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**Continuity of Care in Cleft Palate  
Speech-Language Pathology Services**

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**Mikaela Bow, BSpPath**

**Faculty of Medicine and Health,**

**The University of Sydney**

**December 2026**

**A thesis submitted in fulfilment of the requirements for the degree of Doctor of Philosophy.**

## **Statement of Originality**

This is to certify that the content and intellectual work presented in this these if my own work.

This thesis has not been submitted for any other degree or purpose. To the best of my knowledge and belief, it contains no material previously published or written by another person, except where due acknowledgement is made. All sources and assistance received during the preparation of this thesis have been appropriately referenced. Approval for these studies was given by The University of Sydney Human Ethics Committee (2023/105).

Name: Mikaela Bow

Date: 10<sup>th</sup> December 2025

## **Declaration of Completion**

This is to certify that the thesis entitled '*Continuity of Care in Cleft Speech Services*' submitted by Mikaela Bow in the fulfillment of the requirements for the degree Doctor of Philosophy, in a form ready for examination.

Name: Patricia McCabe

Date: 10<sup>th</sup> December 2025

## **Acknowledgement of Country**

I acknowledge the Gadigal people of the Eora Nation, the Traditional Custodians of the land on which The University of Sydney stands. I pay my respect to their Elders past and present, and extend that respect to all Aboriginal and Torres Strait Islander peoples. I recognise their continuing connection to land, culture, and knowledge.

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## Author Attribution Statement

**Chapter 2** of this thesis has been published as:

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I co-designed the study, conducted the review, analysed the data, and wrote the manuscript with my co-authors Professor Patricia McCabe and Professor Alison Purcell

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I co-designed the study, collected and analysed the data, and wrote the manuscript alongside my co-authors Professor Patricia McCabe and Professor Alison Purcell.

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Bow, M., McCabe, P., Sutherland, R., & Purcell, A. (2026). Collaboration begins with connection: Experiences of community-based speech-language pathologists in cleft palate continuity of care. *International Journal of Speech-Language Pathology*. 1-12. <https://doi.org/10.1080/17549507.2026.2622405>

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I co-designed the study, collected and analysed the data, and wrote the manuscript alongside my co-authors Professor Patricia McCabe, Doctor Rebecca Sutherland, Ms. Alison Delzotto and Professor Alison Purcell.

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I co-designed the study, analysed the data, and wrote the manuscript alongside my co-authors Professor Patricia McCabe, Doctor Rebecca Sutherland, Ms. Alison Delzotto and Professor Alison Purcell.

Candidate Signature

I certify that the statements of my contribution to each chapter are accurate and that all co-authors have approved the inclusion of the published and submitted manuscripts in this thesis.

Name: Mikaela Bow

Signature:

Date: 11/12/2025

#### Primary Supervisor Certification

I certify that the authorship attribution statements above are correct and that the student's contribution is accurately described.

Name: Professor Patricia McCabe

Signature:

Date: 11/12/2025

## **Artificial Intelligence**

During the preparation of this thesis, the author used a generative AI tool, Co-pilot for the purposes of text enhancement. This included spelling corrections, minor sentence restructuring, and clarity enhancement. All AI modifications were carefully reviewed by the author to identify and correct any potential errors, inaccuracies or bias. The author takes full responsibility for the submitted thesis, confirms the work is their own, and has used generative AI in accordance with University guidelines and policies.

## Publications and Presentations Arising from this Thesis

### Peer-Reviewed Publications

**Bow, M., McCabe, P., Sutherland, R., Delzotto, A., & Purcell, A. (n.d.).** *Connecting the team: The Tri-Care Cleft Speech Pathology Model for continuity in cleft speech services* (Manuscript submitted for publication).

**Bow, M., McCabe, P., Sutherland, R., Delzotto, A., & Purcell, A. (n.d.).** *“I Have to Be My Child’s Voice”: Parents’ Experiences of Continuity of Care in Cleft Speech Services* (Manuscript submitted for publication).

**Bow, M., McCabe, P., Sutherland, R., & Purcell, A. (2026).** Collaboration begins with connection: Experiences of community-based speech-language pathologists in cleft palate continuity of care. *International Journal of Speech-Language Pathology*. 1-12.  
<https://doi.org/10.1080/17549507.2026.2622405>

**Bow, M., McCabe, P., & Purcell, A. (2025a).** *Experiences of cleft team speech-language pathologists in continuity of care: Building relationships beyond broadcasting*. *Cleft Palate-Craniofacial Journal*, 1–11. <https://doi.org/10.1177/10556656251348297>

**Bow, M., McCabe, P. & Purcell, A. (2024)** *Speech–language therapy services for children with cleft palate: A scoping review on continuity of care*. *International Journal of Language & Communication Disorders*, 1–18. <https://doi.org/10.1111/1460-6984.13091>

### Peer-Reviewed Presentations

**Bow, M., McCabe, P., Sutherland, R., & Purcell, A.** *Experiences of Cleft Speech Pathologists in Continuity of Care: Building Relationships Beyond Broadcasting*. Presentation at The 15th International Cleft Congress on Cleft Lip/Palate and Related Craniofacial Anomalies in Kyoto, Japan, 2025.

**Bow, M., McCabe, P., & Purcell, A.** *Improving continuity of care for children with cleft palate.*

Presentation at The International Association of Communication Sciences and Disorders Conference in Auckland, New Zealand, 2023.

**Bow, M., McCabe, P., & Purcell, A.** *Speech-language pathology services and cleft palate: A*

*scoping review of the handover process from cleft team speech-language pathologists to*

*community speech-language pathologists.* Presentation at The 15th International Cleft

Congress on Cleft Lip/Palate and Related Craniofacial Anomalies in Edinburgh, Scotland,

2022.

**Bow, M., McCabe, P., & Purcell, A.** *Speech-language pathology services and cleft palate: A*

*scoping review of the handover process from cleft team speech-language pathologists to*

*community speech-language pathologists.* Presentation at The University of Sydney

Research Symposium in Sydney, Australia, 2022.

## Notes on Style

This thesis has been prepared in a thesis-with-publications format. It incorporates five papers, presented in the style of journal articles, which appear as Chapters 2 through 6. As these chapters consist of published or submitted manuscripts, there is some unavoidable overlap particularly in the background sections of each paper. Efforts were made to minimise repetition wherever possible.

### Spelling

- Two included journal articles (Chapters 3 and 6) are written in American English in accordance with the instruction for authors from the journal, *The Cleft Palate Craniofacial Journal* and *American Journal of Speech-Language Pathology*.
- The remainder of the thesis is written in Australian/British English.

### Style

- The journal article chapters (Chapters 2–6) follow the style and formatting requirements of the respective journals in which they were published or submitted.
- The remainder of the thesis adheres to APA 7th edition guidelines, with the exception of tables, which are single-spaced and embedded to enhance readability.
- References are embedded within the text of each chapter, with individual reference lists provided at the conclusion of each chapter.

### Terminology

- The term *speech-language pathologist* is used throughout this thesis, with the exception of Chapter 2. In this chapter, the term *speech-language therapist* is used in alignment with the conventions of the *International Journal of Language and Communication Disorders*.

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## Glossary

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Term	Meaning
ACPA	American Cleft Palate Craniofacial Association
CoC	Continuity of Care
CP±L	Cleft palate with or without lip
PD	Professional development
SLP	Speech-language pathology or speech-language pathologist
SLT	Speech-language therapy or speech-language therapist

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## Preface

Very early in my career as a student speech-language pathologist, I had the privilege of volunteering with Global Smile Foundation, a charity led by Dr Usama Hamdan. In Peru and Ecuador I worked with children with cleft palate and their families, as well as a team of health professionals from across the world. I left knowing this was the field I wanted to devote myself to.

When I started working as a speech pathologist in private practice, I actively sought opportunities to support children with cleft. I loved the work and the collaboration with cleft clinicians. At the same time, I noticed how hard it could be to make collaboration happen. Everyone cared, but it just wasn't always easy to connect the pieces.

In pursuit of learning more, I attended an observation day at a cleft unit and met Professor Alison Purcell. We started talking and I expressed interest in completing a PhD and we quickly started bouncing ideas around. It was reflecting on our experiences that we realised this disconnect between community SLPs, cleft SLPs, and families that made it harder than it needed to be - especially for community clinicians doing their best to help. That is where this PhD began.

This thesis grows out of those experiences. It aims to make collaboration simpler and kinder for families and clinicians. My hope is that these pages help us work together with less friction and more focus on what matters most - the child and families in front of us.

## Thesis Abstract

Children born with cleft palate often require long-term, specialised speech-language pathology (SLP) intervention to support their communication development. In Australia and New Zealand, care is typically provided by a centralised, hospital-based cleft team speech-language pathologist<sup>1</sup> (SLP), complemented by ongoing therapy from a community-based SLP closer to the child's home. This dual service model requires effective coordination and collaboration between cleft team SLPs, community SLPs, and parents. Achieving continuity of care across these parties is critical to optimise speech, language and feeding outcomes, yet persistent challenges in communication, information transfer, and shared decision-making impact service delivery. Importantly, while continuity of care is recognised as essential in broader healthcare literature contexts, little is known about how it is enacted within cleft speech services, and few studies have explored the perspectives of cleft team SLPs, community SLPs or families in this. This gap underpins the need for the present research.

Continuity of care (CoC) refers to the degree to which health services are experienced as connected, coordinated and consistent over time (Haggerty et al., 2003). Drawing on Haggerty et al.'s (2003) framework, this thesis explores three interrelated dimensions of CoC in cleft SLP services: informational continuity (the transfer of key knowledge between providers and families), management continuity (coordinated and complementary care across settings), and relational continuity (sustained, trusting relationships between families and professionals).

The thesis includes five publications: one scoping review, three qualitative studies exploring the perspectives of cleft team SLPs, community SLPs and parents, and a final synthesis paper that translates findings into evidence-based recommendations and introduces the Tri-Care

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<sup>1</sup> In New Zealand, the profession is referred to as Speech-Language Therapist (SLT)

Cleft Speech Pathology Model for improving continuity of care. These are framed by an introductory chapter, which established the clinical and theoretical background to CoC and outlines the study aims, and a concluding discussion chapter, which integrates findings across all studies.

Following an introductory chapter, the thesis begins with a scoping review (Bow et al., 2024) that examined how continuity of care has been experienced internationally within cleft SLP services. The review highlighted that processes to achieve continuity remain fragmented and inconsistent. Key barriers included ambiguity around roles and responsibilities, as well as community SLPs reporting limited confidence, knowledge, and access to specialist support. These findings highlighted the importance of capturing the perspectives of cleft team SLPs, community SLPs, and families, which were largely absent in the literature.

Building on this, three qualitative studies were conducted with stakeholders in Australia and New Zealand. Semi-structured interviews with cleft team SLPs, community SLPs and parents, providing in depth accounts of their experiences of CoC. A reflexive thematic analysis approach (Braun et al., 2023) was used to interpret the data.

Interviews with cleft team SLPs (Bow et al., 2025) emphasised the importance of relationships in achieving effective continuity of care, with trust and collaboration viewed as essential for supporting families and community clinicians. While committed to education and support, cleft team SLPs noted that their engagement often relied on information dissemination rather than interactive, two-way dialogue. Some community SLPs were seen to be proactive in seeking guidance, yet a lack of engagement from others highlighted persistent communication gaps. Despite these challenges, cleft team SLPs expressed dedication to building collaboration and strengthening the capacity of community clinicians. A shift from a primarily consultative stance to a more co-facilitative role was seen as key to improving care. Strategies such as joint

sessions, structured mentoring, and more intentional follow-up were identified as ways to foster reciprocal learning and shared problem-solving, with an emphasis on framing communication to empower both clinicians and parents as active partners in the process.

These findings were echoed, and at times contrasted, with the perspectives of community SLPs (Bow et al., submitted). Community clinicians described challenges in accessing timely and consistent information from cleft teams, often relying on parents to act as intermediaries. Many expressed uncertainty about therapy priorities, their expected role, and the best avenues for communicating with cleft SLPs. Despite these barriers, participants demonstrated a strong commitment to delivering collaborative, high-quality care, frequently making proactive efforts to communicate, advocate, and coordinate services. However, variability in access to cleft team input, limited clarity around professional roles, and fragmented communication systems hindered their ability to provide consistent continuity of care. These experiences underscored the importance of strong relationships, clear role delineation, structured communication pathways, and accessible specialist support to enable community SLPs to effectively contribute within the cleft care pathway.

Parents, situated at the centre of these interactions, offered yet another perspective (Bow et al., n.d.-b). Their accounts reflected both the successes and shortcomings described by professionals. While some described coordinated and transparent care, others encountered fragmented pathways, uncertainty regarding SLP roles and the broader cleft care journey, and the burden of carrying critical information between providers. Parents emphasised the importance of strong relationships, knowing who to contact, receiving education about the cleft journey and the roles of different SLPs, and having ongoing feedback loops. They saw themselves as their child's primary 'voice' and advocate, often feeling reassured that providers had their child's best

interests in mind, yet also recognising that active advocacy on their part was necessary to ensure this was realised.

