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New Zealand Speech-language Therapists' Association
Te Kāhui Kaiwhakatikatika Reo Kōrero o Aotearoa

Guideline for Speech-language Therapists Working with Individuals with Orofacial Cleft and Velopharyngeal Incompetence

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Document Control

Date	Version	Approved by	Review date	Amendments made
22 Mar 24	1.0	NZSTA Board	2028	NA
17 April 24	2.0	Executive Director	2028	Tweaks to spelling and information relating to MoE.

All policy effective as above except where individually noted

Table of Contents

1. Scope of the Guideline

The need for Aotearoa New Zealand (NZ) speech-language therapists (SLT) to develop a guideline for children who have orofacial clefts and velopharyngeal insufficiency (VPI) has become increasingly apparent. SLTs work across different sectors that can have collaborative input into service provision for this population (including, but not limited to, the Ministry of Education (MoE), Health New Zealand - Te Whatu Ora (HNZTWO), and child development service providers contracted by Whaikaha). A natural crossover exists between MoE and TWOHNZ, and joint working is necessary for the best outcomes. SLTs new to working with this population require guidance.

Aotearoa New Zealand, has a diverse population. Our indigenous Māori population is at a higher risk of being born with a cleft palate (Thompson et al., 2016) and, therefore, an increased risk of feeding and speech difficulties. Most babies born with cleft lip and/or palate will initially require SLT support to manage their feeding. In Aotearoa NZ, a recent study (Morrison et al., 2021) found that 85% of children at age five still present with speech-related difficulties requiring intervention from a speech-language therapist. Having consulted with a Māori health unit and drafted the tangata whenua and application of Te Tiriti o Waitangi section, it became clear that adapting a guideline from another country does not honour the cultural landscape and diversity of Aotearoa New Zealand. Thus, we elected to write our practice standards, highlighting the unique differences innate to our population.

Speech-language therapists from different service providers may become involved during the patient's journey. The SLTs working in the regional cleft palate team will be referred to as the **specialist cleft team SLT**. This SLT provides a link for the families between the specialist cleft team and other providers, supporting families and therapists and monitoring and supporting the child as needed. Typically, a whānau will receive SLT support from Health NZ and child development services – both in the acute/inpatient setting and in the community - antenatally or from birth until the child is 2-3 years old. At this time, SLT services are transitioned to the MoE SLT service. The exact timing of the transition will depend on the MoE-MoH Local Level Agreement (LLA). SLT involvement may look different across different providers throughout Aotearoa NZ. Families may also choose private speech-language therapy. In this document, the SLTs supporting children in their community contexts will be called **community SLTs** (whether based in health, education or private practice).

Of our five internationally affiliated Mutual Recognition Agreement (MRA) partners, only two have developed guidelines for this patient/client group: The American Speech Hearing Association (ASHA) and the Royal College of Speech and Language Therapists (RCSLT).

2. Purpose of the Guideline

A guideline from our national body (NZSTA) will contribute to understanding the depth of the specialist cleft team SLT in supporting regional cleft teams and highlighting the need for community SLTs to be part of a regional cleft team. The purpose of this document is to provide comprehensive guidance for SLTs in providing feeding and speech intervention services for the cleft/VPI population in Aotearoa New Zealand.

There is a defined role for the specialist cleft team SLT, who has input from the beginning with the infant and their family/whānau offering advice, assessment and intervention, which may include referral to community-based services.

SPECIALIST CLEFT TEAM SLT

For whānau:

- Sits as part of the regional specialist cleft multidisciplinary team (alongside plastic, ear, nose and throat surgeons (ENT), maxillofacial surgeons, orthodontists, and clinical nurse specialists/coordinators)
- Provides support for feeding disorders
- Completes initial assessment and management of speech disorders
- Completes systematic assessments of speech at predetermined times (including pre- and postoperatively)
- Completes instrumental assessments of velopharyngeal function
- Contributes to decisions about secondary surgery
- Provide diagnostic therapy; this may continue into adulthood.

For community SLTs:

- Contributes to education and continuing professional development
- Provides case management support for feeding and speech disorders
- Acts as a resource to assist in the differential diagnosis of speech sound errors
- Provides assessment and guidance on strategies and techniques for managing the speech disorder (see Appendix 2).
- Provides information about planned management from the wider cleft team.

Community SLTs manage children with a cleft as a relatively small part of their highly varied caseloads and may require upskilling. The specialist cleft team SLT can also provide the community SLT with information regarding planned management from the wider team. The specialist cleft SLT will complete an initial assessment and advise on managing speech disorders, involving community SLT colleagues, as they can offer intervention closer to home and within preschool/school settings - a more naturalistic context for families/whānau to support the individual.

Community SLT colleagues are an essential part of the cleft team. As stated in the RCSLT clinical guideline (2005) for cleft palate and non-cleft velopharyngeal abnormalities, perceptual assessment of speech has a 'central position in assessing velopharyngeal dysfunction' (p43). The detection of hypernasality, nasal air escape or turbulence during any standard speech assessment or observation should prompt referral to the specialist cleft team SLT. These children do not need a concurrent referral to ENT unless separate and distinct features require ENT assessment (e.g., obstructive sleep apnoea). Currently, the specialist cleft team SLT will carry out clinical and/or instrumental assessments to establish the cause of the speech issue.

Following differential diagnosis by the cleft team SLT and the assessment of the wider cleft team, possible therapy management recommendations will be made, which will be supported by SLTs based in the community, including pre-operatively if appropriate.

