overseas evidence that education and support to prevent and manage sleep problems in infancy can effectively prevent up to 50% of child obesity measured at 5 years of age. • Underappreciated and undertreated obstructive sleep apnoea (OSA) risks significant adverse consequences for cardiovascular & neurocognitive health. • Often children with sleep problems have comorbidities (e.g. Down syndrome, obesity), requiring polysomnography (PSG) in a sleep laboratory setting, and sleep specialist input as part of their multidisciplinary management. • Some children require non-invasive (NIV) or invasive ventilatory support which requires continued specialist follow-up & support. • Increased recognition of sleep disorders in NZ children by health professionals is creating pressure on the limited number of specialist facilities for diagnosis and treatment. • The provision of paediatric sleep medicine services for NZ children continues to lag behind services available for adults in NZ and that available for children in Australia. Since 2001 the gap has widened. • Significant investment in child friendly national sleep medicine facilities, training and maintenance of expertise (paediatric sleep medicine specialists and physiologists) by DHBs and government is needed to address this deficiency. • We suggest investment in well child services linked to sleep expertise to deliver sleep problem prevention and intense management when problems emerge (about 30% of children) would have a major effect on improving child and parent well-being.
Submission Content	

We are delighted that the government is taking the initiative on addressing child wellbeing. While we support a full range of measures to improve child wellbeing the expertise of our network group is in paediatric sleep and sleep disorders and so we will restrict our submission to this area.

We represent health care professionals who work in child health services around the country covering a wide range of sleep related issues ranging from primary care, to secondary level surgical intervention for sleep apnoea, psychological services for behavioural sleep disorders, as well as specialist investigation into sleep issues with formal sleep studies (PSGs, polysomnography), and management and support of families with children on home respiratory support.

Sleep is a critical component of a child's life and health.

Over the last 15-20 years there has been increased recognition of the importance of sleep for children's health and well-being. Insufficient or poor quality sleep across childhood is common. It is estimated that 1 in 4 children and young people have a problem with sleep that warrants a doctor's attention. There are over 60 diagnosable paediatric sleep disorders ranging from behavioural (e.g. insomnia) and non-respiratory conditions (parasomnias e.g. night terrors) to respiratory disorders of sleep, the commonest being obstructive sleep apnoea (OSA).

The New Zealand Paediatric Sleep Medicine Clinical Network (CN) has recently written to the MOH to express concern about the paucity of services for New Zealand children with sleep disorders. Our submission to the Child and Youth Wellbeing Strategy is a summary of the issues raised.

What's the problem and why is it important?

An awareness of the potential significance of poor quality sleep in children is very important but is largely off the radar in New Zealand. Growing evidence suggests that inequities in sleep health begin at a young age in New Zealand.[1] There is now good NZ and overseas evidence that education and support to prevent and manage sleep problems in infancy can effectively prevent up to 50% of child obesity measured at 5 years of age.[2]

Obstructive sleep apnoea is a condition where narrowing of the airways at the back of the nose and throat during sleep is enough to cause a child to have difficulty breathing, or results in pauses in their breathing. The child will then wake up briefly because they cannot breathe properly, often with a loud gasp or snort. Oxygen saturations may or may not be reduced, but sleep can be disrupted.

These episodes can happen many times through the night and the disturbed sleep can result in changes in behaviour during the day such as sleepiness, hyperactivity, impulsivity, poor attention and difficulty learning at school. One in 10 children snore most nights and up to 1 in 20 has OSA. Unlike adults children with OSA are much more likely to be hyperactive or inattentive than sleepy.

In New Zealand OSA in children is still underappreciated and undertreated which risks significant adverse consequences of which the two most concerning relate to cardiovascular and cognitive health:

- impacts on cardiovascular health (e.g. hypertension) including risks that extend into adulthood
- poor sleep quality, leading to impaired daytime functioning affecting development, behaviour, mental health and learning and therefore potentially longterm effects on educational achievement and psychosocial functioning.

In most children OSA is caused by large tonsils and/or adenoids and symptoms may be addressed by adenotonsillectomy, but many children have comorbidities (e.g. Down syndrome, obesity, craniofacial abnormalities or neuromuscular weakness), requiring fully observed sleep study (PSG) in a sleep laboratory setting, and sleep specialist input as part of their multidisciplinary management[3]. Some children require non-invasive or invasive ventilatory support which requires intensive follow-up and support.

Referrals of children to sleep services have increased alongside the obesity epidemic in New Zealand children. Obesity is a significant risk factor for OSA in children as well as adults.

Referrals are also increasing for assessments of children with neuromuscular disorders such as Duchenne muscular dystrophy as it is now recognised that non-invasive ventilation not only improves night time sleep for those affected but also the sleep of their caregivers.

What has been done so far and what impact has this had?