The final synthesis paper (Bow et al., n.d.-a) integrates findings across all four empirical studies to provide a comprehensive understanding of continuity of care in cleft speech pathology services and translate these into practical, evidence-based solutions. Drawing together stakeholder perspectives, the paper presents a set of clinically relevant, evidence-informed recommendations designed to strengthen informational, management and relational continuity across service settings, providers and individual clinicians. Central to this paper is the introduction of the Tri-Care Cleft Speech Pathology Model, a triadic framework that positions cleft-team SLPs, community-based SLPs, and parents as collaborative partners with shared responsibility for decision-making, goal setting, and care coordination. Through this integrative lens, the synthesis key barriers to continuity of care, including fragmented communication systems, variable access to specialist input, and a lack of clarity around professional roles and responsibilities. Limited opportunities for joint decision-making, goal setting, and reciprocal problem-solving further impacted coordination across providers. At the same time, important facilitators were evident: established professional relationships, proactive efforts by both cleft team and community SLPs to connect, and structured processes such as joint sessions, mentoring, and consistent follow-up supported collaboration. Across all perspectives, relational continuity encompassing mutual trust, familiarity, and respect between professionals and families, emerged as a central driver. Where strong relationships were present, information flowed more effectively, management was better coordinated, and parents felt empowered as partners in their child's care.

This thesis contributes new knowledge by capturing, for the first time, the perspectives of cleft team SLPs, community SLPs, and parents as they navigate the complexities of cleft speech care. It shows that continuity of care cannot be achieved through uni-directional information

transfer alone. Rather, it relies on relational continuity - mutual trust, familiarity, and respect - as the foundation for effective information-sharing and coordinated management. Structured, collaborative models that foster joint decision-making, clear role delineation, and reciprocal problem-solving are essential for integrating specialist and community services while positioning parents as active partners in the process. The synthesis paper advances this work by translating these insights into a cohesive set of practice recommendations and proposing the Tri-Care Cleft Speech Model, a triadic framework to guide collaborative practice across settings. Practical recommendations are offered for service redesign, professional education, and policy reform, with the aim of strengthening continuity of care and ultimately improving speech and quality-of-life outcomes for children with cleft palate.

## References

- Bow, M., McCabe, P., & Purcell, A. (2025). Experiences of cleft team speech-language pathologists in continuity of care: Building relationships beyond broadcasting. *The Cleft Palate Craniofacial Journal*, 1-11. <https://doi.org/10.1177/10556656251348297>
- Bow, M., McCabe, P., Sutherland, R., Delzotto, A., & Purcell, A. (n.d.-a). Connecting the team: The Tri-Care Cleft Speech Pathology Model for supporting continuity in cleft speech services *Manuscript submitted for publication*.
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# **Chapter 1: Introduction**

## **Background: Cleft palate and speech**

Orofacial clefts are among the most common congenital conditions worldwide, affecting approximately 1 in 1000 live births (Salari et al., 2022). In Australia, registry-based data from Western Australia report prevalence rates of 12.05 per 10,000 births for cleft lip with or without cleft palate and 10.12 per 10,000 births for cleft palate only, with Aboriginal Australians almost twice as likely to be affected as non-Aboriginal populations (Bell et al., 2013). In New Zealand, the national incidence of orofacial clefts between 2000 and 2009 was 1.79 per 1,000 live births (approximately 1 in 559), with Māori children disproportionately affected at a rate of 2.37 per 1,000 live births compared to 1.63 per 1,000 for non-Māori (Thompson et al., 2016).

A cleft palate (with or without cleft lip; CP±L) disrupts the anatomy and physiology needed for speech, resonance, and feeding, both before and after surgical repair. While surgical closure of the palate typically aims to be completed during the first year of life in Australia and New Zealand (MacKinnon, 2024), speech difficulties remain common. More than half of children with cleft palate experience speech problems, and around one in five continue to face persistent and severe difficulties despite intervention (Hardin-Jones & Jones, 2005; Sell et al., 2015). Speech difficulties associated with cleft palate, commonly referred to as “cleft palate speech”, may include hypernasality, audible nasal emission, and articulation and phonology difficulties (Kummer, 2011; Peterson-Falzone et al., 2016). These difficulties often result from velopharyngeal insufficiency and have substantial psychosocial consequences, including reduced intelligibility, bullying, and diminished self-esteem (Nicholls et al., 2019). Adolescents and adults with unresolved cleft-related speech difficulties consistently report negative impacts on education, employment, relationships, and social participation (Nicholls et al., 2019).

Access to effective, timely, and coordinated speech-language pathology intervention is therefore essential, not only to support children’s communication and feeding development but

also to improve their long-term quality of life. Achieving these outcomes requires integrated, multidisciplinary cleft care, delivered through collaborative team-based service models (American Cleft Palate Craniofacial Association, 2022, 2024).

### **Team-based cleft care**

Cleft care is recognised as complex and longitudinal, requiring coordinated, multidisciplinary input sometimes before a child is born through to adulthood. Optimal outcomes rely on contributions from surgeons, orthodontists, audiologists, psychologists, dentists, nurses, and speech-language pathologists (SLPs), among others. Internationally, the ACPA Parameters of Care (2024) and the Standards of Approval for Cleft and Craniofacial Teams (2022) emphasise the need for structured, interdisciplinary, and family-centred care throughout the lifespan.

Different service delivery models have been developed around the world to manage the challenges of geography, caseload distribution, and equitable access. In the United Kingdom, cleft care was reconfigured following the recommendations of the Clinical Standards Advisory Group (1998) with centralization of services and subsequent evolution of a hub-and-spoke model (Bearn et al., 2001; Clinical Reference Group for Cleft et al., 2016). Under this structure, a small number of centralised specialist hubs provide surgical and specialist cleft services, while “spoke” sites deliver follow-up and routine care closer to families’ homes. This reorganisation aimed to consolidate expertise, reduce variability in outcomes, and ensure children benefit from both centralised specialist input and local accessibility. Evidence following implementation has shown improvements in surgical and speech outcomes, as well as greater consistency in care delivery (Persson et al., 2015; Sell et al., 2015).

In Australia and New Zealand, cleft services are also coordinated through centralised hospital-based teams, which function as the main hubs of expertise. However, unlike the UK, there is no generally formalised hub-and-spoke system. Instead, families move between specialist

hospital care and community-based services depending on their needs and location. Outreach and shared-care arrangements exist in some contexts, but they are not consistently structured across states or regions. This can create variability in how services are accessed and delivered, often leaving parents to act as the main link between providers.

Speech-language pathology services reflect this complexity. In New Zealand, publicly funded therapy is commonly delivered through the Ministry of Education for children with speech and language needs, alongside hospital-based services for those requiring cleft-specific expertise. This arrangement means that SLPs employed within education systems may have limited exposure to cleft palate speech disorders, increasing the importance of collaboration with specialist hospital teams.

Thus, while the UK hub-and-spoke model demonstrates how centralisation can be balanced with structured outreach, the Australian and New Zealand systems remain more fragmented, with variable funding arrangements and fewer formalised mechanisms to ensure consistency between specialist and community care. This underscores the importance of exploring how continuity of care is achieved in these contexts, particularly for speech-language pathology services.

### **Organisation of speech-language pathology services in Australia and New Zealand**

Australian and New Zealand, speech-language pathology service delivery is shaped by a mix of publicly funded and privately funded systems, resulting in considerable variability in access, frequency, and duration of therapy. The information presented here reflects typical clinical practice patterns rather than published service utilisation data, as national data on therapy intensity and duration for children with cleft palate are limited.

For both countries cleft team SLPs based in tertiary hospitals tend to provide periodic review rather than ongoing weekly therapy. Reviews commonly occur every 6-12 months in early childhood and reduce frequency over time, depending on clinical need.

Although patterns for ongoing speech and language intervention vary depending on geography and funding pathways, Australian children with cleft palate typically receive speech-language pathology intervention intermittently across early childhood and school years. Therapy sessions commonly range from 30 to 60 minutes in duration and may occur weekly, fortnightly, or in block-based service models depending on service availability and funding. In Australia, therapy may be publicly funded through community health services, privately funded by families, or supported through the National Disability Insurance Scheme (NDIS), which provides individualised funding for children with disability or developmental needs.

In New Zealand, ongoing speech-language therapy is commonly delivered through Ministry of Education services, alongside hospital-based cleft team reviews. These mixed funding and service pathways contrast with some international models where cleft-related therapy is more consistently embedded within hospital systems or national health services.

Other high income countries have other organisational and funding systems. For example, in the United Kingdom, cleft care operates within a nationalised health system where specialist cleft teams provide oversight while therapy may be delivered through local National Health Services within a hub-and-spoke network. In contrast, in the United States, therapy is more frequently delivered within hospital-based cleft programs, within education systems, or from private speech-language pathology practices, often funded through private insurance or state-based early intervention systems

## **Cleft speech team: the cleft team SLP, the community-based SLP, and parents**

SLPs are integral to cleft care, yet their roles and responsibilities differ markedly depending on whether they work within a specialist cleft team or in the community. Cleft team SLPs are based in tertiary hospital services and provide highly specialised expertise in cleft palate speech disorders. Their responsibilities include monitoring children's speech and resonance development over time, diagnosing velopharyngeal insufficiency (VPI), advising on timing of surgery, and guiding long-term care planning (Sommer & Wombacher, 2025). They also play a critical role in interdisciplinary decision-making within cleft teams, ensuring that speech outcomes are considered alongside surgical, orthodontic, and psychosocial needs. Because their involvement is often limited to periodic review rather than ongoing therapy, cleft team SLPs frequently provide recommendations, progress reports, and treatment plans intended to support care delivered outside the hospital setting.

Australian and New Zealand community-based SLPs, in contrast, provide the regular, ongoing therapy that most children with cleft palate require (Alighieri et al., 2021; Bedwinek et al., 2010; Grames & Stahl, 2017). These clinicians typically work in local health services, private practice (sometimes funded through schemes such as the National Disability Insurance Scheme [NDIS] in Australia), or, in New Zealand, through the Ministry of Education. Community SLPs support not only cleft-related speech difficulties but also broader speech, language, and literacy needs. However, many community clinicians report limited training and confidence in cleft management, reflecting the fact that cleft is a relatively low-prevalence condition in speech-language pathology, and is often under-represented in university curricula (Alighieri et al., 2021; Bedwinek et al., 2010). This lack of experience can lead to uncertainty in therapy approaches, reliance on families to interpret team recommendations, and, at times, the provision of inappropriate therapy.

Previous qualitative research has begun to explore these challenges. For example, Alighieri et al. (2021) examined the experiences of speech-language pathologists providing therapy for children with cleft palate in Belgium. Using qualitative interviews, the study found that clinicians often experienced uncertainty, self-doubt, and limited preparation for managing cleft-related speech disorders when working outside specialist teams. While this work provides important insight into clinicians' experiences, it was conducted within a European healthcare context where cleft services, referral pathways, and therapy provision differ from those in Australia and New Zealand. Furthermore, the study focused on clinicians' experiences in isolation, rather than examining how community clinicians interact with specialist cleft teams and families within shared-care arrangements.

Parents also play a pivotal role in speech therapy. Findings from Alighieri et al. (2020) show that parents highly value clear, consistent, and accessible information from SLPs, including both oral and written updates about therapy goals, progress, and home practice. Parents described wanting to feel like partners, not just bystanders, and emphasised that being given guidance on how to support practice at home was essential. They also suggested practical tools, such as communication books that travelled between home and therapy. They also described the desire to be treated as partners in the therapy process, not just bystanders. They wanted guidance on how to support practice at home. Lastly, they also valued their SLP having experience with cleft palate (Alighieri et al., 2020).

Despite these interconnected roles, there is very little in the literature describing how continuity of care is achieved between cleft-team SLPs, community SLPs, and parents. Although all three are central to a child's speech journey, the processes through which they share information, coordinate management, and build collaborative relationships remain poorly documented.

Some models are emerging that suggest ways these gaps could be addressed. For example, in the United States, Grames and Stahl (2017) described a collaborative treatment model where community SLPs, cleft team SLPs, children, and parents participate together in a coordinated appointment. In this model, therapy targets are jointly established, techniques are demonstrated and practiced, and future management is jointly mapped out. This collaborative model resulted in greater confidence, improved appropriateness of therapy, and stronger ongoing partnerships between providers. Such models illustrate the potential benefits of structured collaboration in ensuring accurate, timely, and consistent care. In the Australian and New Zealand context, however, no such formalised models to build collaborative care to improve continuity of care currently exist.

### **Continuity of care**

The challenges faced by cleft-team SLPs, community-based SLPs, and parents highlight the need for a unifying framework to guide collaboration and service delivery. CoC has become a cornerstone concept in health systems internationally, recognised by the World Health Organisation (WHO) as a fundamental component of quality, equity, and universal health coverage. Continuity is particularly important for people with chronic or complex conditions, such as cleft palate where services extend across providers, settings, and time (World Health Organisation, 2018).