Community SLTs:

- Complete assessment of feeding at birth or diagnosis.
- Provide support for managing feeding, including breastfeeding or guidance around supplementation using an appropriate bottle/teat system.
- Advice/guidance around language development.
- Perceptual speech assessment during routine involvement.
- Referral back to specialist cleft team SLT if concerns are identified during the perceptual assessment of speech.

3. Definitions

Cleft/VPI/SMCP labels:

Other potential diagnoses within this cohort of children include those with a **submucous cleft palate (SMCP)**, often discovered as speech sound differences are detected when the child starts to develop speech and language. Surgery is likely to be offered at any time in the early years according to the speech and language development of the child. Speech/resonance errors are often picked up by a community SLT or ENT surgeon, with onward referral to the specialist cleft team SLT for assessment.

Some children exhibit features of cleft speech with no history of cleft but unusual hypernasal resonance. These children are referred to the specialist cleft team SLT for differential diagnosis and may be diagnosed with **velopharyngeal insufficiency (VPI),** for which surgery may also be offered. VPI can be due to a deep pharyngeal space (congenital or post-adenoidectomy), a short palate, or a poorly functioning palate (cerebral palsy, brain injury).

Another group of children present as having unusual nasality, which may be mistaken for a submucosal cleft or non-cleft VPI, when in fact, they have an **active nasal fricative (ANF),** also known

as **phoneme specific nasal emission (PSNE)**. This can be effectively and quickly managed with therapy only.

4. Context and Use

There is a higher incidence of cleft in Aotearoa NZ, than in other Western societies (1:559, compared with 1:700, Thompson et al., 2016), a significantly higher number in our Māori population. This comes with the likelihood of an increased need for speech intervention services. It is widely researched and documented that our current health service is inequitable for Māori (Simpson - Health Sector review; Māori Health Strategy, Ministry of Health). Their health outcomes differ from those in Aotearoa NZ, who are Pākeha or tauiwi New Zealanders (non-Māori). Adding to these inequities is the realisation that Western models of care do not consider cultural factors specific to Māori, which further compounds the issue. Te Tiriti o Waitangi and its reviewed principles (ref Whakamaua, MoH Māori Strategy), combined with the NZSTA Principles and Rules of Ethics to uphold Te Tiriti, sets out our responsibility as health practitioners in Aotearoa NZ to address the inequities in health between tāngata whenua (indigenous people of NZ) and Pākeha.

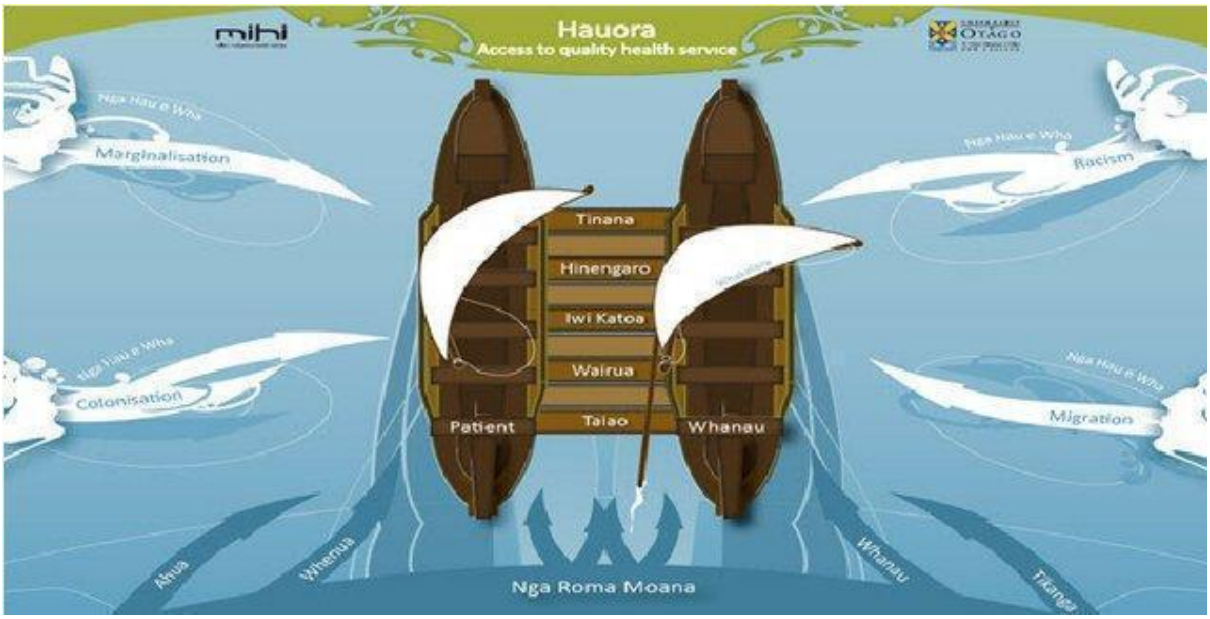
NZSTA Principles and Rules of Ethics set out to maintain professional integrity by upholding principles of Te Tiriti o Waitangi (NZSTA Principles and Rules of Ethics, 2005), thus requiring our service to contextualise our guiding principles to meet the health needs and health literacy appropriate for Māori. We must strive to understand the principles of Te Tiriti and the characteristics that are recognised within them.

He Pikorua is the practice framework for Te Mahau (Ministry of Education) and Resource Teachers for Learning and Behaviour (RTLB) learning support practitioners. It brings learning support practitioners together alongside whānau and educators to support the learning and well-being of mokopuna. He Pikorua is underpinned by a set of guiding practice principles, including being mokopuna and whānau centred, collaborative, strengths-based, culturally affirming and responsive, inclusive, and ecological (the impact of different environments on an individual/whānau).

