

Auckland Regional Cleft Palate Service: service accessibility and speech outcomes

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ABSTRACT

AIM: This study explored speech outcomes for five-year-olds born with cleft palate residing in the Auckland Regional Cleft Palate Service catchment, with a focus on ethnicity and geographical influences on service accessibility and speech outcomes.

METHOD: A retrospective audit of children born with cleft palate between 2013–2016 was conducted (n=89), including secondary surgeries, ethnicity, distances travelled, services offered and attended. Speech outcomes at five years were compared to international benchmarking.

RESULTS: Seventy-nine children were included; 10 were lost to follow-up before their 5 years review. At 5 years, 30% children presented with moderate to severe velopharyngeal incompetence; 30% had residual cleft speech characteristics which warranted speech therapy intervention. There was no significant difference in speech outcomes for Māori vs non-Māori. Attendance at clinic was not significantly associated with distance from centre. However, Māori had significantly lower attendance at clinic appointments and were significantly more likely to be referred to community services.

CONCLUSION: Auckland Regional speech outcomes are better than the national average, yet still do not compare favourably with international benchmarking. While speech outcomes were not associated with ethnicity, attendance at specialist clinic appointments was lower in Māori. Community services were offered, but attendance at, and satisfaction with, these appointments is unknown. Further work is needed to reach all children regionally in a timely manner to ensure Aotearoa New Zealand speech outcomes meet international standards.

When a child is born with an orofacial cleft and lives between Cape Reinga in the far North and Mercer in the middle of the North Island, they fall under the care of the Auckland Regional Cleft Palate Service, based in South Auckland, Aotearoa New Zealand. The Auckland Regional Cleft Service consists of a multidisciplinary team (MDT) with a Clinical Nurse Specialist (CNS), Plastic Surgeons, Orthodontists, Health Psychologists, Otorhinolaryngologists (ORL) and Speech-language Therapists (SLT). Each profession plays a key role at differing times in the cleft journey. The CNS is a constant point of contact from diagnosis through to point of discharge. It is the CNS who provides support and education to whānau and links in with other community support services, where needed, to support attendance and engagement. All surgical procedures are carried out at Middlemore Hospital, or Starship Children's Hospital for tamariki with additional medical needs. Outpatient appointments are held at Middlemore Hospital or off-site in a community outpatient facility in South Auckland. Given the catchment area for this service,

twice-yearly clinics are also held in Whangārei Hospital, Northland. Tamariki may access additional speech therapy through community child development services (<3 years old), at school (Ministry of Education funded, ~5 years+) and/or privately.

From the point of diagnosis, whānau meet with the MDT. Tamariki with a cleft lip will undergo surgery for lip repair (+/- hard palate repair) at 4–6 months old, and a cleft palate repair takes place at approximately 9–12 months. Internationally, it is accepted that the goal is to have “normal” speech by 5 years, with an acknowledgement that 20–30% may require secondary surgical speech procedures before 5 years for reduced or absent velopharyngeal closure—referred to as velopharyngeal incompetence (VPI) or fistula.^{1–5} They may require grommet insertion, alveolar bone grafting at 9–11 years and possibly orthognathic surgery once growth is complete. In addition, many tamariki born with a cleft palate +/- cleft lip will require speech therapy intervention, orthodontic treatment and psychological support. There are internationally recognised psychosocial impacts

on whānau, especially those with lower household incomes.⁶⁻⁸ Psychosocial wellbeing and positive engagement with services has been strongly linked with early diagnosis and counselling, establishing a close relationship with the MDT and social supports.⁷