Continuity of care was selected as the overarching lens for this thesis because cleft speech services are inherently longitudinal and span multiple providers and service contexts. The framework proposed by Haggerty et al. (2003) offers a structured approach to examining how care is experienced across time through informational, management, and relational dimensions. This lens enables analysis not only of collaboration between stakeholders, but of how that collaboration translates into coherent and connected care for children and families.

Continuity of care is generally defined as the degree to which patients experience healthcare as connected, coherent, and consistent with their evolving needs (Haggerty et al., 2003). For families, it means that providers are aware of past events, agree on management plans, and can be relied upon for future care. For clinicians, it reflects confidence that their input is acknowledged and integrated into the broader care process.

Haggerty et al. (2003) identified three interdependent forms of continuity:

- Informational continuity, where knowledge of the patient's history, context, and goals is shared and used to make care appropriate across settings.
- Management continuity, where care is delivered in a consistent, complementary, and coordinated way, adapting as the patient's needs change.
- Relational continuity, which emphasises the importance of enduring, trusting relationships between patients and providers, and between providers themselves.

These dimensions operate synergistically. Without informational continuity, management becomes fragmented. Without management continuity, interventions may be duplicated or contradictory. And without relational continuity, trust and collaboration can falter, undermining the other two forms.

The evidence base for high quality CoC is strong. For example, studies across primary care, paediatrics, and rehabilitation have shown that sustained continuity reduces hospitalisations and emergency department visits, improves preventive service use, enhances patient satisfaction, and is associated with lower mortality (Cabana & Jee, 2004; World Health Organisation, 2018).

For speech-language pathology services, continuity has been highlighted as critical in several areas that require long-term, multi-setting, or multi-provider management. In paediatric feeding disorders, hybrid and telehealth models support improved access to a specialised feeding services, improvements in community-based providers confidence in supplying ongoing care, and

ease and convenience communication between teams with these models (Clawson et al., 2008; Raatz et al., 2023). In head and neck cancer, structured shared-care arrangements between specialist tertiary SLPs and rural clinicians, supported through tele-handover, joint case discussions, and co-managed appointments, demonstrate robust pathways for maintaining aligned plans whilst empowering local SLPs to deliver high-quality rehabilitation services (Foley et al., 2023; Patterson et al., 2023). Beyond specific clinical populations, collaboration within SLP demonstrates that continuity is sustained not only by formal processes, but also by interpersonal and relational factors. Croker et al. (2019) show that attributes such as curiosity, willingness, mutual respect, and shared purpose underpin effective cross-setting collaboration, supporting clearer communication and coordinated care. Similarly, Wallace et al. (2022) found that SLPs view interprofessional collaboration as dependent on shared goals, open communication, psychological safety, and mutual role understanding – all of which mirror the relational continuity required for cohesive care across service settings. Together, these studies illustrate that when SLP care spans multiple providers and contexts, continuity is central to achieving optimal and consistent outcomes.

Applied to cleft services, continuity of care appears to be essential. Cleft palate speech is a long-term condition, requiring timely information-sharing, coordinated management, and trusting relationships among cleft team SLPs, community SLPs, and parents. Understanding what is happening to facilitate continuity of care and how continuity can be fostered, and where it currently breaks down, is therefore critical to improving communication and feeding outcomes for children with cleft palate.

### **Continuity of care in cleft speech pathology services**

Service provision for children with cleft palate provides a clear example of where continuity of care is both critical and challenging to achieve. Children with cleft palate require

input from multiple providers over time, including cleft team specialists, community-based clinicians, and educational services. For communication outcomes in particular, effective care depends on consistent information-sharing, coordinated planning, and strong relationships between families and providers across different contexts.

While the complexity of cleft care and the need for collaboration are well established, it is unclear how best to structure and support the roles of specialist SLPs, community SLPs, and parents to achieve continuity.

To address this gap, there is a need to systematically map existing literature, explore the lived experiences of key stakeholders, and develop evidence-based strategies to strengthen collaboration.

### **Thesis aim**

The overall aim of this thesis is to explore how continuity of care is realised in cleft speech-language pathology services across Australia and New Zealand, and how collaboration between specialist SLPs, community SLPs, and parents can be strengthened.

### **Overarching research questions**

1. What is known from the existing literature about processes for continuity of care in cleft speech therapy services?
2. What does communication and collaboration currently look like between parents, community SLPs, and cleft team SLPs from the perspective of each stakeholder?
3. What processes are currently being used by cleft-team SLPs, community-based SLPs, and parents to support continuity of care for children with cleft palate?
4. What are the barriers impacting continuity of care in cleft speech services?
5. What are the facilitators that promote continuity of care across cleft team, community, and family contexts?

## **Research design**

This thesis employed a sequential, multi-phase qualitative research design, informed by the continuity of care framework (Haggerty et al., 2003). The design comprised:

- A scoping review to map existing evidence and identify gaps in knowledge.
- Three qualitative interview studies exploring the perspectives of specialist cleft team SLPs, community-based SLPs, and parents.
- A final synthesis phase integrating findings across studies to generate evidence-informed recommendations and propose the Tri-Care Cleft Speech Pathology Model.

The scoping review informed the development of the qualitative interview studies by identifying areas of limited evidence and highlighting the need to examine stakeholder perspectives within the Australian and New Zealand context.

The studies were intentionally sequenced to build progressively across stakeholder groups. The scoping review identified significant gaps in understanding stakeholder experiences of continuity of care. The qualitative study with cleft-team SLPs explored continuity from the specialist perspective and informed refinement of interview questions for subsequent stakeholder groups. The community SLP and parent studies were designed to extend this work, enabling comparison and integration of perspectives across the cleft care triad. A parent advisor with lived experience of cleft care contributed to the parent interview study, supporting interpretation of findings and ensuring that parent perspectives were accurately represented. Findings were synthesised in the final phase to generate an integrated model of collaborative continuity.

## **Overview of the Thesis**

This thesis presents seven chapters.

*Chapter 1* provides an introduction to cleft palate and its impact on speech, outlines the complexity of team-based cleft care highlighting the speech-language pathology service delivery model, and frames the importance of continuity of care across services and settings.

*Chapter 2* presents a scoping review. This chapter is a journal article published in the *International Journal of Language and Communication Disorders* and maps what is known from the existing literature about processes for continuity of care in cleft speech therapy services.

*Chapter 3* reports a qualitative study exploring the perspectives of cleft team SLPs in CoC. This is in the form of a journal article published in *The Cleft Palate-Craniofacial Journal*.

*Chapter 4* reports a qualitative study of community-based SLPs perspectives on CoC, presented in the form of a journal article submitted for peer-review.

*Chapter 5* reports a qualitative study exploring parents' perspectives on CoC. This is in the form of an unpublished manuscript that has been submitted for peer-review.

*Chapter 6* presents a general discussion that synthesis the key findings from the thesis, outline the contributions to knowledge and the implications for clinical practice, service design, and policy. It integrates evidence from the preceding studies into an evidence-based set of recommendations for clinicians and services, presented in the form of an unpublished manuscript submitted for peer review.

*Chapter 7* provides the final conclusion of the thesis, summarising the overarching insights, reflecting on the significance of the research and identifying directions for future investigation and implementation.

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**Chapter 2: Speech–language therapy services for children  
with cleft palate: A scoping review on continuity of care**

## **Chapter 2: Speech–language therapy services for children with cleft palate: A scoping review on continuity of care**

This chapter consists of the published version of the following article, reprinted with permission:

Bow, M., McCabe, P. & Purcell, A. (2024) Speech–language therapy services for children with cleft palate: A scoping review on continuity of care. *International Journal of Language & Communication Disorders*, 59, 2423–2440. <https://doi.org/10.1111/1460-6984.13091>

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This paper was developed to explore current evidence surrounding continuity of care in speech–language therapy services for children with cleft palate. Specifically, the scoping review sought to map how informational, management, and relational continuity are conceptualised and operationalised across cleft care pathways. This work provided foundational insight into existing models of service delivery and identified key gaps and inconsistencies in the literature, thereby informing the direction and focus of subsequent empirical components of the thesis.

**Statement of Contribution to Co-Authored Published Paper**

This study was designed and written in collaboration with my supervisors, Professor Patricia McCabe and Professor Alison Purcell.

**Speech–language therapy services for children with cleft palate: A scoping review on continuity of care**

Mikaela Bow

Patricia McCabe

Alison Purcell

Correspondence concerning this article should be addressed to Ms. Mikaela Bow, Faculty of Medicine and Health, The University of Sydney, Camperdown, NSW 2006, Australia.

[mikaela.bow@sydney.edu.au](mailto:mikaela.bow@sydney.edu.au)

## REVIEW

# Speech–language therapy services for children with cleft palate: A scoping review on continuity of care

Mikaela Bow<sup>1</sup>  | Patricia McCabe<sup>1</sup>  | Alison Purcell<sup>1,2</sup> 

<sup>1</sup>Faculty of Medicine and Health, The University of Sydney, Camperdown, NSW, Australia

<sup>2</sup>School of Health Sciences, The University of Western Sydney, Camperdown, NSW, Australia

## Correspondence

Mikaela Bow, Faculty of Medicine and Health, The University of Sydney, Camperdown, NSW 2006, Australia.  
Email: [mikaela.bow@sydney.edu.au](mailto:mikaela.bow@sydney.edu.au)

[Correction added on 5 September 2024, after first online publication: The abbreviation for ‘cleft palate with or without a cleft of the lip’ has been corrected from ‘CP+L’ to ‘CP±L’ throughout the article, in this version.]

## Abstract

**Background:** Children with a cleft palate (with or without a cleft of the lip) often require speech–language therapy (SLT) services to achieve age-appropriate speech. For many children, this involves attending SLT services delivered by both specialised cleft team speech–language therapists (SLTs) and a local, community or school-based SLT. Given that these two different SLTs are typically involved in the child’s care, it is important to ensure that effective communication, coordination and collaboration occur between them. This is known as continuity of care. While continuity of care in speech therapy has not generally been evaluated, in medicine it has been shown to improve health outcomes.

**Aims:** To identify what is known from the existing literature about processes for continuity of care in cleft speech therapy services.

**Methods & Procedures:** A scoping review was conducted using Arksey and O’Malley’s methodological framework. Seven databases were searched including MEDLINE via OVID, EMBASE via OVID, CINAHL via EBSCO, PsychINFO, Scopus, Web of Science and SpeechBITE. Covidence was used to screen 733 initial articles and five studies met the inclusion criteria. Thematic analysis was conducted to identify global and subthemes.

**Main Contribution:** Five papers were included for analysis. These identified two salient characteristics of cleft speech therapy continuity of care: (1) it is a continuous cycle and (2) it is complex. Although parents are integral team members, cleft and community SLTs must be responsible for initiating communication and collaborating. Furthermore, cleft SLTs have a crucial role in disseminating information and resources, as well as offering guidance and support.

**Conclusions & Implications:** Given that only five studies were included, there is a need to gather more information from parents, community SLTs, and cleft SLTs to understand their experiences and perspectives. From what is known, there are breakdowns in the processes needed for continuity of care, including confusion regarding roles and responsibilities, and community SLTs lacking

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confidence, knowledge and support. Recommendations are provided to facilitate improvements in continuity of care.

#### KEYWORDS

cleft palate, continuity of care, speech therapy

#### WHAT THIS PAPER ADDS

##### *What is already known on the subject*

- Children with CP±L often require SLT from two different clinicians including a specialised cleft SLT and a community or school-based SLT. As such, it is important that effective communication and collaboration occur between them to ensure continuity of care.

##### *What this study adds to the existing knowledge*

- This study identified a breakdown in the processes necessary for continuity of care. According to community SLTs, there is a discrepancy between their expectations and current practices. This scoping review has identified two critical characteristics of effective continuity of care: (1) it operates as an ongoing cycle; and (2) it is a complex, multifaceted endeavour.

##### *What are the practical and clinical implications of this work?*

- This study highlights the importance of cleft and community SLTs taking the initiative in communication and collaboration, rather than solely relying on parents as intermediaries. By offering practical recommendations, this research aims to improve continuity of care, potentially fostering greater awareness and advancements in service delivery.

## BACKGROUND

Cleft palate with or without a cleft of the lip (CP±L) is a congenital abnormality that impacts speech development (Kuehn & Moller, 2000). A cleft of the palate can occur with or without a CP±L and is a relatively common craniofacial birth defect, occurring in approximately 1 in 1000 live births globally (Salari et al., 2022). Children with CP±L undergo surgical procedures to repair their cleft. One of the primary aims of this surgery is normal resonance (appropriate nasal and oral balance on vowels and consonants) and no abnormal nasal air emission during speech (Kummer et al., 2012). However, for a child's speech to be both acceptable and intelligible, they also need age-appropriate acquisition of sounds (Sell et al., 2015).

Achievement of successful speech outcomes varies, with many children with CP±L not acquiring age-appropriate speech before they start school (Britton et al., 2014; Willadsen et al., 2019). By the age of 5, typically developing

children are expected to have acquired nearly all speech sounds, however, children with CP±L are frequently not meeting these expectations (Britton et al., 2014; Willadsen et al., 2019). For example, in the UK at 5 years of age, only 48% of children had speech within the normal range (Britton et al., 2014). Similarly, in Denmark and Sweden, there was a large gap in the percentage of consonants correct (PCC) of 5-year-old children with and without CP±L with only 22% of children with CP±L achieving age-appropriate PCC scores at age 5 (Willadsen et al., 2019). From these studies, it is clear that a large group of children with CP±L do not have typical speech at age 5.