SLTs working with people with a cleft must strive to understand the articles of Te Tiriti and how these interact with our clinical practice. Guidelines for working collaboratively with pēpi, tamariki and rangatahi with cleft or VPI conditions and their whānau should incorporate the guiding principles of Te Tiriti, incorporating Māori models of health and education, for example, Te Whare Tapa Whā, the Meihana model and He Pikorua.

The Meihana model (Pitama et al., 2007) is a framework designed as a model of health that aims to intertwine clinical and cultural competencies to provide better health services for Māori (figure 1). It comes straight from te ao Māori (Māori world view) and considers tinana: physical body; hinengaro: consciousness and awareness; iwi katoa: wider support; wairua: spiritual wellbeing; and taiao: environmental wellbeing.

Figure 1 – the Meihana model (Pitama et al., 2007)



Consideration must be given to colonisation, stereotypes and biases that Māori are subject to, including socioeconomic status, access to education, the ability to access services, and the impact of living in a racialised society. To achieve this, within our culturally safe care, our workforce needs to:

- be aware of how their own culture and biases impact the quality of care provided
- reflect on and adjust what they do to improve the quality of care they provide.

To this end, a number of whānau Māori were contacted to take part in a hui to discuss various aspects of their journey through the health and education systems in Aotearoa NZ; we sought to identify whānau experiences and what their journey would ideally look like. We aimed to acknowledge the journey so far for our whānau Māori and envision intertwining services to provide a gold standard service for all.

SLT services should strive to provide whānau-centric care. SLTs should review their clinical assessments against and within the context of whānau aspirations. We must bridge the differences between clinical practice, what is central and aspirational for Māori and their whānau, and what is acceptable to those working alongside them. This journey will need to be reviewed in line with the review of this guideline (See the 'final word' section for a summary of the whānau hui).

5. Navigating the cleft journey

We have chosen to follow the child through the various ages/stages of life to provide the structure for this guideline. Within the cleft journey, working in partnership with the infant/child and their

whānau is imperative, drawing on the collective knowledge and empowering them to be part of their child's treatment/progress. We will achieve the best outcomes through collaboration between whānau and services, each valuing different perspectives and building capability.

	Specialist Cleft Team SLT	**Local acute or Community SLT**
Diagnosis	Linking community SLT with the specialist cleft team plan for management (feeding supports, surgery timing, etc.)	Whanaungatanga - • Support with establishing feeding skills • Support with obtaining appropriate bottle/teat system, if required • Education to support whānau understanding of the journey
The first year of life	Supporting local SLTs with feeding, speech development and planned surgeries	Support the feeding journey at the transition to solids Assess early speech and language development
Feeding	Antenatal parental education (where possible) Advise as needed post-operatively	Support from birth with feeding advice and bottle provision as required.
6-24 months	• Monitor transition to solids • Monitor babble patterns and speech development • Provide education on language development • Maintain contact with audiology • Advise on postoperative management, including altered food consistency. • Parent education sessions as needed.	Continue to support bottle feeding and assess eating and transitional cup-drinking skills
2-5 years	• In-depth yearly assessment and management plan to support typical speech production by age five. • Referral to MoE if needed. • Advise and educate whānau and community SLTs	Therapy provision to support speech development
School years	• Regular assessment • Regular reviews with the whole cleft team • Diagnostic therapy, if required	Therapy provision to support speech development

	• Instrumental assessments to support surgical decision-making • Advise and educate whānau and community SLTs	
Adulthood	• Assessment and advice if required. • Possible investigation after orthognathic surgery.	No input

5.1 The first year of life

Diagnosis: An acute or community (HNZTWO) SLT will engage with the infant and their family/whānau shortly after birth or diagnosis of cleft lip/palate to support feeding development. The SLT will be part of a wider team supporting feeding, including lactation consultants, midwives, nurses, dieticians, neonatologists, and paediatricians. The specialist cleft team SLT becomes involved when the child is referred to the cleft service. The community SLT HNZTWO) will also support speech development in this first year.

Discussions with whānau over the years, and in a specific whānau hui as part of this guideline process, have shown families can be confused about who the many different professionals are when it comes to their child's care. In the early days, following a hui process can be helpful, including a mihimihi (introductions, including names and roles), then touching on some shared connections (whakawhanaungatanga), moving on to the reason you are meeting (kaupapa) and making clear what the next steps going forward are going to be (poroporoaki). These areas are helpful to cover at each consultation but are often overlooked. It is respectful to all consumers of our services that there is clarity in whom they meet with and why. Sometimes, the crossover between health workers and therapists in health and education can be tricky for families to comprehend. Hence, we need to take every opportunity when we reconnect with them, whether in the hospital or school, to re-establish our particular role and to work in partnership, continuing to empower their significant role with their child.

Establishing good relationships with families/whānau from the outset is essential, as is providing clear information about the cleft condition and building whānau capability to navigate the early stages.

5.2 Feeding

Whānau aspirations for feeding their pēpī should be discussed, and SLT support to achieve these aspirations should be provided. Where a whānau aim to breastfeed, this should be supported and encouraged while supporting an understanding of the pepi's current function and ability to manage

this. In some cases, full breastfeeding may be difficult, and in this case, support in finding a suitable bottle supplementation system should be offered.

5.2.1 Feeding Management by Cleft Type

FEEDING

All babies born with a cleft, regardless of type, should be encouraged to go to the breast at birth. Having time at the breast will help with colostrum and breast milk production and with bonding and attachment. Expressed colostrum/breast milk can be put in a syringe/bottle if required. If the cleft involves the palate and/or is associated with a syndrome, a nasogastric tube (NGT) may have to be placed (see Appendix 1).