Māori and orofacial cleft

Māori have highest incidence of cleft palate in the world. The incidence of cleft palate in Māori is over twice that of European (1.54 vs 0.73 per 1,000 live births).⁹ As a result, the overall incidence of orofacial cleft in Aotearoa New Zealand, over a 10 year period, was found to be 1.79 per 1,000 live births.¹⁰ Māori experience disparities in outcomes compared to the rest of the population across nearly all areas of health, due to inequity in determinants of health, including access to quality healthcare.¹¹ Māori have on average the poorest health status of any ethnic group in Aotearoa New Zealand.¹² Manatū Hauora – Ministry of Health have identified health equity and cultural safety as two strategic areas for review.¹³ For many Māori, the existing public health system can be experienced as hostile and alienating. The large number of health professionals involved and the lack of relationships with health professionals have been cited as a barrier to whānau engagement.¹⁴ When we also consider the large geographical area that the Auckland Regional Cleft Service covers, it is noteworthy that Māori are more likely to be living in small urban areas (15% of the Māori population) and rural areas (18%), compared with the total population (10% and 16% respectively),¹⁵ potentially resulting in long travel times and disruption to the ability of whānau to access services.

Measuring speech outcomes

Orofacial cleft outcomes are often measured objectively by velopharyngeal function, speech, dental occlusion and general facial appearance.¹⁶⁻¹⁷ Parent-reported measures are common and are considered valid measures of facial appearance, psychosocial function and speech.¹⁸ There are other functional measures that are important to consider such as hearing status, success in both social and educational contexts¹⁹ and psychosocial wellbeing of the whole whānau.⁷ One of the key outcome measures for tamariki with orofacial cleft is speech. The velopharyngeal mechanism serves to separate the oral cavity from nasal cavity

during speech and to allow an adequate build-up of intra-oral pressure for speech and efficient oral transit of food/fluid. VPI can be graded by perceptual speech analysis as mild, moderate, severe or profound.²⁰⁻²¹ VPI can result in nasal regurgitation when eating/drinking, hypernasal resonance, nasal air emission and weakened pressure consonants during speech. Reduced or absent velopharyngeal closure can have a significant impact on speech and is only remediable through surgery. Active cleft speech characteristics (CSCs) refer to “alternative articulatory gestures which function in place of intended consonants”.²² These are patterns of misarticulation that the child makes in order to compensate for the structural deficit caused by cleft palate. They are remediable through speech therapy intervention. Early intervention and education to whānau on how to model early, anterior pressure consonants can have a positive impact in reducing the extent of speech therapy later on.²³

In addition to reporting VPI and CSCs, SLTs also rate speech outcomes in the functional parameters of intelligibility and acceptability. Having speech that is clear, easy to understand and sounds the same as one’s peers is a key factor in social-emotional wellbeing, communicative confidence and educational achievement.²⁴ Children with orofacial cleft are at increased risk of developmental speech and language disorders compared with their peers²⁵ and, therefore, speech and language development must be assessed and treated alongside cleft speech. For children with ongoing poor hearing status, limited phonetic capacity and reduced communicative confidence can also impact on educational achievement and again, requires specific speech and audiology therapies.

Morrison et al.²⁶ recently published Aotearoa New Zealand’s first speech outcomes for children with orofacial cleft at 5–10 years of age. This study looked at speech outcomes across the nation and included five cleft centres. Results were broken down by age and cleft diagnosis. No account for ethnicity or location was considered. This paper showed that further speech and/or surgical intervention was required in 85% with cleft lip and palate, 65% with cleft palate and 26% with cleft lip. With this complexity of MDT involvement in the early years for tamariki with orofacial cleft, it is important to audit service outcomes in Aotearoa New Zealand. In this study, we explored the speech outcomes for five-year-olds born with cleft palate who live in the catchment area of the Auckland Regional Cleft Palate Service, with a

Table 1: Primary diagnosis by ethnicity.

	Māori	European	South East Asian	Other Asian	Pasifika	Other	Total
Cleft palate	17 (77% of total for Māori)	19 (57% of total for European)	4 (40%)	2 (50%)	4 (66%)	2 (50%)	48
Unilateral Cleft Lip and Palate	2	10	5	2	2	1	22
Bilateral Cleft Lip and Palate	3	4	1	-	-	1	9
Total	22 (28%)	33 (42%)	10 (13%)	4 (5%)	6 (7%)	4 (5%)	79

Table 2: Distance (km) travelled to access service.