As a result of these ongoing speech difficulties, many children with CP±L need to access speech therapy to improve their speech outcomes. In a US study of 212 pre-schoolers with CP±L, Hardin-Jones and Jones (2005) found that 68% of children had received or were waiting for speech intervention. Participation in speech therapy has been shown to benefit individuals with CP±L and

for a review of interventions see Sand et al. (2022). As a result, speech–language therapists (SLTs) are an essential member of the cleft team and work with children with CP±L from birth to adulthood. The SLT's role is to assess feeding and speech and language development, provide recommendations for management, including the need for speech intervention, provide speech (and/or language) intervention, monitor progress and evaluate surgical success and treatment outcomes (American Cleft Palate–Craniofacial Association (ACPA), 2018). SLTs can be involved at various times in a child with CP±L's life including prenatally, postnatally, pre-surgery, post-surgery, annual review assessments and provision of speech therapy intervention as warranted. SLTs may therefore provide long-term support which continues until the child's speech, resonance and language are no longer of concern or the child is discharged from the cleft team's care. Discharge from the cleft service is based on the cleft team's model of care and is country and system dependent. For example, in Australia, each state and hospital have their own model of care including how often and when children are seen, what services are provided and when they are discharged from the cleft service.

The responsibilities of the SLT, as outlined above, are typically divided among two separate types of SLTs, those in cleft-specific roles and those in the community. For example, children may travel large distances to attend centralized cleft services that have a specialized cleft SLT, and it is not expected that a child will attend ongoing intervention with this service, rather a local SLT will provide regular treatment services. Second, cleft speech–language therapy (SLT) services may not have the capacity to offer intervention for all children with cleft.

Therefore, the first type of service is provided by SLTs who work as part of a specialized, multidisciplinary cleft team in a tertiary facility, often a children's hospital. These SLTs work with a relatively higher ratio of children with CP±L as part of their caseload. The cleft SLT is typically responsible for conducting reviews of the child's speech and providing recommendations for management, including recommending speech intervention and making appropriate referrals (possibly to a local, community SLT).

The second type of service is provided by SLTs who work in a community setting such as a school, a primary health care setting or private practice. They usually work with a much smaller number of children with CP±L as their caseload typically consists of people with a diverse range of communication and/or swallowing difficulties. When working with children with CP±L, their role is typically to conduct intervention and this may include speech intervention as well as intervention in other areas, such as language. Due to the diversity of their caseload, the community SLTs may provide services for children with

CP±L infrequently and will have varied levels of experience working with children with CP±L (Bedwinek et al., 2010). Bedwinek et al. (2010) reported that community SLTs infrequently saw children with CP±L. In fact, 28% of respondents had never seen a child with a CP±L, and 55% had seen five or fewer children with CP±L. Only 17% had seen more than six children with CP±L over their careers. Unsurprisingly, Alighieri et al. (2021) reported community SLTs felt 'unprepared' to work with children with CP±L.

Given that children with CP±L typically interact with these two types of SLT services, it is important that the processes of continuity of care need to occur to ensure optimal speech outcomes (Golding-Kushner, 2001; Peterson-Falzone et al., 2016). Continuity of care involves informational continuity, management continuity and relational continuity and includes processes such as appropriate transfer of information to link providers, consistent and coordinated delivery of services and sharing management plans (Haggerty et al., 2003). For SLTs working with children with CP±L, informational continuity includes the appropriate transfer of information such as details about past or planned surgeries, speech, language and other health provider's assessment results, speech therapy and other health provider's goals and progress, and the family's experiences and preferences.

Given that children with CP±L often attend services with multidisciplinary providers, management continuity is also of high importance. Management continuity requires services to be provided in a timely and complementary manner, particularly from those who could potentially work at cross purposes, such as community and cleft team SLTs (Haggerty et al., 2003). This may include sharing the child's management plan, understanding the roles and responsibilities of the SLTs involved and ensuring services are both timely and complementary.

Lastly, relational continuity involves an ongoing relationship between the patient and their providers and bridges past, current and future care (Haggerty et al., 2003). Depending on the cleft team, a child may see several cleft SLTs on their journey from birth to adulthood. Similarly, a child may be involved with a number of community SLTs.

The ACPA has developed resources to guide practice in the area of cleft. In ACPA's Standards of Approvals for cleft teams (ACPA, 2022), it acknowledged that the cleft palate team needs to ensure that care is coordinated and that it is provided in a consistent manner with appropriate sequencing of assessment and treatment. These care guidelines recommend that the specialist cleft team requires a process for exchanging information with the relevant community team members including schools and other health professionals to promote continuity of patient care (ACPA, 2022). These models of collaboration should change over time due to the changing needs of the individual as well as

availability of resources (Dailey & Wilson, 2015; Grames, 2004). Elsewhere, such as in generalist and special medical fields, improved continuity of care has resulted in improved health outcomes and significant reductions in mortality for individuals (Cabana & Jee, 2004; Pereira Gray et al., 2018).

Currently, little is known about continuity of care between cleft expert and community SLTs. Given the paucity of information in this area, a scoping review was undertaken to summarize what is known on the topic in regard to cleft SLT services to identify gaps in the existing literature, and to make recommendations for future research (Arksey & O'Malley, 2005). The question this scoping review aimed to answer was, 'What is known from the existing literature about processes for continuity of care in cleft speech therapy services?'

## METHOD

A scoping review of the literature was conducted utilizing Arksey and O'Malley's (2005) methodological framework, with the addition of Levac et al.'s (2010) suggested advancements. Scoping reviews are useful for topics with emerging bodies of literature, such as continuity of care in cleft speech therapy services, as it enable us to map the area of study and identify gaps for further research (Arksey & O'Malley, 2005). In conducting the scoping review, the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) guidelines were adhered to ensure comprehensive and transparent reporting of the search process and selection criteria.

Author 1 currently works as both a cleft specialist and a community SLT and this research is part of her PhD. Authors 2 and 3 have more than 20 years of experience each as researchers. Author 2 has seen children with CP±L in community practice and author 3 has previously worked as a cleft specialist SLT.

### Stage 1: Articulating the research question

As Arksey and O'Malley (2005) suggested, the first step in a scoping review was to articulate the research questions. This scoping review aimed to answer the question: 'What is known from the existing literature about processes for continuity of care in cleft speech therapy services?'

### Stage 2: Identifying relevant studies

The second step involved searching for relevant studies to include in the scoping review. This involved conducting

searches of electronic databases, reference lists, the grey literature and hand searching of key journals. The electronic databases searched included MEDLINE via OVID, EMBASE via OVID, CINAHL via EBSCO, PsychINFO, Scopus, Web of Science Core Collections and SpeechBITE. No language restrictions were applied in the search strategy. Searches were conducted for the terms in Table 1 in the keywords, title and abstracts.

Additionally, hand-searching of reference lists and key journals was undertaken. The *International Journal of Speech–Language Therapy*, *The Cleft Palate–Craniofacial Journal*, *The Journal of Speech–Language and Hearing Research*, *The International Journal of Language and Communication Disorders* and the *American Journal of Speech–Language Pathology* were hand-searched. The search also included some grey literature sources, such as dissertations. Reference lists from relevant papers were also hand-searched and alerts were created on Google Scholar and Web of Science. The original search was conducted in May 2020 and a new search of the databases was completed in May 2023 to ensure any new articles were included.

### Stage 3: Study selection

The third step involved selecting relevant studies to be included. Initially, inclusion and exclusion criteria were decided by all three authors in line with Levac et al. (2010) suggestion. The first and third authors then independently reviewed the title and abstracts using the Covidence platform to determine eligibility for inclusion if they met the inclusion and exclusion criteria (Table 2). If there was a disagreement between the two reviewing authors, the second author determined final inclusion of the article using the procedures of the Covidence platform, leading to a two out of three agreement for that paper. All articles deemed relevant from the title and abstract screen then went through the process of a full text screen and those that met the inclusion criteria were included for analysis. Throughout this process, authors met at the beginning, midpoint and final stages of the abstract review process to refine the search strategy as needed (Levac et al., 2010). See Table 3 for author roles.

### Stage 4: Charting the data

Stage 4 involved the research team collectively identifying what data was to be extracted in order to answer the research question. The extraction fields included: authors, year of publication, study location, methodology and participants.

**TABLE 1** Key search terms used in the review.

Keywords	Synonyms/alternative words terms
Cleft*	CP* OR VPI OR VPD OR CLP OR velopharyngeal insufficiency* OR velopharyngeal dysfunction
Speech and language patholog*	Speech therap* OR speech patholog* OR speech and language therap* OR speech–language therap* OR speech–language patholog* OR speech intervention
Child*	Paediatric* OR pediatric*
Continuity of care	Handover* OR patient handoff OR communication OR patient transfer OR continuity of patient care OR transition* OR pathway*

**TABLE 2** Inclusion and exclusion criteria.

Inclusion criteria	Exclusion criteria
<p>Articles were included if:</p> <ul style="list-style-type: none"> <li>• Children with CP±L and/or velopharyngeal insufficiency and were syndromic or non-syndromic</li> <li>• Speech therapy services via any role (e.g., parent, AHA, teacher, community nurse)</li> <li>• Continuity of care, pathway, handover, communication, patient transfer or transition</li> <li>• Original research published in journals or research theses and dissertations</li> </ul>	<p>Articles were excluded if they:</p> <ul style="list-style-type: none"> <li>• Only concerned patients over 18 years of age</li> <li>• Not written in English</li> <li>• Not peer-reviewed</li> <li>• Only included surgical intervention</li> <li>• Not a full paper (e.g., abstract available only)</li> </ul>

**TABLE 3** Role of the authors.

Stages (Arksey & O'Malley, 2005; Levac et al., 2010)	Author(s) responsible
<i>Stage 1: Articulating the research question</i>	Authors 1–3
<i>Stage 2: Identifying relevant studies</i>	
Creating the search strategy	Authors 1–3
Searching the electronic databases	Author 1
Hand searching key journals	Authors 1–3
Searching the grey literature	Authors 1–3
Searching reference lists	Authors 1–3
<i>Stage 3: Study selection</i>	
Determining inclusion/exclusion criteria	Authors 1–3
Review of title and abstracts	Authors 1 and 3
Determining inclusion if there was a disagreement	Author 2
Full text screening	Authors 1 and 3
<i>Stage 4: Charting the data</i>	Authors 1–3
<i>Stage 5: Collating, summarizing and reporting the results</i>	Authors 1–3
Qualitative appraisal of journal articles	Authors 1–3

## Stage 5 Collating, summarizing and reporting the results

Stage 5 involved thematic analysis of the articles using Braun and Clarke's (2022) six-step approach to identify and synthesize themes. All authors were involved in the thematic analysis. The authors were certified practising speech therapists. The first step involved the first author familiarizing themselves with the data through immersion. This was followed by step 2 where the first author generated initial codes in the margins of the papers. Step 3 consisted of all authors meeting to search for global

themes, which were further divided into subthemes. Step 4 involved all authors reviewing the themes to ensure they accurately reflected the data. Step 5 consisted of 'defining and refining' the themes to ensure they capture the 'essence' of what each theme is about. Step 6 involved writing up the findings of the analysis relating to your research question (Braun & Clarke, 2022).

## Qualitative appraisal of journal articles

A qualitative appraisal of the identified studies was conducted following Levac et al.'s (2010) recommendation

to include an evaluation of methodological quality as an extension to Arksey and O'Malley's (2005) framework (Levac et al., 2010). The method for evaluating the methodological quality of the included papers was determined by the type of methods included. The studies were either appraised using the Consolidated Criteria for Reporting Qualitative Research, a 32-item checklist (COREQ; Tong et al., 2007) or the Critical Appraisal Checklist for a Questionnaire Study (Roever, 2015).

## RESULTS

### Identifying relevant studies and study selection

The search yielded 733 titles and abstracts after duplicates were removed including 24 hand-searched articles. Of the 733 articles, 696 studies did not meet the inclusion criteria and 37 studies remained for full text review. Two reviewers (authors 1 and 2) independently conducted 37 full-text reviews. Of these, there was one paper in which there was disagreement between the two reviewers. This paper was then reviewed by author 3 using the Covidence platform. In total, five met the inclusion criteria and were included for analysis. Three consisted of semi-structured interviews, one was a survey study and the fifth consisted of a participatory action research cycle. These studies were published between 2006 and 2022. A PRISMA flowchart is provided in Figure 1 outlining the search results. Distribution of publications by author, year of publication, country of origin, methodology and participants are shown in Table 4.