Pacifier use can be an option for infants with a cleft, though the lack of suction may be compromised and maintaining the pacifier in the mouth may be difficult. However, some infants will be able to compensate for this. It may take trialling different types of pacifier before a suitable one is found. (Clinical experience suggests the 'cherry' shaped pacifier can be successful.) If the use of a pacifier is achieved this may have to be stopped prior to surgeries.

Feeding management by cleft type

Feeding recommendations will vary depending on the type of cleft the baby has. They are often categorised into the following:

Cleft lip only (no palatal involvement):

- Breastfeeding can be successful for a baby with a cleft lip, as the breast tissue can help occlude the cleft in the lip to complete the seal required to establish breastfeeding.
- Consider different feeding positions to support the best feeding results.
- Mother can place a finger over the cleft to help limit air entry and create a seal.

Cleft with palate +/- lip involvement:

- Breastfeeding may be partially achieved depending on the location and size of the cleft palate. Each infant requires a speech-language therapist (SLT) assessment to determine the efficiency of suck feeding and discuss feeding options with the family. A specialist feeding bottle/teat may be needed to achieve the required nutrition and will likely be the primary means of feeding. If bottle feeding is required, mothers will be encouraged to express breast milk to use with bottle feeds.

Specialist feeding bottles/teats:

Babies with a cleft palate (with or without lip involvement) have an oral phase and likely pharyngeal phase dysphagia with reduced sucking strength.

A specialist feeding bottle and teat can achieve safe, effective and efficient feeding. Few babies with cleft palate can successfully sustain breast or bottle feeding from a standard bottle and teat. In some cases, a nasogastric tube may be required, particularly if comorbidities are present (e.g. if the baby has a syndrome or congenital heart disease).

The hospital-based/acute SLT will assess the baby's feeding and determine the appropriate specialist bottle and teat and when this may be introduced. Day 1-2 is focused on time at the breast/breastfeeding, bonding and having expressed colostrum/expressed breast milk (EBM)/pasteurised donor milk (PDM)/infant formula (IF) via a syringe. The midwife, neonatal nurse, or lactation consultant can support the mother in hand-expressing colostrum for the baby as required. A bottle/teat may then be introduced on day 2-3, though in some cases, particularly if hypoglycaemia is present, a bottle may be introduced earlier.

Several specialist bottles and teat options are routinely used in New Zealand; the choice is based on the baby's presentation and the SLT assessment (see Appendix). These specialised bottles/teats consider the specific feeding needs of a baby affected by a cleft lip +/- palate. This feeding system needs to be appropriate for post-surgical repair(s) to reduce the likelihood of dehiscence or damage, meaning discussion with the surgeon may be appropriate.

Once the appropriate bottle/teat for a baby's needs is established, the HNZTWO SLT will provide two (2) sets for discharge home. The specialist cleft or HNZTWO SLT can apply for funding for specialist feeding equipment from AccessAble or Enable New Zealand. A SLT will be available for ongoing feeding and speech support, ensuring ongoing access to the specialist feeding equipment as required. An assessment of eating skills, once introduced, is recommended as eating skill may also be impacted upon by the cleft

Following primary surgical repairs, further feeding advice and support may be required from an SLT. Depending on local protocols, generic dietary recommendations will be made post-operatively, typically a puree/soft diet for 2-3 weeks.

5.3 Hearing

Children with a cleft palate have a high incidence of eustachian tube dysfunction. Approximately 75-90% of babies born with a cleft palate will develop otitis media with effusion (OME) early in life. They have an increased likelihood of acute infection and chronic otitis media. For children with cleft palate, who have a higher risk of persistent OME, and significant chronic hearing loss (CHL) and a higher risk of speech disorder, the impact of OME on development may be greater than for other children. In Aotearoa, New Zealand, all newborns will have a hearing screen at birth, and those with a cleft palate will have ongoing monitoring from audiology. Some children will have grommets placed at their primary palate operation, and many will receive bone-conduction hearing aids before this. It is important to find out about hearing status and whether there is a recent test or know the hearing status before starting speech therapy input.

Following the initial palate repair, many children will have ongoing middle ear dysfunction and need ongoing ENT and audiology input. Audiologists are experts in identifying and managing hearing loss and actively managing children with cleft palate. Audiologists also monitor speech and language and may be aware of typical/non-typical cleft speech errors, along with the Advisors on Deaf Children (AODC) from the education sector (Te Mahau).

5.4 6-24 months

There is a high degree of variation between health teams around service provision for a cleft at this age. Babies/children of this age may not yet receive services from the Ministry of Education. Some, but not all, child development services are funded to provide input for feeding and beyond into early language and speech development. Services should continue to educate the family/whānau of the child, empowering them to be their child's first teacher/s and acknowledging the tino rangatiratanga they possess.

All tamariki with a cleft should expect to receive an initial assessment of speech by the specialist cleft team SLT between 18 and 24 months when the child is expected to develop vocabulary and language skills. Early assessment allows for the early diagnosis of any potential for cleft speech characteristics that are starting to emerge and may require remediation. If a community SLT is not yet involved, this should occur at the point of assessment.

Speech intervention for children with a cleft should begin when they begin to babble. Children with a cleft palate tend to have a restricted phonetic inventory (mainly nasals, glides and approximants; a tendency to use backed sounds, with fewer made anteriorly; there is a tendency to use glottal or pharyngeal sound substitutions.) A significant number of babies do not reach the canonical babbling stage by nine months (Chapman et al., 2001), which has been proposed as an indication of a speech and language disorder in the future (Oller & Eilers, 1999). Of course, differential diagnosis as to the impact of fluctuating hearing loss at this stage is also challenging.