Travel distance from home to Middlemore	Total cohort (N=79)	Māori (n=22)	non-Māori (n=57)
0–20 km	37 (47%)	9	28
21–50 km	22 (28%)	6	16
51–100 km	7 (9%)	1	6
101–299 km	10 (13%)	3	7
>300km	3 (3%)	3	0

Table 3: Speech therapy services offered and attended.

	Total cohort (N=79)	Māori (n=22)	non-Māori (n=57)
Speech therapy attended through Auckland Cleft Service	44 (56%)	11 (25%)	33 (75%)
Number of sessions	Median 9.3, range 1–23		
Attendance		Average 63% attendance rate 3 (27%) children had 100% attendance	Average 95% attendance rate 28 (85%) of children had 100% attendance
Additional speech therapy in the community	46 (58%)	18 (82%)	27 (49%)

Table 4: VPI and CSC characteristics for Māori and non-Māori at 5 years plus distance from cleft centre.

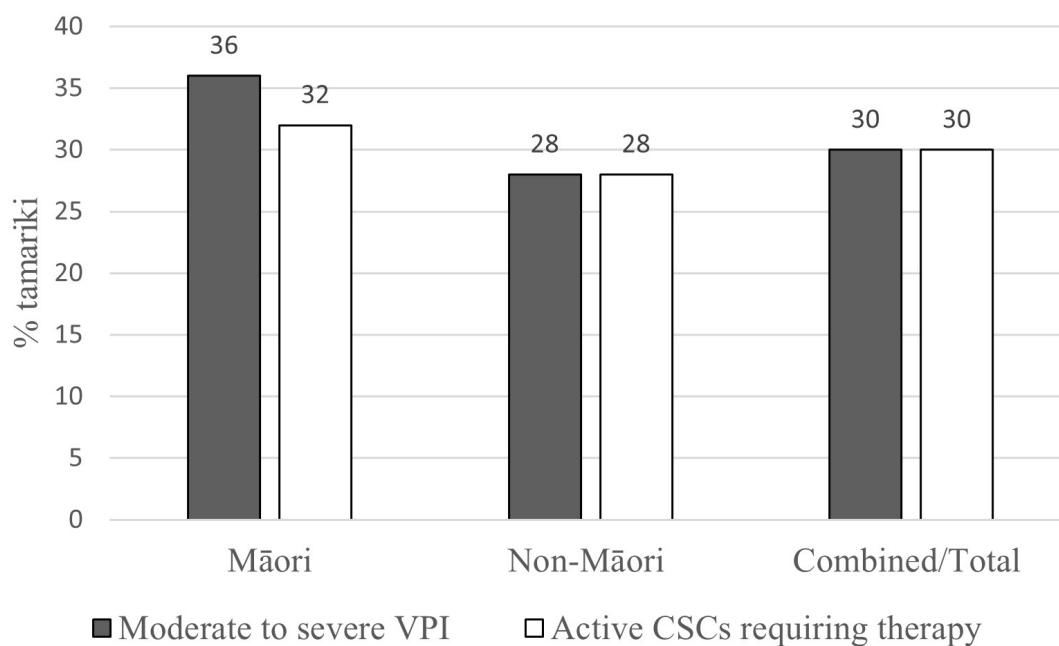
Speech outcome		Māori (n=22)	non-Māori (n=57)	Total	Kms
VF dysfunction*	Normal to Mild (0-1) Monitor Only	7	25	32	<20 km
		3	8	11	21-50 km
		1	5	6	51-100 km
		0	3	3	101-299 km
		3	0	3	300+ km
	Moderate (3-5) Require investigation and probable surgery	2	2	4	<20 km
		2	4	6	21-50 km
		0	1	1	51-100 km
		2	0	2	101-299 km
				0	300+ km
	Severe (6-7) Require investigation and likely surgery	0	3	3	<20 km
		1	4	5	21-50 km
				0	51-100 km
		1	2	3	101-299 km
		0	0	0	300+ km
Presence of cleft speech characteristics (CSC)	Normal speech (anterior or development errors) Monitor only	8	25	33	<20 km
		5	14	19	21-50 km
		1	5	6	51-100 km
		0	4	4	101-299 km
		3	0	3	300+ km
	Glottal/pharyngeal articulation/Active Nasal Fricatives Severe CSCs require therapy	1	1	2	<20 km
		0	1	1	21-50 km
		0	0	0	51-100 km
		2	0	2	101-299 km
		0	0	0	300+ km

Table 4 (continued): VPI and CSC characteristics for Māori and non-Māori at 5 years plus distance from cleft centre.