### Qualitative appraisal of journal articles

The COREQ (Tong et al., 2007) was used to evaluate the quality of three qualitative studies. The first domain evaluated the research team and reflexivity. All three studies provided information regarding the interviewer, credentials, occupation, gender and experience. Only one study included information about the relationship with participants (Alighieri et al., 2020) and one study provided details about the interviewer characteristics (Alighieri et al., 2022). Domain 2 covered aspects of the study design. All three studies covered most aspects of this domain, however, in two studies it was unclear if any participants were excluded or withdrew. None of the three studies provided details about the presence of non-participants during the interviews or whether repeat interviews were conducted. Two studies provided information regarding data saturation and none of the three studies returned the data transcripts to participants for review. Lastly, all three stud-

ies covered most aspects of domain 3 which evaluated the data analysis and findings. The full appraisal is shown in Appendix A1.

One study was evaluated using a Critical Appraisal Checklist for a Questionnaire Study (Roever, 2015). A questionnaire collecting quantitative and qualitative data appeared to be an appropriate method to answer the research question (Bedwinek et al., 2010). Additionally, inter-rater reliability was high when conducting thematic analysis. No piloting was reported prior to disseminating the questionnaire and there was no evaluation of the reliability of the study. A sample size of 332 people appeared sufficiently large and representative of the population. The results, conclusion and discussion appeared to align with the results. The full appraisal is shown in Appendix B1. One study was unable to be appraised using any published tool due to the methodology utilized by the researchers (Prathanee et al., 2006).

### Creating, summarizing and reporting the results

Thematic analysis generated three global themes, as well as seven subthemes addressing the aim 'To identify what is known from the existing literature about processes for continuity of care in cleft speech therapy services'. The global themes and subthemes can be seen in Figure 2.

#### Global theme 1: Continuity of care: Whose role is it?

This theme addressed the roles and responsibilities of the cleft team SLTs, and community SLTs in working with children with CP±L. This global theme was further divided into two subthemes, each reflecting distinct perspectives on the division of roles and responsibilities between the speech therapists.

1. **That's not my role, it's yours.** This subtheme highlights the perspectives of parents and community SLTs regarding their expectations of specialist cleft SLTs. Community SLTs reported they thought the specialist cleft SLTs roles included initiating initial communication, and providing appropriate information, such as the child's specific treatment program and education about cleft. Community SLTs also believed that specialist SLTs should be responsible for conducting any communication assessments for children with cleft palate. Parents said they expected the community SLT to communicate with the cleft team and reach out if they had insufficient experience. Exemplars included:

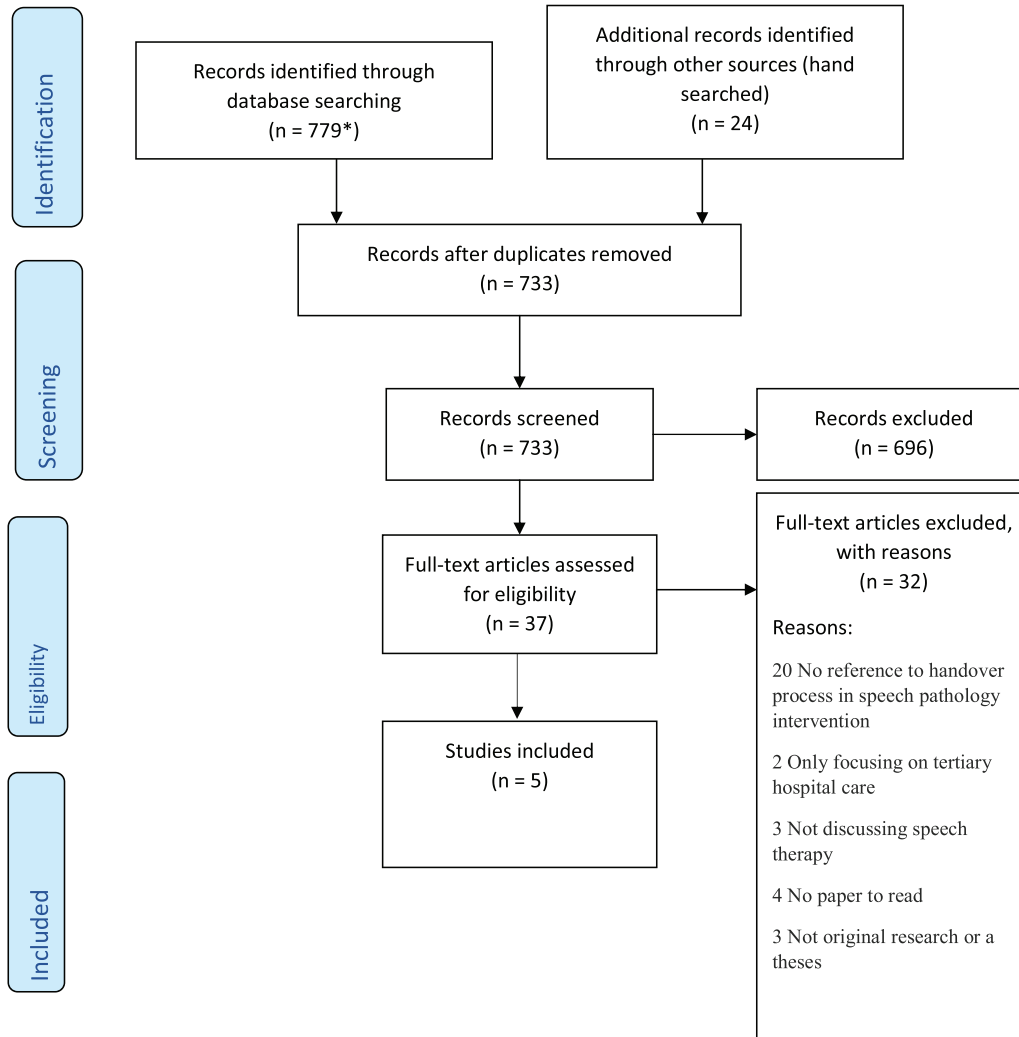
TABLE 4 Charting the data.

Authors	Title	Date of publication	Country of origin	Methodology	Participants	Study aim
Bedwinek, Kummer, Rice and Grames	Current training and continuing education needs of preschool and school-based speech-language pathologists regarding children with cleft lip/palate	2010	USA	Survey study	565 preschool and school-based SLTs	To obtain information regarding the education and experience of preschool and school-based SLTs regarding the assessment and treatment of children born with CP±L and to determine their continuing education needs in this area.
Prathanee, Dechongkit and Manochioping	Development of a community-based speech therapy model for children with cleft lip/palate in Northeast Thailand	2006	Thailand	Participatory action research with three cycles	In Stage 1, the participants consisted of: <ul style="list-style-type: none"> <li>• 23 SLTs</li> <li>• 2 doctors</li> <li>• 2 nurse speech assistants</li> <li>• 4 nurses</li> <li>• 1 special educator</li> </ul> In Stage 2, the participants consisted of: <ul style="list-style-type: none"> <li>• 105 participants including nurses, healthcare providers from Primary, Secondary and Tertiary Healthcare Units, community leaders, teachers, parents of children with cleft lip/palate, and chair of the Northeastern Cleft Lip/Palate Parents Club</li> </ul> In Stage 3, it consisted of: <ul style="list-style-type: none"> <li>• 8 SLTs who were interested in cleft care</li> </ul>	To outline a community-based model for speech disorders for children with cleft lip/palate in Northeast Thailand

(Continues)

TABLE 4 (Continued)

Authors	Title	Date of publication	Country of origin	Methodology	Participants	Study aim
Alighieri, Bettens, Verhaeghe and Van Lierde	Speech diagnosis and intervention in children with a repaired cleft palate: A qualitative study of Flemish private community speech-language pathologists' practices	2022	Belgium	Qualitative study: Semi-structured interviews	11 community SLTs	To investigate the practice patterns of Flemish private community SLTs when diagnosing and treating active or compensatory speech errors in children with a CP±L
Alighieri, Bettens, Verhaeghe and Van Lierde	Speech diagnosis and intervention in children with a repaired cleft palate: A qualitative study of Flemish private community speech-language pathologists' practices	2021	Belgium	Qualitative study: Semi-structured interviews	18 community SLTs	To explore how community SLTs perceive and experience the provision of speech intervention to child with CP±L
Alighieri, Peersman, Bettens, Van Herreweghe and Van Lierde	Parental perceptions and expectations concerning speech therapy-related cleft care—a qualitative study	2020	Belgium	Qualitative study: Semi-structured interviews	11 parents	To provide in-depth insight into parental perceptions and expectations concerning speech therapy-related cleft care



\* search conducted May 2020 = 729, search conducted May 2023 = 50 (additional searches)

FIGURE 1 PRISMA flow chart.

- a. 'The (community) SLTs desired that each patient was seen by a specialized cleft team SLT and to receive an appropriate plan' (Alighieri et al., 2021: 745).
  - b. 'Some therapists reported that they found it the responsibility of the cleft team SLPs to take a first step in this communication' (Alighieri et al., 2021: 745).
2. **This is my role.** This subtheme outlines how community SLTs recognize their role is to communicate with the school and support the child in their school environment. Some community SLTs also acknowledged their role was to have sufficient knowledge about the speech development of children with cleft palate to provide appropriate speech therapy intervention. Exemplars included:
- a. 'The school-based SLP can be the liaison between the cleft team and the school team' (Bedwinek et al., 2010: 409).

- b. 'Community SLPs felt responsible about having sufficient knowledge on a CP±L' (Alighieri et al., 2021: 745).

## Global theme 2: Help: I'm a generalist

This was a dominant theme and was related to community SLTs identifying barriers that impacted their ability to support children with cleft palate. This global theme was further divided into five subthemes.

1. **I don't have the knowledge or experience.** Community SLTs raised a lack of knowledge and experience in working on speech disorders related to cleft and raised the desire for more education. They raised that they infrequently saw children with CP±L and

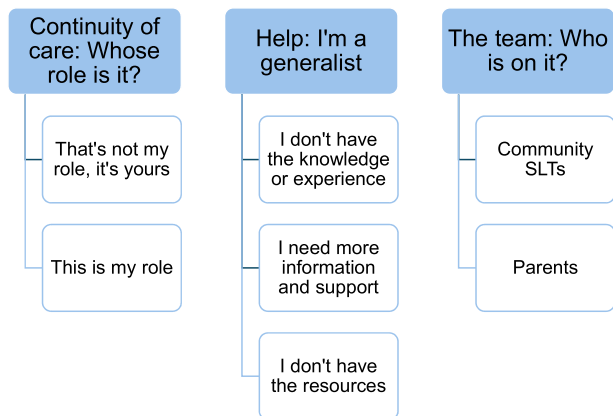


FIGURE 2 Global themes and subthemes.

acknowledged gaps within academic programs, lack of knowledge on cleft, their desire for education on this topic and not knowing where to access this information. Parents also raised the SLTs knowledge of cleft as a key factor in selecting an appropriate SLT. Exemplars included:

- a. *'All the SLPs (regardless of their educational level) reported that they had received few theoretical and practical information on cleft palate speech during their educational programmes' (Alighieri et al., 2021: 745).*
  - b. *'Professional self-doubt emerged from an unfamiliarity and lack of experience with the population of children with a CP±L' (Alighieri et al., 2021: 745).*
  - c. *'Experience with this population was a determining factor in their (parents') selection of a SLP' (Alighieri et al., 2020: 5).*
2. **I need more information and support.** Community SLTs wanted more information from the cleft team SLT regarding the child they were working with. They also identified the desire for more support and communication from the cleft team SLT. This included wanting support with creating treatment programs, as well as more communication and collaboration in general. Exemplars included:
    - a. *'(There was a theme of need for) collaboration with specialists' (Bedwinek et al., 2010: 412).*
    - b. *'(Some SLPs) expressed some concerns about the availability of the cleft team SLPs. In these cases, the community SLPs reported to receive either a late response or no response at all' (Alighieri et al., 2021: 745).*
    - c. *The determination of the first treatment goals felt like an obstacle to them because of the lack of information and/or instructions from the hospital and their own lack of knowledge and experience. (Alighieri et al., 2022: 58).*

3. **I don't have the resources.** This subtheme identified that community SLTs reported a lack of resources to work with children with CP. Examples included:
  - a. *'In rural areas, public school funding is very limited. Therefore, equipment like See-Scape, nasometry are hard to acquire' (Bedwinek et al., 2010: 411).*
  - b. *'Scientific papers were considered to be difficult to read, not useful for their clinical practice and expensive to access' (Alighieri et al., 2022: 60).*

### Global theme 3: The Team: who is on it?

This theme is related to where the community SLT and parents fit within the child's team for the processes for continuity of care. Two subthemes were identified.