Many whānau expect that following palate surgery (between 9 -12 months old), 'everything will come right'. A significant number of children with a history of cleft palate will continue to use similar patterns to those in their pre-repair repertoire; some of these are atypical 'learned' errors, some are developmental substitutions, while others indicate ongoing palatal insufficiency (Hardin-Jones & Chapman, 2019). While some children acquire typical speech following repair, many still require speech-language therapy (Morrison et al., 2021), and some require further surgeries.

Ongoing access to SLT, both pre- and post-op, is imperative. A differential diagnosis can be made as vocabulary expands in the early preschool years. Therapists across health and education can work together to enhance surgical outcomes, ensuring they work together on the appropriate targets. It is essential to involve families/whānau in early language and sound work, ensuring they are given skills and strategies to be a part of their child's progress.

5.5 2-5 years

At a hui run as part of this guideline development, whānau expressed concern about a lack of transition between hospitals and health and education services. Practitioners in these roles need to ensure good communication with each other and the whānau. Some of their frustration may not be due specifically to speech-language therapy.

The goal is to have developmentally appropriate speech by five years of age (Sell et al., 2001), which will be achieved with a combination of surgery and speech-language therapy.

Management of children with cleft lip and palate should include early identification and intervention for delays in speech, language and reading (Chapman, 2011), and SLT provision should not be restricted to a set number of sessions and instead should be needs-based for as little or as much as is needed.

In 1998, Homer et al. stated, 'The success of medical treatment of these children is not merely defined by mending the cleft, but also extends to the maintenance or improvement of the children's Quality of Life after surgery'. Chapman (2011) recommended that managing children with cleft lip and palate should include early identification and intervention for speech, language and reading delays. The authors' recommendations include a focus on pre-literacy activities, targeting alphabet knowledge and print-related concepts, and incorporating these into intervention sessions for those with cleft palate, hoping to significantly enhance outcomes for these youngsters in the future.

Draw on collective whānau knowledge; they are the experts regarding their child, engage the family when planning services and value their perspective, strengths and insights. Some children attend kōhanga reo (Māori language nest) and kura kaupapa (Māori-medium school) and communicate in te reo Māori. In such cases, the clinician will need to acknowledge and build the whānau aspiration of using te reo into the plan and seek support (if needed) to provide assessment and intervention in te reo if the family requests this. However, if whānau request te reo Māori assessment and they are unavailable, be clear with whānau about what you are able and unable to provide and make a plan with whānau.

Diagnostic therapy may be available within a regional cleft service at this age to determine the involvement of the physical structure on speech. See Appendix 2 for a breakdown of speech characteristics into 'active' and 'passive' (13.2 Core indicators to assist community SLTs in classifying Cleft Speech errors).

'Active' speech errors contribute to reduced intelligibility and should be treated with direct intervention from an SLT. Two major SLT approaches have been adopted to treat active speech errors: 1) a motor-phonetic–based approach grounded in the theory that motor skill is learned through repeated actions of that specific skill using a hierarchical structured therapy (Albery & Enderby, 1984; Ruscello & Vallino, 2014) and 2) a language (linguistic)–phonological approach that

focuses on the organisation and representation of the sound system of a particular language (Chapman, 1993, for a little more detail see appendix 3).

There is much research that describes the best therapeutic approaches for the treatment of cleft speech disorders associated with cleft palate. No one method has been identified as the best, and thorough assessment with individualised therapy planning is recommended. Most describe articulatory, phonological or combined articulatory and phonological approaches. “Objectives may target normal or adaptive articulation. Intervention may be necessary from a very young age into adulthood. Extended periods of therapy input may be necessary. Intensive therapy has been shown to be effective in both individual and group therapy contexts" (Taylor-Goh, S. 2005. p. 44).

In these very early years, the use of input modelling is helpful; this can also be useful for children who are shy or whose confidence has been knocked down because they have limited intelligibility. Providing the whānau with education about what the therapist is doing and why is important to ensure the family is comfortable with doing further practice at home. Utilising a structure like the Hui process (Pitama et al., 2007) - which is an adjunct to the Meihana model) provides a good way of gathering information about the family context, and the addition of elements of the Meihana model will give clinicians a more holistic view of potential barriers for whānau when establishing roles/responsibilities in the ongoing care pathway.

5.6 School years

Children with a cleft remain under regular review by the multidisciplinary cleft team. They are typically seen every 1-2 years to review structural changes, speech and dentition. If an individual has ongoing VPI, this is investigated by the specialist cleft team SLT and surgeon; follow-up monitoring is provided, with support/education for the community SLT as needed (see Appendix 2 for classification of errors and Appendix 3 for generic cleft speech therapy goals). The NZ MoE SLT may continue working collaboratively to provide the support that enables those around the child to increase their competence and confidence in aiding the child’s communication development.

At the time of writing, Claire Winward, specialist service lead, Te Pae Aronui at Te Mahau, stated, ‘Ministry of Education speech-language therapists work within the Ministry’s Learning Support Delivery Model (LDSM) to help make sure the learning support needs of all ākonga (students) are met. The Ministry’s practice framework, He Pikorua, guides SLTs in collaborating to deliver support within the LSDM. He Pikorua is a flexible framework that focuses on a child’s learning needs within their whānau and their learning and community environments.

Support provisions for ākonga depend on the child's needs and the teaching team's strengths. SLTs and teachers use a collaborative inquiry process to agree on students' identified needs and develop the appropriate learning support approach. SLTs guide action plans, strategies and goals and provide regular support for class teachers, aides and the teaching team.

Mana Motuhake | Empower Others is the goal of He Pikorua in action. SLTs help to empower the team around a learner to build capability and confidence so that they can continue to provide quality speech and language support in the classroom without ongoing regular SLT input.