The early focus of the CN was to raise the profile of sleep and sleep issues in relation to children's health, and to generate Guidelines for the management of sleep disordered breathing (SDB) including obstructive sleep apnoea (OSA)[4]. Continued work through national workshops and presentations to disseminate and implement the Guidelines has resulted in:

1. Increased recognition of the symptoms and consequences of OSA in children, particularly in those overweight and obese. This has led to increased referrals to paediatricians for diagnosis, and otorhinolaryngologists (ORL) for adenotonsillectomy, but not to increased medical or surgical resources. There is also on going evidence of regional inequity[,5,6].
2. Increased use of screening tools such as questionnaire and overnight oximetry studies for the assessment of a child with suspected OSA. Parallel increases in definitive testing (PSG and sleep specialists) are needed and lacking. Research undertaken by the CN has shown that facilities for investigating sleep disorders in New Zealand children is far behind Australia and the gap is growing.
3. Overnight PSG is an important tool because it can not only recognise OSA but it can also rule out the need for intervention such as surgery or need for non-invasive ventilation if the study is normal.
4. Other research undertaken by the CN has also shown that there has been an exponential increase in the number of children requiring domiciliary respiratory support (because of available technology and increased concern for disability) which has benefited children with a wide range of health issues[7,8,9]. However, delivery of safe and effective ventilation particularly in those most dependent remains a significant challenge and has added an increasing additional burden to limited sleep medicine facilities.

Recommendations to improve child health and wellbeing in relation to sleep and sleep disorders are:

As part of routine health consultations ALL children should be assessed for sleep issues and sleep disorders (e.g. at the B4 school check or routine immunisations (e.g. Boostrix; HPV). Parents should be asked about daytime functioning and snoring or noisy breathing in particular.

Improved resources and parental education on benefits of sleep and healthy sleep habits should be readily available, as should appropriate support to promote good sleep health at a young age. Resources must be culturally relevant to address early inequities in sleep health.

To address the current gaps and issues for New Zealand children experiencing sleep disorders significant investment is required to result in:

1. Sleep problem prevention in infancy.
2. Increased availability of ORL services providing adenotonsillectomy for the treatment of OSA.
3. Consistent access to a nationally integrated tertiary paediatric sleep service for the investigation and management of sleep disordered breathing
4. Increased availability of paediatric diagnostic sleep medicine services, especially observed PSG (these services are currently only available in Auckland and Wellington).
5. Increased support for children on domiciliary respiratory support.

Significant investment in child friendly national facilities, training and maintenance of expertise (paediatric sleep medicine specialists and physiologists) by DHBs and government is needed (e.g. there has been no new RACP sleep specialist in New Zealand in a decade). The CN has a vision of how services could to be developed, and hope to be able to present this to the Ministry of Health. For some DHBs services will need to be supported as regional services in a hub and spoke model with potentially 3 centres of excellence across the country sharing facilities with adult practices where appropriate. (This model works very well in Wellington). Regardless significant investment is needed to better meet the growing demands and support the care of New Zealand children with sleep disorders to ensure that their childhood potential can be fully recognised.

References:

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2. Taylor RW, Gray AR, Heath A-LM, Galland BC, Lawrence J, Sayers R, et al. Sleep, nutrition, and physical activity interventions to prevent obesity in infancy: follow-up of the Prevention of Overweight in Infancy (POI) randomized controlled trial at ages 3.5 and 5 y. The American Journal of Clinical Nutrition. 2018;108(2):228-36
3. Pamula Y, Nixon GM, Edwards E, Teng A, Verginis N, Davey MJ, Waters K, Suresh S, Twiss J, Tai, A. Australasian Sleep Association clinical practice guidelines for performing sleep studies in children. Sleep Medicine 36 (2017) S23eS42
4. https://www.starship.org.nz/for-health-professionals/new-zealand-child-and-youth-clinical-networks/paediatric-sleep-medicine-clinical-network/purpose-of-the-network-

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5. https://www.hqsc.govt.nz/our-programmes/health-quality-evaluation/projects/atlas-of-healthcare-variation/surgical-procedures/
6. https://www.hqsc.govt.nz/assets/Health-Quality-Evaluation/Atlas/SurgerySF/atlas.html
7. Edwards EA, Nixon GM. Paediatric home ventilatory support: Changing milieu, proactive solutions. Journal of Paediatrics and Child Health. 2013;49(1):13-8.
8. Edwards E, Hsiao K, Nixon G. Paediatric home ventilatory support: The Auckland experience. Journal of Paediatrics and Child Health. 2005;41(12):652-8.
9. Tan E, Nixon GM, Edwards EA. Sleep studies frequently lead to changes in respiratory support in children. Journal of Paediatrics and Child Health. 2007;43(7-8):560-3.

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