1. **Community SLTs.** The community SLTs position within the child's team was a subtheme. From the perspective of community SLTs, there appeared to be feelings of inferiority to the cleft team and a need to be considered a part of the child's cleft team. Exemplars included:
  - a. *'The results revealed that community SLPs put themselves in a subordinate position towards the cleft team SLPs' (Alighieri et al., 2021: 748).*
  - b. *'I think it is imperative for a school speech–language pathologist to be part of the child's cleft lip/palate team in order to best plan therapy services' (Bedwinek et al., 2010: 419).*
2. **Parents.** Lastly, this subtheme outlined the role and responsibilities of parents within the child's team. This included outlining the importance of parental involvement in intervention and home practice, as well as ensuring parents did not take on inappropriate responsibilities such as being the liaison between the cleft SLT and community SLT. Parents mostly expressed a desire to be involved. An example:
  - a. *'Situations where parents acted as intermediaries (between cleft and community SLTs) were considered to hinder adequate information transfer' (Alighieri et al., 2021: 745).*

## DISCUSSION

This scoping review sought to describe the continuity of care in cleft palate speech therapy services. Prior to commencing the review, it was expected there would be limited literature on the topic and as such, the search would need to be broad and inclusive. To manage this potential paucity, a systematic scoping review was conducted to provide an overview of continuity of care. It was evident that research

in this area is still emerging as only five studies met the inclusion criteria. These studies included three exploring the perspectives of community SLTs, one exploring the perspectives of parents and the fifth outlining an approach for reaching and treating children with CP±L in remote areas.

Three global themes emerged; 'Continuity of care: Whose role is it?', 'Help: I'm a generalist' and 'The Team: Who is on it?'. These themes describe the uncertainty that exists regarding roles and responsibilities in relation to the processes involved in continuity of care including communication and collaboration, as well as the community SLTs need for more support and knowledge. Thus, the available literature highlights that, from what is known, there are breakdowns in the processes needed for continuity of care and community SLTs do not feel confident working with children with CP±L.

### Improving continuity of care

This review shows the need for improved processes in continuity of care for children with CP±L attending speech therapy services due to the reported breakdowns in the processes involved in the three types of continuity of care: (1) informational continuity, (2) management continuity and (3) relational continuity. In this study, breakdowns in informational continuity occurred as the community SLTs identified that they needed information from the cleft SLT's including details about the child's past and upcoming surgeries, as well as specific treatment recommendations. Considering that a cleft SLT has access to this information this appears to be an appropriate suggestion. Information regarding a treatment program may be guided by a cleft SLT and would align with the ACPA's (2018) recommendations for the cleft SLT to collaborate with and provide guidance to community SLTs.

Parents also have a key role to play in assisting informational continuity as they can provide information about activity limitations and participation restrictions that the child may experience because of their speech difficulties (McKean et al., 2012). Evidence-based practice involves integrating scientific literature, clinician expertise and clinical data, as well as the child and family's informed preferences (American Speech & Hearing Association (ASHA), 2005). This may include understanding life events, such as starting school, or the challenges the child may be facing, and the funding available which can directly impact access to community services. Ensuring that community SLTs, cleft SLTs and parents collaborate to share information and determine an appropriate management plan aligns with a family-centred, holistic approach and their input as a team would be invaluable in this

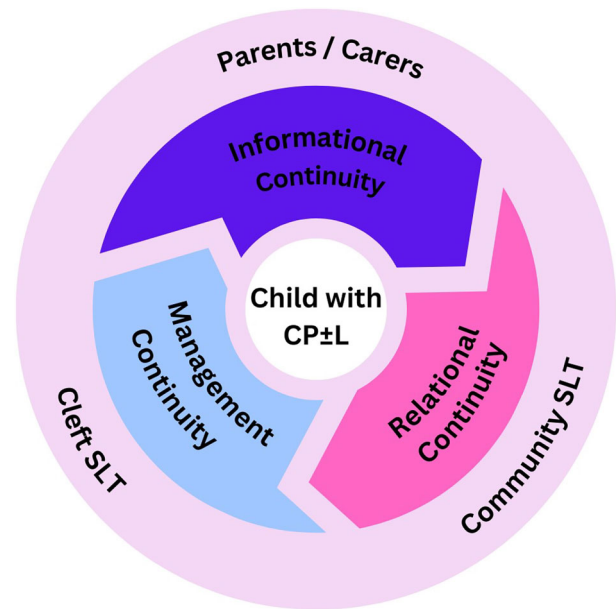


FIGURE 3 Continuity of care in cleft speech therapy services.

evidence-based decision-making process (Cronin et al., 2020).

In terms of management continuity, community SLTs identified the need for improved collaboration with cleft SLTs as well as assistance with the child's treatment plan (Bedwinek et al., 2010). Improved collaboration may assist in ensuring that there are clearly defined roles and responsibilities and services are complementary to one another, however, this needs to be bidirectional. In order for the service to be coordinated, the community SLT needs to be aware of upcoming cleft appointments and the cleft SLT needs to have information regarding the child's progress in the community. Both have a responsibility to ensure adequate management continuity of care occurs.

Lastly, in terms of relational continuity, despite the number of speech therapy providers that a child with cleft palate and their families may engage with, this review found that relational continuity was raised the least, with only parents reporting that it was important for a community SLT to have a connection with them and their child (Alighieri et al., 2020). More information is needed to better understand the experiences of relational continuity from children with CP±L and their families. Figure 3 describes the relationships in continuity of care in cleft SLT services.

It could be argued that continuity of care extends beyond the three types of continuity mentioned above, particularly in specialized areas within a field, such as cleft. Community SLTs reported a lack of knowledge, resources and experience when working with children with CP±L and this could be considered a component of informational continuity that extends beyond a specific child. Given

cleft SLTs have access to such education, knowledge, and resources, as identified by community SLTs, it may be that this should be the responsibility of cleft SLTs. Such role definition may be seen as challenging to the cleft SLT's scope of practice and workload as they may be required to communicate with, provide education to, and give guidance to numerous community SLTs. There needs to be further investigation into the barriers that exist to make this a reality in current practice.

As described previously, community SLTs reported they lacked the knowledge to treat children with CP±L. A number of factors are likely contributing to this including prior education in the cleft, difficulty accessing current evidence and infrequency of treating children with CP±L. The remembered lack of training SLTs had in their initial tertiary education and their desire for continuing education in this area have been previously documented (Bedwinek et al., 2010; Vallino et al., 2008). Although all participants in Bedwinek et al. (2010) had received some graduate education in cleft, only 19% had pursued continuing education in this area. This raises a few questions. Firstly, is it a lack of education provided, or is it more so related to when the training occurred, such as the number of years between the training to and working with a child with CP±L. Additionally, whether one or two children on a clinician's caseload would warrant continuing professional development in this area.

Should cleft-specific skills be expected of a new graduate? As the field develops, the areas that SLTs work in are evolving to include more low-incidence pathologies and more diverse groups including, for example, in mental health, and with long-COVID, increasing the number of varied, specialized population groups. This presents an increasing challenge to provide adequate, timely education and practical experiences in the broad range of areas that a SLT may encounter across in their career. It is likely that initial training can only provide underpinning skills and, as discussed, cleft team SLTs have a role in providing ongoing education to community SLTs. Lastly, community SLT's self-reported lack of knowledge is likely impacted by the opportunities or lack of opportunities, they have to work with children with CP±L on a regular basis (Bedwinek et al., 2010). Even if education is provided, it is challenging to retain knowledge unless it is utilized.

The findings presented here suggest the ACPA (2022) recommendations are not being met. ACPA described standards including the composition and functioning of cleft teams to enhance team care. The standards recommend regular meetings with core team members to promote collaboration and ensure coordination of patient care. The definition of a 'core team member' is vague and it is unclear whether this includes community professionals, such as SLTs, who play a vital role in achieving optimal outcomes

for children with CP±L in many cleft care models worldwide. The parameters of care (ACPA, 2022) also described the team's role including referral to other professionals and ensuring appropriate transfer of information to the individual's community services. This scoping review suggests we do not know if this parameter is currently being met.

## Limitations

While expected, the primary limitation of this study was the small number of papers included for analysis. Despite comprehensive search terms (Table 1), it is possible that additional terms may have retrieved additional papers. For example, we searched child\*, paediatric\*, pediatric\*, the addition of girl\* or boy\*, may have found one or two additional papers. Furthermore, there is a scarcity of data regarding the experiences and expectations of cleft SLTs and parents.

## Possible approaches to improve continuity of care

As evidenced by the themes described in this paper, there are repeated calls for improvement in continuity of care in cleft speech therapy services. Models of collaboration have been described to improve communication between the two SLT teams. For example, an interactive web-based system with the aim of facilitating communication between the cleft team SLT and community SLT (Karnell et al., 2005). The website was reported to consist of a public section which contains educational information, and a private section which had patient-specific information and was designed to enhance collaboration. This website was reported to have had elements of evidence-based knowledge translation, such as educational materials and also includes processes that promote continuity of care, such as shared management plans. The effectiveness of this approach requires evaluation to determine the extent it impacts speech outcomes for children with CP±L.

Using another approach, Grames and Stahl (2017) tested a collaborative care program that aimed to support the needs of community SLTs and meet the therapy needs of children with CP±L through collaboration. In this program, the cleft SLT invited the parent and community SLT to a session where they all listened to the child's speech, reviewed and classified speech sound errors and developed therapy targets. Therapy was mapped out, therapy techniques trialled, and home practice discussed. All 107 community SLTs involved agreed or strongly agreed that they felt better prepared to work with a child with CP±L following the program. Cleft team SLTs



reported that it also enhanced communication between the two SLTs. These proposed models of collaboration are examples of ways forward; however, more research needs to be conducted to evaluate the effectiveness of such models in improving continuity of care and effectiveness of improving speech outcomes.

Despite the standards detailed by ACPA (2022) and the models of collaboration described above, this scoping review highlights a breakdown in the processes needed for continuity of care for children with cleft palate. To date, research has focused largely on the community clinician and their needs rather than the family and child's needs. Hearing from parents, and cleft team SLTs will assist in identifying the barriers and facilitators affecting continuity of care and assist in identifying the processes needed for continuity of care to occur.

Communication between cleft and community SLTs needs to extend beyond 'handover'. Handover is defined as the 'transfer of professional responsibility and accountability for some or all aspects of care for a patient, to another person... on a temporary or permanent basis' (Haikerwal et al., 2006). As discussed, a child with CP±L is often linked in with both a community and cleft SLT simultaneously and neither relinquishes responsibility until discharge from their service. Therefore, considering the child is continuously, cyclically and often simultaneously, linked in with both services, we suggest that continuity of care should not be a 'transfer of responsibility', rather it should be a continuous, shared responsibility between cleft and community SLTs.

This scoping review leads to the conclusion that there are two salient characteristics of continuity of care: (1) it is a continuous cycle and (2) it is complex. This responsibility should not fall upon parents. As a profession, SLTs need to include this responsibility in our care of children with CP±L to ensure that this process is continuous, cyclical and collaborative rather than unidirectional, as handover implies. Grames and Stahl's (2017) collaborative treatment program, Karnell et al.'s (2005) collaborative web-based system and ACPA's (2022) standards and parameters of care are starting points for planning how this should work in clinical practice. These models of collaboration promote family-centred practice and patient-centred learning and address the issues that raised by community SLTs in this scoping review.

## Recommendations

To improve continuity of care a set of recommendations were developed. The recommendations take into consideration the evidence that is available on continuity of care, including ACPA's (2022) standards and parameters

of care documents, the models of collaboration described previously (Grames & Stahl, 2017; Karnell et al., 2005), as well as the authors' own clinical experiences. These recommendations include the following.

### 1. Collaborative care:

Under the collaborative care approach, effective communication forms the backbone of a cohesive care strategy. Both cleft and community SLTs have a responsibility to initiate continuous and cyclical communication, actively involving parents in the process and decision-making. This ensures that all stakeholders are informed and engaged in the child's care journey.

Joint sessions represent a proactive approach to collaboration, drawing upon Grames and Stahl's (2017) model. These sessions might involve inviting community SLTs to participate in assessments, reviews, and therapy sessions, leveraging advancements in telehealth platforms for increased accessibility. Expertise can then be shared seamlessly across locations, enhancing the quality and continuity of care.

Incorporating videos into collaborative care practices offers an additional layer of support for local SLTs and parents alike. Recording speech assessments or intervention sessions (with consent) can provide them with valuable insight into the child's progress and allow for remote evaluation. Instructional videos created by cleft SLTs demonstrating specific cues and strategies could provide a valuable resource for the community SLT and parents, empowering them with practical techniques to support the child's speech development effectively.

### 2. Education and resources:

Access to education and resources is essential in ensuring community SLTs are able to provide evidence-based assessment and intervention. As cleft SLTs hold specialist knowledge in cleft, they have a responsibility to provide ongoing education to community SLTs. This could be in the form of workshops, webinars or recorded talks.

Development of specific CP±L checklists have the potential to ensure consistency in assessments and interventions. By providing a structured framework, these checklists can guide community SLTs in conducting assessments and formulating intervention goals, thereby enhancing the quality of care delivered to children with CP±L.

Recognizing the nuances of local health and education systems, establishment of a regionally based special interest group can allow for individualized assistance tailored to the unique challenges and requirements of different jurisdictions and localities. By fostering collaboration and

sharing best practices within the community, such groups can facilitate continuous learning and professional growth among cleft and community SLTs, ultimately improving outcomes for patients.