5.7 Adulthood

Speech difficulties associated with cleft lip and palate can persist into adolescence and adulthood. They can impact self-esteem and ease of communication in educational, social, and vocational settings (see Appendix 4).

Speech difficulties can persist for a number of reasons, including a lack of access to adequate speech services when the child was younger, resulting in habituated speech patterns. (https://www.asha.org/practice-portal/clinical-topics/cleft-lip-and-palate)

Cleft service intervention will continue for individuals with a cleft should they require it, e.g. unrepaired clefts from overseas, orthognathic surgery, and ongoing VPI. The Ministry of Education is not funded to provide services for people over the age of 21.

6. Final word . . . Whānau Voices

Many of us were born here in Aotearoa New Zealand, while others have chosen this land as their home, coming from overseas. New Zealand was first discovered by tāngata whenua, the people of the land, the indigenous Māori people. Following the settlement by NZ Europeans and the signing of Te Tiriti o Waitangi, there developed what was considered to be a state of mutual 'understanding'. However, through historically documented differences in understanding (different versions of the signed treaty), inequality quickly took root and persists today. The cause of this has come about and is being sustained due to 'the unequal distribution of the determinants of health, such as income, employment, education, housing, health care and social support' (Signal et al., 2008).

A whānau hui took place with families who have journeyed through a cleft service, supported by our allied professions Māori lead. Their stories are not specific to particular regions or services and span health and education. The collective stories aligned with the observation made by Signal et al. (2008) that Māori experience an unequal distribution of the determinants of health. We must make efforts to redress these inequities.

Families reported they wanted services to treat them from a neutral position like they were *'just a normal person'.* Sadly, one kōkā (mother) stated, *'I just don't think anyone was bothering'* when referring to keeping her informed about the clinical plan for her son.

When asked what they felt was working well as per the services they were receiving, one stated, '*Nothing is working'.* One participant stated, '*To be fair, probably any kind of health or education service, the fact that you're Māori puts you on the back foot to start with, so everything you get*

following that is usually because we've sort of done many hakas on repeat', another responded to this statement by saying ', a*nd that's just to get the service your friend down the road gets. We're not asking for anything more; we're just trying to get the same'. 'I don't think they look at us as an individual person; they just look at us as Māori, it's two separate things . . . There are so many expectations that they have of us Māori people to me',* as our allied professions Māori lead reflected that data/info about the collective group of Māori often adds an additional lens to any conversation involving our Māori consumers.

One parent stated, *'I would say our health is poor, not because we don't know any better, it's because we weren't given better – literally'.*

Discussion around having to listen to the professional guidance to help the child included, *'If you follow, then it'll happen, and if it doesn't, then you're doing something wrong'*, or, '*That's what I thought; I failed my own child by not being able to listen to your professional hat, but yet you've actually not understood what kind of condition he has [cleft]'.*

As one parent stated, 'it's all about the whakawhanaungatanga (the process of establishing relationships) – all of the points made within the kōrero come under this umbrella and include:

- Communication
- Need for consistency
- Bottle education/support
- Take the time to demonstrate
- Needing a clear journey to be delineated and support of those diagnosed at an early age (sometimes pre-birth) – "I figured someone was doing something in the background" (this was stated multiple times during the hui)
- Clarity of roles/services for families – need to know what services are likely to be involved and when to expect them – "*You don't know what you don't know."*
- Lack of transition between hospitals and between health and education.
- Inconsistent care between areas
- Unresponsive staff – lack of responses to family getting in touch via email, text, or phone.
- Huge turnover of Ministry of Education SLTs, leaving one child wondering if it was because they didn't like him
- They would like updates, guidance, and education for families by staff
- Time-restricted slots for intervention were felt to be very limiting.
- Withdrawal of child to a space in the class with negative connotations, not helpful to the process
- Bullying occurring - with one sibling hitting the perpetrator in defence of her brother with a cleft, then being sent home, the school did not act on the mother's info about the situation before this occurred.

We end this section with a quote from the kawa whakaruruhau (cultural safety) presentation by J Roberts (presented in 2022), '**Health organisations and professionals need to commit to our formal**

collective approach, we need to disrupt the status quo to address oppression and strengthen equity in a decolonisation approach'. NZSTA is committed to fulfilling our Tiriti obligations, and relationship development should be second nature to therapists in our caring profession.

7. Recommendations of this guideline

This piece of work aims to provide clear information about each stage of a cleft-affected person's potential journey, a bit of a road map for those professionals with limited experience or exposure to working alongside this population, made available at a national level.

Developing a national special interest group for Cleft/VPI (SIG) is desirable. It would make education/learning open to all SLTs in our NZ community. Currently (2022), the MoE has practice support networks in place that share in-house info every month. Health SLTs are keen to continue to engage with education SLTs to work jointly with this population and effect the best outcomes.

Those working in this profession must honour and value tāngata whenua as citizens of this land, whose contribution should be sought and honoured; by working closely in partnership, we aim to achieve the best outcomes for Māori.

A further recommendation is that this guideline be implemented at an operational level within individual regions to develop local-level agreements (LLA) between health and education; each area (district/region) in Aotearoa NZ currently operates and is funded differently regarding service provision.

The guideline is not intended as a dictatorial piece; rather, it is to be utilised and shaped according to the individuals involved; it is purely intended as a framework with lots of room to be adapted as necessary.