Presence of cleft speech characteristics (CSC)	Backing to velar or uvular place	0	2	2	<20 km
		1	1	2	21–50 km
		0	1	1	51–100 km
		1	3	4	101–299 km
		0	0	0	300+ km
	Moderate CSCs Require therapy				

* Rhinocleft composite score (0= no impairment; 7=severe impairment).

** Anterior CSCs (dentalisation, lateralisation, palatalization) were not included here as they may not require ongoing therapy intervention. In cases where there was the presence of both backing to velar/uvular and glottal/pharyngeal or Active nasal fricatives, this was only counted once.

Figure 1: Speech outcomes for Māori and non-Māori (%).

focus on ethnicity and geographical factors that may influence service accessibility. We ask the research questions: what are the outcomes for tamariki in our regional service, does ethnicity or distance from Auckland impact on outcomes, and how does this compare to international standards?

Methods

This retrospective clinical file audit received ethical approval through The University of Auckland Human Patients Ethics Committee (012601). We

collated data from all tamariki who received primary surgical repair through the Auckland Regional Cleft Service between 2013–2016 (inclusively). All tamariki included in this study had a cleft palate +/- cleft lip and continued in the service until they received their five-year review. Those with a cleft lip only (i.e., an intact palate) were excluded. Tamariki with an additional diagnosis of syndrome, sequence or developmental disability were included, provided their expressive language skills were sufficient to undertake standardised speech assessment. Information

was collected on residential address and primary ethnicity from the health board Clinical Portal. Information on timing and technique for surgical procedures was collected from health records. Any secondary surgeries, including fistula repair or speech surgery for VPI, and speech therapy appointments were also recorded. Surgical procedures such as grommets or dental extractions were not included.

At the time, primary surgical palate repair was carried out by one of four cleft surgeons. Since then, the Auckland Regional Cleft Palate service has reduced the number of surgeons carrying out primary cleft surgery, but there have been no significant changes in surgical techniques, timing of initial repair or care pathway within the MDT. Speech assessments were carried out by two SLTs, both with over 15 years' experience of working with cleft palate speech using the Rhinocleft assessment.²¹ Speech reviews were scheduled at 5 years of age.

The service routinely reports the following speech parameters:

1. The degree of VPI using a validated ordinal rating scale—the Rhinocleft® Perceptual Cleft Palate Speech Assessment²⁰—rated as absent, mild, moderate or severe. This is a cumulative score that reflects perceptual ratings in the areas of hypernasality, audible nasal air emission and weak or nasalised pressure consonants. Absent or mild VPI do not warrant further surgery.
2. The presence of active CSCs such as glottal articulation, pharyngeal articulation, backing to velar or uvular place of articulation.

Data were collated in Excel and explored through descriptive statistics and graphing. Differences between Māori and non-Māori and distance from centre were explored using Chi-squared test ($p < .05$).

Results

Eight-nine tamariki received primary surgical repair between 2013–2016. Ten were excluded as they had no follow-up at 5 years of age; seven had moved out of the area and three were lost to follow-up. The average age of primary repair was 12 months (range 6–15). Speech reviews, while scheduled at 5 years of age, in practice occurred between 4 years and 6 months and 7 years (mean

age 5 years and 4 months). Primary diagnosis by ethnicity is presented in Table 1. Thirteen children had additional medical diagnosis including (but not limited to) 22q11 deletion syndrome, global developmental delay and Pierre Robin sequence.