### 3. Systems:

To make the aforementioned recommendations feasible and realistic, good systems need to be in place. Both generic and local templates, developed by cleft SLTs, could serve as valuable tools for streamlining communication processes. These templates could encompass various forms of correspondence, from educational emails addressing frequently asked questions to outlining specific speech elicitation strategies. By standardizing communication, templates ensure consistency and clarity in information exchange between cleft SLTs and their counterparts in the community.

Implementing automated systems, such as emailing prescheduled pre-appointment questionnaires to local SLTs, can facilitate data collection and streamline the coordination of care. By automating such routine tasks, resources can be allocated more effectively, enabling cleft SLTs to focus on delivering high-quality care and support to children with CP±L.

Cloud storage solutions may offer a useful centralized platform for secure data sharing and collaboration. Confidential cloud drives could provide a secure environment for storing and sharing large files, such as videos, while ensuring compliance with local data confidentiality policies. By establishing shared folders with selective, secure access, cloud storage could enhance accessibility and facilitate information exchange within the care network.

## CONCLUSIONS

This review has identified a breakdown in the processes necessary for continuity of care in cleft palate SLT services including confusion regarding roles and responsibilities, and community SLT's lacking confidence, knowledge and support. Continuity of care is a continuous cycle and is complex and multifaceted. While parents are integral team members, both cleft and community SLTs should be responsible for ensuring management, relational and informational continuity of care occurs. Furthermore, cleft SLTs have a crucial role in disseminating information and resources, as well as offering guidance and support, leveraging their expertise and access to such valuable assets. Given only five studies were included, there is a need to gather further insights from parents, community SLTs and cleft SLTs to gain a deeper understanding of their perspectives and expectations. This will assist in

identifying the facilitators and barriers impacting continuity of care and assist in providing recommendations to improve optimal speech therapy care for children with cleft palate.

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## CONFLICT OF INTEREST STATEMENT

The authors declare no conflicts of interest.

## DATA AVAILABILITY STATEMENT

The data that supports the findings of this study are available in the appendices in the supplemental data online.

## ORCID

Mikaela Bow  <https://orcid.org/0009-0007-0569-5189>

Patricia McCabe  <https://orcid.org/0000-0002-5182-1007>

Alison Purcell  <https://orcid.org/0000-0002-4623-4086>

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## APPENDIX A

TABLE A1 Consolidated criteria for reporting qualitative research (COREQ)

Authors	Aligheri et al. (2022)	Aligheri et al. (2021)	Aligheri et al. (2020)
Title	Speech diagnosis and intervention in children with a repaired cleft palate: A qualitative study of Flemish private community speech-language pathologists' practices	From excitement to self-doubt and insecurity: Speech-language pathologists' perceptions and experiences when treating children with a cleft palate	Parental perceptions and expectations concerning speech therapy-related cleft care—A qualitative study
<b>Domain 1: Research team and reflexivity</b>			
<b>Personal characteristics</b>			
Interviewer/facilitator	First author conducted interviews	Primary investigator (first author) conducted interviews	Fourth author conducted interviews
Credentials	SLT	SLT	SLT
Occupation	SLT	SLT	SLT
Gender	Female	Female	Female
Experience and training	4 years' experience treating children with CP	4 years' experience treating children with CP	Not on a cleft team
Relationship with participants	Unclear	Unclear	No relationship prior to interviews
Relationship established	Unclear	Unclear	Unclear
Participant knowledge of the interviewer	Unclear	Unclear	Unclear
Interviewer characteristics	Findings of the study may have been influenced by peer relationships between interviewer and participants	Unclear	Unclear
<b>Domain 2: Study design</b>			
<b>Theoretical framework</b>			
Methodological orientation and Theory	Inductive thematic analysis	Inductive thematic analysis	Thematic analysis
<b>Participant selection</b>			
Sampling	Purposive	Purposive	Unclear
Method of approach	Informational flyer distributed through social media. They were asked to contact the primary investigator	Advertised on social media and through a platform for Dutch-speaking SLTs. They were asked to contact the primary investigator	Parents were recruited from the multidisciplinary craniofacial team at Ghent University Hospital
Sample size	11 female SLTs	18 female community SLTs	11 parents of 9 children
Non-participation	Unclear	Two were excluded due to being a member of a cleft team and one cancelled due to personal circumstances	Unclear

(Continues)



TABLE A1 (Continued)

<b>Setting</b>			
Setting of data collection	Face-to-face in a quiet location convenient to participants	Face-to-face in a location convenient to participants	Participants' home
Presence of non-participants	Unclear	Unclear	Unclear
Description of sample	Dutch-speaking private community SLTs based in Flanders that had treated at least one child with a repaired CP	Community SLTs that had treated at least one child with a repaired CP	Parents that had a child with a repaired CP that had participated in at least 1 year of speech therapy focusing on cleft-related problems and did not have an associated syndrome, cognitive difficulty or learning disability. Parents could not have any type of craniofacial anomaly themselves
<b>Data collection</b>			
Interview guide	Semi-structured interviews with an interview guide which was attached to the article	Semi-structured interview with an interview guide (included as an appendix). This was reviewed after the first nine interviews to allow for continuous exploration of themes	Semi structured interviews with an interview guide
Repeat interviews	No	No	No
Audiovisual recording	Audio recording	Audio recording	Audio recorded
Field notes	Minimal field notes	Minimal field notes	No
Duration	53–74 min	53–153 min (mean = 98 min)	Not recorded
Data saturation	Yes	No	Yes
Transcripts returned	No, however, a member check was performed during the interview	No	No
<b>Domain 3: Analysis and findings</b>			
<b>Data analysis</b>			
Number of data coders	Three	One	Two
Description of coding tree	Yes	Yes	No
Derivation of themes	Derived from data	Derived from data	Derived from data
Software	NVivo	NVivo	NVivo
Participant checking	Yes	No	No
<b>Reporting</b>			
Quotations presented	Yes	Yes	Yes
Data and findings consistent	Yes	Yes	Yes
Clarity of major themes	Yes	Yes	Yes
Clarity of minor themes	Yes	Yes	Yes

## APPENDIX B

TABLE B1 Critical appraisal checklist for a questionnaire study

<b>Authors</b>	<b>Bedwinek et al. (2010)</b>
<b>Title</b>	<b>Current training and continuing education needs of preschool and school-based speech-language pathologists regarding children with cleft lip/palate</b>
<i>Research question and study design</i>	
Was a Q the most appropriate method?	Yes
<i>Validity and reliability</i>	
Have claims for validity been made and are they justified?	No No information on how questionnaire was validated.
Have claims for reliability been made and are they justified?	Yes High inter-rater reliability during thematic analysis
<i>Format</i>	
Are example questions provided?	Yes
Did the questions make sense, and could the participants in the sample understand them? Were any questions ambiguous or overly complicated?	Yes
<i>Piloting</i>	
Are details given about the piloting undertaken?	No
Was the questionnaire adequately piloted in terms of method and means of administration on people who were representative of the study population?	No
<i>Sampling</i>	
Was the sampling frame for the definitive study sufficiently large and representative?	Yes
<i>Distribution, administration and response</i>	
Was the method of distribution and administration reported?	Yes
Were the response rates reported, including details of participants who were unsuitable for the research or refused to take part?	Yes
Have any potential response biases been discussed?	No
<i>Coding and analysis</i>	
What sort of analysis was carried out and was this appropriate? (e.g., correct statistical tests for quantitative answers, qualitative analysis for open ended questions)	Quantitative data were analysed using the Statistical Package for Social Sciences (SPSS) software Qualitative data were analysed thematically
<i>Results</i>	
Were all relevant data reported?	Yes
Are quantitative results definitive (significant), and are relevant non-significant results also reported?	n.a.
Have qualitative results been adequately interpreted (e.g., using an explicit theoretical framework), and have any quotes been properly justified and contextualized?	Yes Yes
<i>Conclusions and discussion</i>	
Have the researchers drawn an appropriate link between the data and their conclusions?	Yes
Have the findings been placed within the wider body of knowledge in the field (e.g., via a comprehensive literature review), and are any recommendations justified?	Yes

**Chapter 3: Experiences of cleft team speech-language  
pathologists in continuity of care: Building relationships  
beyond broadcasting**

**Chapter 3: Experiences of cleft team speech-language pathologists in continuity of care:  
Building relationships beyond broadcasting**

This chapter consists of the published version of the following article, reprinted with permission:

Bow, M., McCabe, P., & Purcell, A. (2025). *Experiences of cleft team speech-language pathologists in continuity of care: Building relationships beyond broadcasting*. Cleft Palate-Craniofacial Journal, 1-11. <https://doi.org/10.1177/10556656251348297>

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This chapter contributes to the overall aim of the thesis by exploring the lived experiences of cleft team speech-language pathologists (SLPs) in delivering care within a continuity of care framework. As a first step in addressing the breakdown in continuity of care between cleft SLTs, community SLPs and parents outlined in the scoping review, this qualitative study sought to understand how cleft team SLPs conceptualise and enact informational, management, and relational continuity in their clinical practice. It also examined the barriers and facilitators of collaboration with community SLPs and parents, providing crucial insight into the realities of care coordination and communication in cleft services.

### **Statement of Contribution to Co-Authored Published Paper**

This study was designed and written in collaboration with my supervisors, Prof Patricia McCabe and Prof Alison Purcell.

## **Experiences of Cleft Team Speech-Language Pathologists in Continuity of Care: Building Relationships Beyond Broadcasting**

Mikaela Bow

Patricia McCabe

Alison Purcell

Correspondence concerning this article should be addressed to Ms. Mikaela Bow, Faculty of Medicine and Health, The University of Sydney, Camperdown, NSW 2006, Australia.

[mikaela.bow@sydney.edu.au](mailto:mikaela.bow@sydney.edu.au)

# Experiences of Cleft Team Speech-Language Pathologists in Continuity of Care: Building Relationships Beyond Broadcasting

Mikaela Bow, BSpPath<sup>1</sup> , Patricia McCabe, BAppSc, PhD<sup>1</sup> ,  
and Alison Purcell, BAppSc, MAppSc, PhD<sup>2</sup> 

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## Abstract

**Objective:** This study investigated the experiences of cleft team speech-language pathologists (SLPs) in relation to continuity of care (CoC). The research aimed to understand the processes used to promote CoC, identify key barriers and facilitators, and examine how cleft team SLPs collaborate with community SLPs and parents.

**Design:** A qualitative study using semi-structured interviews was conducted with Australian and New Zealand cleft team SLPs. Thematic analysis was used to identify key themes.

**Setting:** The study focused on SLPs working within specialized multidisciplinary cleft teams in hospital settings across Australia and New Zealand, as well as their interactions with community-based SLPs and parents.

**Participants:** Ten specialized cleft team SLPs participated in this study. Experience in speech-language pathology ranged from 8 to 47 years (mean = 23.5 years), and their experience in cleft services ranged from 3 to 29 years (mean = 15.4 years).

**Results:** Six key themes were developed: (1) The Multifaceted Role of the cleft team SLP, (2) Ways We Communicate and Collaborate, (3) Our Relationships, (4) Community SLPs are Central, (5) Families are Key, and (6) The Landscape of Healthcare is Not Working.

**Conclusions:** This study highlights the importance of relationships in promoting CoC for children with cleft palate. While cleft team SLPs provided education and support, communication was often one-directional. A co-facilitative model, fostering shared decision-making between cleft and community SLPs, could strengthen collaboration. Parents also play a key role as advocates and active participants in therapy. Strategies such as joint sessions, structured mentoring, and intentional follow-up may enhance engagement.

## Keywords

cleft palate, speech therapy, continuity of care

## Introduction

The intricate care required for children with cleft palate with or without a cleft lip (CP ± L) spans multiple disciplines, including speech-language pathology, plastic surgery, orthodontics, audiology, and psychology.<sup>1</sup> Speech-language pathologists (SLPs) play a pivotal role from birth to adolescence, addressing the unique challenges related to communication and feeding that arise from a cleft. Their involvement within the multidisciplinary team is essential for effectively managing these issues.<sup>2</sup> Many children benefit from SLP services provided by both specialized cleft team SLPs and a more local community or school-based SLP.<sup>3</sup>

In addition to the care provided by both specialized and community SLPs, parents are crucial partners in their child's journey through cleft care and speech development.<sup>4</sup>

They may be required to advocate for their child, assist with monitoring their overall progress, conduct therapy at home, and communicate their child's needs to the SLPs and other professionals providing services to their children. This partnership not only enhances the effectiveness of treatment, but may also empower parents to navigate the complexities of cleft speech

<sup>1</sup> Faculty of Medicine and Health, The University of Sydney, Camperdown, NSW, Australia

<sup>2</sup> School of Health Sciences, Western Sydney University, Campbelltown, NSW, Australia

### Corresponding Author:

Mikaela Bow, Faculty of Medicine and Health, The University of Sydney, Camperdown, NSW 2006, Australia.

Email: mikaela.bow@sydney.edu.au

care. Given the involvement of the different SLPs and the integral role of parents, ensuring effective communication, coordination, and collaboration among all parties is vital. This process is known as continuity of care (CoC).