Whakatauākī

E kore e taea te whenu kotahi ki te raranga i te whāriki	*The tapestry of understanding cannot*
kia mōhio tātou ki ā tātou.	*be woven by one strand alone.*
Mā te mahi tahi ō ngā whenu,	*Only by the working together of strands*
mā te mahi tahi ō ngā kairaranga,	*and the working together of weavers*
ka oti tenei whāriki.	*will such a tapestry be completed.*
I te otinga	*With its completion,*
me titiro tātou ki ngā mea pai ka puta mai.	*let us look at the good that comes from it*
Ā tana wā,	*and, in time, we should also look*
me titiro hoki	*at those stitches which have been dropped*
ki ngā raranga i makere	*because they also have a message.*
nā te mea, he kōrero anō kei reira.	

Nā Kūkupa Tirikatene (1934–2018)

Acknowledgements

The project team wants to acknowledge the valuable input of the whānau who have shared their experiences throughout their journeys in the hope of improving service provision and future generations' engagement with services.

Rawiri Hirini has provided invaluable cultural support, bringing together whānau and service providers for valuable kōrero in the quest to improve our services for Māori.

Jana Carr, paediatric speech pathologist, John Hunter Children's Hospital, Australia, for reviewing the document and making several helpful suggestions.

The clinicians who have willingly shared their time and knowledge of the cleft field both from health and education.

Claire Winward, specialist service lead, Te Pae Aronui, Te Mahau (Ministry of Education).

Libby Coates, speech-language therapist, Te Whatu Ora, representative of Health Leaders Forum.

Review Plan

The guideline should be reviewed every five (5) years. There is a requirement for guidelines to embed critical Te Tiriti policy analysis as part of this review, as per Came et al. (2020), a recommendation made by NZSTA for all project works from 2022. To be reviewed in 2028.

8. Related documents

NZSTA Scope of Practice

NZSTA Principles and Rules of Ethics

Cleft Competencies – Morrison (2019)

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10. Appendices

10.1 Feeding supports

Initial feeding support (at birth and prior to specialist feeding system introduction)

- Infants and families will require a multidisciplinary approach by the health team to support development.
- If an antenatal diagnosis of a cleft palate is made, mothers can be recommended to express prior to birth. This provides a 'bank' of breast milk that can be used if baby takes longer than expected to start sucking feeds.
- Encourage skin-to-skin. Baby can be put to the breast to encourage attachment and milk production.
- Encourage the mother to stimulate the let-down before bringing the baby to the breast. This may encourage the baby's interest in breastfeeding.
- Mother should start expressing. midwife/LC can assist with the same. Breast pumps for home use are available through Cleft NZ at no charge.
- Mother can hand express with baby at the breast if colostrum/breast milk is not transferred. Colostrum +/- EBM (+/- donor milk) can be given via a 1ml syringe. It is important that this is given safely to prevent aspiration or refusal behaviours. Babies should be awake/alert. Small volumes can be slowly placed into the corner of the baby's mouth if they are at the breast. If they are not at the breast, babies should be positioned upright and small volumes placed into the midline of their mouth.
- An NGT may need to be inserted if the baby is not attaining adequate nutrition/hydration, colostrum/EBM/PDM is unavailable, or if there is a medical requirement.

Commonly used specialist bottles/teats

Pigeon specialist feeding system: Responds to tongue and jaw activity, rewarding compression and a weak suck. The top of the teat (air vent notch up) is thicker and firmer to provide a surface for the tongue and jaw to press against. The teat is thinner and softer underneath, allowing it to compress more easily with tongue and jaw movement. The white one-way valve ('bobbin') prevents milk in the teat from going back into the bottle so that milk is constantly available to the baby.

Putting the system together:

- Ensure that you have the appropriate teat (small/regular). Initial assessment should typically be carried out with the small teat. (The bottle usually has a small and regular-size teat included.)
- Put the teat into the collar as usual.
- Place the valve into the teat – the flat side (with a heart on it) should face the inside of the teat - and screw the collar onto the bottle.

Using the system:

- Place the teat on the baby's lower lip and allow the baby to draw it into their mouth with the air vent at the top, under their nose.
- Ensure milk is against the one-way valve so it transfers into the teat.
- You do not have to pre-fill the teat as this can fill itself with baby's first sucks; however, you can "prime" the teat by squeezing it with your finger and thumb (with the milk against the valve) so that milk is available from when the baby first sucks.
- Milk only flows when the baby is actively feeding.

Dr Brown's specialist feeding system: This system works similarly to the Pigeon system, responding to the baby's tongue and jaw activity. The bottle is similar to other Dr Brown's bottles with an added valve. The blue one-way valve prevents milk in the teat from returning to the bottle so that milk is constantly available to the baby. This bottle allows for more variation in flow rate as all Dr Brown's teats fit the system. It is worth considering if the Pigeon small teat is too fast for a baby to feed safely, effectively, and efficiently.

Putting the system together:

- Ensure that you have the appropriate teat.
- Put the teat into the collar as usual.
- Place the valve into the teat - the flat side should face the inside of the teat
- Screw the collar onto the bottle.

Using the system:

- Place the teat on the baby's lower lip and allow the baby to draw the teat into his/her mouth.
- Ensure milk is against the one-way valve so it transfers into the teat.
- You do not have to pre-fill the teat.

Medela specialist feeding system (also known as Haberman feeder): This system allows for variation of flow rate across a feed. Lines on the teat correspond to how much the teat aperture opens and, thus, the rate of milk flow. The short line is slow flow; the middle line is medium flow; the long line is fast flow. This system may be a better option for babies with other medical concerns (e.g., respiratory, cardiac) alongside their cleft.

Putting the system together:

- Pull the teat through the yellow collar.
- Push the round white valve membrane into the yellow valve plate. It should lie flat at the bottom, surrounded by the rim.
- Place the assembled valve into the teat and collar. The high rim side of the yellow valve plate should sit inside the teat.
- Screw your assembled teat to the bottle.