Table 2 displays the distance that families travelled from their home to Middlemore Hospital, with an average of 59km (range 4–350km). Where attendance at clinic appointments proved difficult, clinical documentation indicated that the Cleft CNS maintained regular contact with both the families and community support services. Where needed, and if parents consented, children were offered community-based SLT and Health Psychology outside of the cleft MDT. Specific numbers of appointments and attendance rates for these external community services were not available. There was no significant correlation between ethnicity and distance to travel to clinic ($X^2 = 5.36$, $p = .25$); however, 27% of Māori lived 100km+ away compared with only 12% of non-Māori.

Speech therapy services

Speech therapy with the cleft palate specialist SLT was offered to 100% of Māori and 70% of non-Māori who lived within 50km of the cleft service. Children received a range of speech therapy services from both the Auckland Regional Cleft Centre and community (Table 3). Specialist clinic attendance was significantly poorer for Māori (63%) than non-Māori (95%) ($X^2 = 6.43$, $p < .01$) (Table 3), but was not significantly associated with distance to travel to clinic. Māori were significantly more likely to be referred to community services (82%) than non-Māori (49%) ($X^2 = 12.56$, $p < .01$).

Speech outcomes

Thirty percent of tamariki, at the age of 5 years, had velopharyngeal insufficiency (VPI) that was deemed clinically to warrant further investigation with possible secondary speech surgery (Figure 1). Thirty-eight percent underwent secondary surgeries for velopharyngeal insufficiency or fistula repair before the age of 5 years. Some tamariki underwent more than one secondary procedure, with 59 secondary speech surgery procedures across 34 tamariki before 5 years of age. Thirty-six percent of Māori children ($n = 8$) had residual moderate to severe VPI at 5 years, compared to 28% non-Māori ($n = 16$) ($X^2 = 0.52$, $p = .47$) (Table 4; Figure 1).

Thirty percent of tamariki, at the age of 5 years, had residual cleft speech characteristics (CSCs) which warranted speech therapy intervention, including 32% of Māori ($n = 10$) compared to 28% of

non-Māori (n=19) ($X^2=0.32$, $p=.32$) (Table 4; Figure 1). There was no significant correlation between VF dysfunction severity and domicile distance from the cleft centre ($X^2= 8.87$, $p=.06$).

Discussion

Māori make up 26% of the Counties Manukau population and 28% of the cleft palate population within the Auckland Regional Cleft Service. There was no significant correlation between ethnicity and distance to travel to clinic; however, more Māori lived 100km+ away from the service than non-Māori. Equality of access to services and equity of outcomes are intertwined. Lost days of paid work and travel costs for multiple surgical and outpatient appointments, plus the large distances that some whānau have to travel are to be considered, not only in regard to the burden of care, but also on outcomes of speech, education and psychosocial wellbeing. It is pleasing to see that, when it comes to speech outcomes for five-year-olds with orofacial cleft, there was no significant difference across ethnicities or geographical location. As a whole cohort, Auckland Regional Cleft Service speech outcomes are better than the national reported outcomes for Aotearoa New Zealand, where 85% required further speech and/or surgical intervention at age 5 years.²⁶ However, internationally, it is widely accepted and reported that 20% of children born with orofacial cleft may have persistent speech disorder at the age of 5 years²⁻⁴ in comparison to our 30% (VPI) and 30% (CSCs).

The building of relationships is an important and recurring theme in the literature around health equity for Māori. This can be difficult in a hospital setting where staff turnover is high. In our cleft team, the team is small, and staffing has remained stable for many years. Whānau have an allocated Clinical Nurse Specialist. She is their key point of contact along their journey with hospital appointments, surgery planning and post-operative follow-up. This key contact person builds relationships, provides stability and gives whānau time. This may contribute to successful engagement and attendance at cleft clinic appointments. The CNS and the Health psychologist on the team have a strong focus on patient engagement, equity of access to services and whānau wellbeing, and engage regularly with community services to reduce inequity for those unable to attend appointments in Auckland.

However, attendance was not high for all

children. A barrier for many whānau may be practical—financial restraints, transport and organising leave/childcare. These can all impact on the ability of whānau to attend appointments.^{14,27} Our health model allocates appointments within business hours, to which families are expected to attend. The establishment of the outreach clinic in Northland may contribute somewhat to facilitating travel burden and attendance at clinics. There may be more that can be done to improve flexibility of appointments and service provision models that can further enhance attendance on a regular basis. Since the COVID-19 pandemic, health professionals have been making more use of telehealth, which has opened up more opportunities for whānau to connect with the cleft team remotely and, in some cases, access remote speech therapy. Anecdotally, it has been noted that phoning or texting a parent following a non-attendance at clinic (for MDT clinics or speech therapy) creates better engagement and an increased attendance rate than merely sending another appointment letter.

While specialist SLT appointments were offered to 100% of Māori, attendance at the cleft service was lower for Māori compared with non-Māori. This did not, however, correlate with a significantly greater rates of VPI or CSCs in Māori. This suggests that Māori are accessing SLT through the community services available in Aotearoa New Zealand. If this is the case, then Te Whatu Ora – Health New Zealand needs to be focussing their support into these regional centres. Tamariki can access additional SLT through community-based Te Whatu Ora – Health New Zealand child development services (<3 years old), at school (Ministry of Education funded, ~5 years+) and/or privately. If Māori tamariki are accessing these services more often than the cleft service, the specialist SLTs in the cleft service need to focus education and training to these regional SLTs to ensure all tamariki get the SLT they need for best outcomes.

Limitations and recommendations

This is a retrospective audit and lacks depth of analysis to truly understand whānau engagement and satisfaction with the service. This audit provides a crude review of the service offering validated speech outcomes at 5 years old and provides a first step to build on for future research. There is an absence of a routine validated parent questionnaire in the service, and this would be an excellent addition to track parent concern and engagement. Hearing is not routinely assessed and therefore we were unable to correlate hearing status to speech

outcomes in this cohort. This is a consideration for future research. There is well established inequality in oral health in Māori compared with non-Māori. It was outside of the scope of this study to audit dental outcomes and tamariki perceptions of appearance, but this would be useful additional data to inform the way that our services are structured nationally, as well as informing the development of a clinical care pathway with health outcomes for Māori at the forefront of our care planning.

We currently use medical model measures to report outcomes. While these quantify our practice and help us measure, they are not the only measures of successful outcomes. We need to consider and work to improve outcomes that are important to whānau. It is imperative that, early on in the relationship we establish what a “good outcome” looks like for them. Parameters such as psychosocial wellbeing, educational achievement, being understood, acceptance and engagement in community activities may be important outcome measures for our patients and should be considered.

Kaupapa Māori research in this area is critically needed to explore attendance, whānau experience and satisfaction with services. Research should explore how we can prioritise Māori participation and success at all levels. It is important to recognise what we are doing well and to consider how we can continually improve our practice. We must all make greater efforts to recognise and respond to tikanga Māori practices.

Examples for consideration and future service development opportunities are considered below:

- Build rapport and warmth of interactions.¹⁴
- Acknowledge and consider all people’s cultural and spiritual practice.
- Evaluate more flexibility in appointment times and structures to prevent the practical barriers of attending appointments.
- Proactively develop policies to improve Māori participation and success at all levels.
- Develop an assessment of cleft speech that uses te reo Māori.
- Establish regular and consistent use of parent-reported outcome measures and patient goal setting.

Conclusions

Auckland Regional Cleft Service must continue to strive for improvements in speech outcomes, both in terms of surgical and speech therapy needs at 5 years old. Consideration must be given, when planning services, to ensure equitable access to services, cultural support and whānau engagement in the process. While speech outcomes did not differ based on ethnicity, attendance at specialist outpatient appointments was lower in Māori. Community services were offered but attendance rates to these appointments is unknown. If we do not provide the best care at the best time for our tamariki, we risk losing them from our service and, therefore, risk not allowing them to reach their best possible outcomes. It is imperative that, in order to achieve the best objective and functional outcomes, whānau are engaged in their treatment, trust their MDT and are able to access timely and effective treatment.

COMPETING INTERESTS

Nil.

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