Using the system:

- With the bottle upright, squeeze the long part of your teat together with your fingers.
- Turn the bottle upside down and release the teat. This will allow milk to flow into the teat.
- The teat needs to be filled with milk, so you will need to squeeze/release the teat more than once.
- Introduce the bottle to the baby with the desired flow setting to the middle of their lower lip.
- If the flow rate needs to be changed during the feed to support coordinated and safe feeding, the teat can be rotated until the line is under the baby's nose.
- (See also Youtube clip: https://www.youtube.com/watch?v=NYXHXzDYIF8)

Most babies with a cleft should be bottle-fed mostly upright to allow for a horizontal bottle position. This encourages sucking skill development, reduces milk flow back to the oropharynx before the baby is ready to swallow and limits milk redirecting/refluxing into the nasopharynx. An elevated side-lying position could be considered in some cases. Swaddling can help postural stability early on if required.

Troubleshooting specialist feeding systems:

- ensure that the teat hole is patent prior to attaching it to the bottle
- ensure that the collar of the bottle is not on too tight as this can impact the function of the bottle's/teat's pressure system
- ensure that parts are put together correctly
- ensure that parts are clean
- bottles/teats should not require squeezing unless recommended by SLT

Cleaning specialist feeding systems:

- Please follow cleaning guidelines as per the manufacturer's instructions.
- Do not leave teats and bottles to macerate in sterilising solution between feeds. Bottles and teats can be removed after 15 minutes, left to air dry, and then stored.

10.2 Core indicators to assist community SLTs in classifying cleft speech errors

Community SLTs may sometimes encounter children with speech issues related to a submucous cleft or velopharyngeal incompetence in a child with no cleft palate. This is in addition to children with a previously repaired cleft with ongoing speech issues. Children without a cleft sometimes develop nasal-sounding speech that is not palate-related (active nasal fricative).

Cleft speech characteristics form 2 groups: active and passive. Passive speech errors include weak/nasalised consonants, nasal realisations of fricatives and plosives and gliding of fricatives/affricates; there may be an increased nasal resonance or passive/obligatory nasal air escape accompanying speech. Surgery alone may resolve these errors when the primary surgical

repair occurs early enough and is successful. Speech therapy will not alter speech issues relating to an anatomical structure.

Active characteristics are those whereby the individual attempts to compensate for a structural deficiency. This may be speech sound errors, such as backing to a velar or uvular place of articulation, lateralisation or palatalisation, and glottal or pharyngeal articulations. These sound alterations will not respond to surgery and are likely to persist post-operatively, requiring therapy to "unlearn" the atypical speech patterns, often resulting in significant phonetic inventory constraints.

The impact of a cleft in a person's lifetime varies and can impact social interactions (beginning with the acceptability and intelligibility of their attempts at communication), literacy (reflecting on and phonologising incorrect compensatory phonetic patterns) and academic achievement.

10.3 Therapy goals for cleft palate speech

Peterson-Falzone et al. (2016) outline four general therapy goals for cleft palate speech (p132):

1. Elimination of maladaptive compensatory errors (which may improve velopharyngeal function)
2. Replacing these maladaptive articulations with correct oral productions (teaching shaping)
3. Modifying/eliminating backing patterns
4. Eliminating learned nasal air emission.

They outline a series of 'treatment components' that can be applied to all therapies for work on these goals (p133):

- Establishing a place map for consonants - educating the child and their carer about mouth parts, giving labels to structures and sounds
- Select appropriate treatment targets
- Get the target sounds into the speech sound inventory
- Teach discrimination between the correct sound versus the error sound
- Establish reliable self-monitoring
- Practice the sound in increasingly more complex contexts (usual treatment hierarchy of isolation to conversational speech)
- Use of input modelling is a great goal for very young children

Useful resources include

- 'My Mouth Music' to help with early speech development (online resource) https://www.childrens.health.qld.gov.au/service-speech-pathology-my-mouth-music/
- Spires book - development. Other useful texts – The Spires book, Speech Therapy in Cleft Palate and Velopharyngeal Dysfunction, 2014, Phippen (Ed)
- Howard and Lohmander (Eds), 2011, Cleft Palate Speech

- Harding-Bell, A. (ed) (2019) Case Studies in Cleft Palate Speech: data analysis and principled intervention, J & R Press Ltd

10.4 Additional analysis/evidence for the effects of cleft on academic attainment

In 2011, Chapman produced an article entitled, 'The Relationship between Early Reading Skills and Speech and Language Performance in Young Children with Cleft Lip and Palate'. This study's findings indicated statistically significant correlations between early reading and speech production abilities and between early reading and language abilities. The children with cleft differed from their non-cleft peers in speech and reading skills. Many children exhibit speech delays into preschool years and beyond.

A further study in 2012 by Persson and colleagues looked at academic achievement in individuals with Cleft. The retrospective study used birth register data to gather a sizable cohort of adolescents with a cleft (of all types) and compared them with a control group of individuals with no cleft. The results showed that the group with cleft had a higher chance of not receiving leaving certificates at school graduation when compared with the general population. The authors concluded that the 'study clearly indicates that adolescents with cleft lip and/or palate in Sweden experience significant deficits in their educational achievements'(p153). The study indicated that additional allocation of resources might be needed for young people with clefts to attain the same educational achievements as their peers. They go on to state, 'Educational achievement is paramount for any young person to avoid being at risk for marginalisation in society as an adult . . . The risk of lower educational achievement is a factor that health care and education providers should take into consideration when implementing care plans for this group' (p158).