CoC is an essential aspect of healthcare delivery that emphasizes the seamless, uninterrupted, and comprehensive provision of services throughout a patient's journey.<sup>5</sup> Three types of CoC are outlined in the literature including informational, management, and relational continuity.<sup>6</sup> In the context of cleft speech services, CoC is crucial given the complex and multifaceted nature of treatment required for children with cleft palate.<sup>3</sup> Using this framework of CoC and applying it to cleft speech services, informational continuity entails ensuring accurate and timely sharing of critical information about a child's medical history, therapy goals, and progress across specialized cleft team SLPs, community SLPs, and parents. This dimension is vital to maintaining a unified and consistent approach to care, especially when therapy transitions between providers or settings. Management continuity consists of coordinating care delivery across disciplines and settings to ensure complementary and cohesive interventions. This includes aligning therapy plans, scheduling follow-ups, and integrating input from other healthcare providers. Management continuity is crucial in preventing gaps in care that can arise from fragmented systems. Lastly, relational continuity is about building trust and long-term relationships among SLPs, parents, and other stakeholders involved in a child's care. Relational continuity fosters effective communication and collaboration, ensuring that parents feel supported and engaged in their child's therapy.

There has been limited research investigating CoC between specialized SLPs, community SLPs, and parents.<sup>3</sup> Despite the scarcity of literature on this topic, existing studies consistently highlight breakdowns in CoC processes between specialized cleft team SLPs and community-based SLPs. According to community SLPs, discrepancies exist between their expectations and current practices, which impacted how they effectively collaborated with specialized cleft team SLPs.<sup>7</sup> For example, community SLPs reported confusion regarding roles, limited support, and insufficient information-sharing, all of which negatively impacted collaborative efforts. Community SLPs also identified the need for improved collaboration with cleft team SLPs as well as assistance with the child's treatment plan.<sup>8</sup>

Despite the pivotal role of cleft team SLPs, their perspectives and experiences on the facilitators, barriers, and nuances to CoC remain underexplored. Understanding these factors and the challenges faced by cleft team SLPs in relation to CoC including differences in expectations and resource availability, can provide valuable insights into improving service delivery. Additionally, exploring the facilitators that promote effective CoC can help identify best practices and strategies that enhance collaboration among all stakeholders, including parents and other healthcare professionals. By investigating these aspects, targeted interventions that address existing barriers and leverage strengths within the system may be developed. Ultimately, a more comprehensive understanding

of the experiences and perspectives of cleft team SLPs is essential for fostering an integrated approach to cleft care that ensures consistent, high-quality support for children and their families throughout their journey.

This qualitative research aimed to explore the experiences and insights of cleft team SLPs regarding CoC for individuals with CP ± L. By capturing their perspectives, challenges, and strategies, the study seeks to address critical gaps in understanding the complexities of delivering comprehensive care in this context. It also seeks to identify barriers and facilitators to inform the development of effective solutions and best practices to enhance CoC. The research questions were as follows:

1. What does communication and collaboration currently look like between cleft team SLPs, community SLPs, and parents?
2. What processes are currently being used by cleft team SLPs to ensure CoC with community SLPs, and parents?
3. What are the barriers impacting CoC?
4. What are the facilitators for promoting CoC?

## Methods

### Procedure

The study was approved by the Human Research Ethics Committee of The University of Sydney (2023/105). An invitation to participate in the study was sent via email to a special interest group comprised of Australian and New Zealand (ANZ) SLPs who were part of a cleft palate team at a tertiary facility. Informed consent was obtained before the interviews commenced and a demographic survey was completed. The interviews were conducted by the first author. Interview topics and questions were discussed across all three researchers and the interviewer had piloted the interview with the third author prior to conducting the interviews with the participants. An interview guide was created and used (see Appendix A). Throughout the interview sessions, open-ended questions were posed to explore the SLPs' experiences, challenges, and perspectives related to CoC within cleft teams.

### Participants

The study recruited SLPs based in Australia and New Zealand, who had been actively working on a cleft team for a minimum of 12 months. Purposive sampling was utilized to recruit participants who could provide insights into CoC in the context of working with children with cleft palate.

### Data Collection and Analysis

Semi-structured interviews were conducted with the selected SLPs. The interviews were held via Zoom to accommodate the geographical dispersion of participants across Australia and New Zealand. The Zoom recording and transcription features were employed to capture the discussions

comprehensively. Contemporaneous field notes were taken to record notable non-verbal communication. The interviews ranged between 29 and 70 min with an average duration of 44 min. The sample size for this study was determined based on the number of participants who were available and able to be recruited within the study's timeframe and criteria, out of approximately 40 eligible SLPs who worked on a multidisciplinary cleft team.

A reflexive thematic analysis approach following Braun and Clarke's (2022) methodology was used to analyze the de-identified, transcribed interviews. This systematic analysis process involved the three authors reading and re-reading the transcripts to become familiar with the data. Once this was complete, all three authors generated initial codes utilizing the qualitative analysis software, NVIVO. Once this was completed, the codes were organized into themes that captured important aspects of the data. Step four consisted of all authors reviewing the themes to ensure they accurately represented the data. The fifth step involved defining and refining the themes. Lastly, step six involved writing up the themes and their significance in relation to the research question.

### Trustworthiness

Several strategies were employed to ensure the trustworthiness of this research. Member checking was conducted by offering participants the opportunity to review their interview transcripts. Of the 10 participants, 5 requested to review their transcripts, and 0 participants provided comments. Consequently, no changes were made during this process.

Researcher triangulation was used to strengthen the credibility and reliability of the data analysis. The research team were all SLPs but had diverse professional backgrounds, which reduced potential bias in coding and provided an enriched interpretation of the findings. The first author, who also conducted the interviews, is a mid-career SLP currently completing a PhD with experience working within a cleft team and in private practice. The first author had a prior professional relationship with all participants due to their joint involvement in the ANZ cleft group. This relationship was managed with reflective journaling to minimize bias. The second author was not a member of a cleft team, providing an external perspective to the analysis. This author is a senior clinical researcher with expertise in speech disorders across the lifespan and experience in both qualitative and quantitative research methodologies. The third author is also a senior researcher with experience conducting cleft-related speech-language pathology research and was previously a member of different cleft teams, adding further depth and cleft-specific insights to the analysis.

## Results

### Participants

Ten specialized cleft team SLPs participated in this study. Their years of experience as SLPs ranged from 8 to 47 years,

with a mean of 23.5 years. The participants had worked in providing specialized speech-language pathology in the area of cleft palate for 3 to 29 years, with a mean of 15.4 years. In terms of education, the participants' highest qualifications included seven with a specialist Bachelor's degree (which is professional entry in Australia and New Zealand), and three with higher degrees. Nine of the ten participants reported receiving instruction on how to work with patients with cleft during their university training, and three of ten had engaged in additional specialized training related to cleft care after graduation. All ten participants had prior and/or current experience working outside of a cleft team, including roles in hospital private practice, community health, and school settings.

### Themes

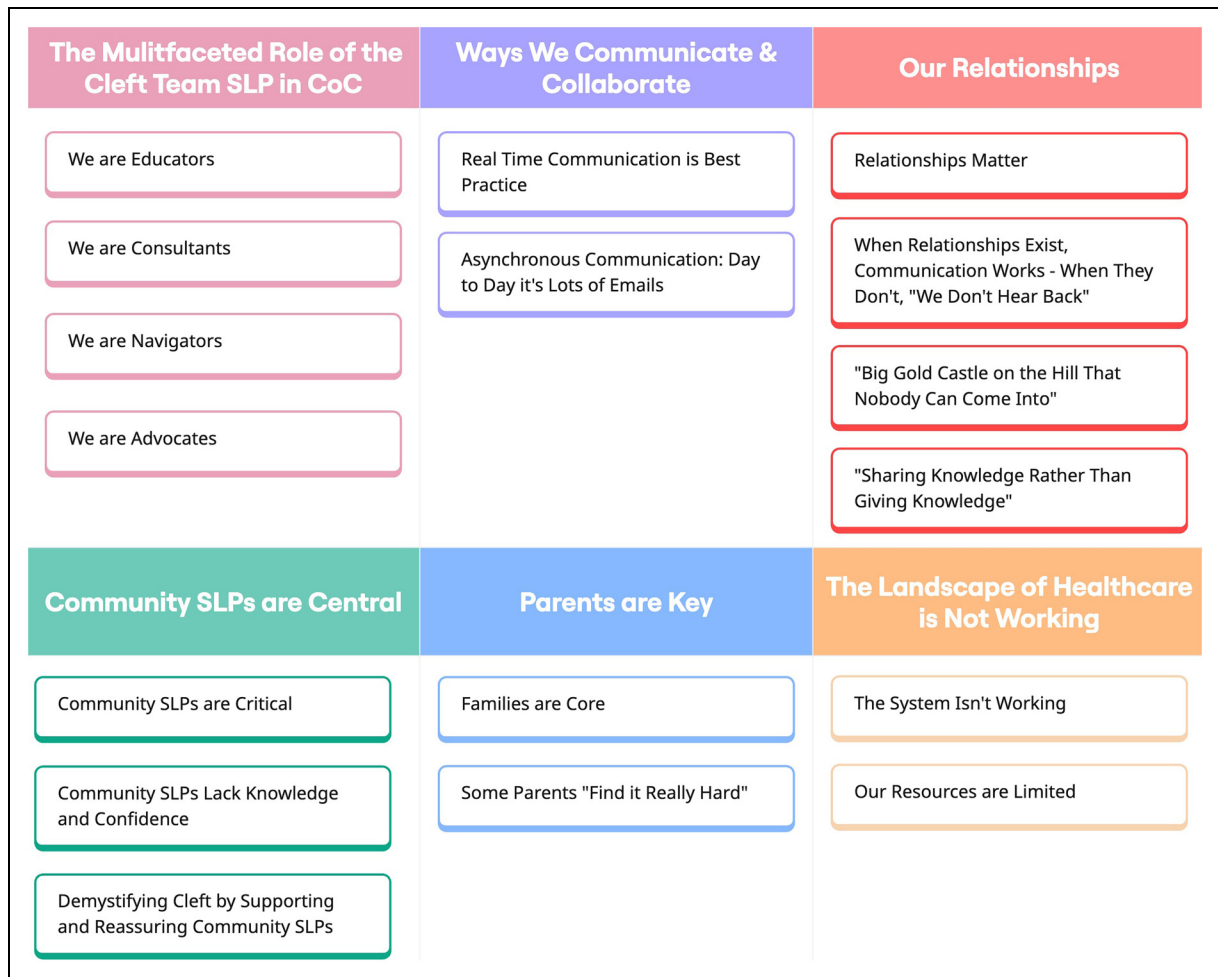
Thematic analysis of the interviews generated 6 themes: (1) The Multifaceted Role of the Cleft Team SLP in CoC, (2) Ways We Communicate and Collaborate, (3) Our Relationships, (4) Community SLPs are Central, (5) Parents are Key, and (6) The Landscape of Healthcare is Not Working. These global themes were comprised of 17 subthemes. A summary of themes and subthemes can be seen in Figure 1.

### *Global Theme One: The Multifaceted Role of the Cleft Team SLP in CoC*

This global theme captures the diverse and interconnected roles that cleft team SLPs undertake to facilitate CoC for children with cleft palate. Beyond direct clinical intervention, SLPs reported they have many critical roles including functioning as educators, consultants, navigators, and advocates, working collaboratively with families, community SLPs, and multidisciplinary teams.

*We are Educators.* SLPs believed they play a critical role as educators with parents and community SLPs. This educational responsibility was seen as central to their work and included providing professional development (PD) to community SLPs through workshops, lectures, and ongoing support. They explained that this education was aimed at enhancing the capacity of community clinicians to manage children with cleft-related speech difficulties. As P4 shared, "*We also do some teaching with ... the non-cleft therapists in the community.*" Educational resources, such as publications on therapy techniques, were also provided as P10 stated, "*I don't just talk to them... but I will send them the publication on the therapy techniques.*" Their reported aim was to provide clinicians with the knowledge and support needed to manage cleft-related speech issues, explaining that introducing cleft speech principles can make others feel more comfortable reaching out for further advice, "*Letting them know who we are and giving them a bit of an introduction to cleft speech and therapy principles can make them feel comfortable contacting us*" (P6).

SLPs also described their role as educators for parents, working to build their understanding of their child's condition,



**Figure 1.** A summary of themes and subthemes.

development, and the journey ahead. They explained that education begins early in many services, starting at birth and continuing as the child develops. P1 shared, “*We have it (parent education) at birth, we have parent education at 6 months, and then we have ongoing contact.*” Simplifying complex information for parents was also identified with P5 explaining, “*You educate them a little bit phonetically and about how speech sounds are made, and then you take them into how do your kids make speech sounds.*” Respondents also provided structured educational opportunities for parents, such as workshops. P5 shared, “*I’m just starting to run some parent workshops.*”

**We are Consultants.** SLPs described their role as primarily consultative, operating both as external consultants, who provide guidance and mentorship to community SLPs and parents, and internal consultants, who play a key role in decision-making within the multidisciplinary cleft team.

### External Consultants

As external consultants, SLPs offered specialized expertise to support community clinicians in delivering therapy, rather

than acting as the primary treating clinician. P9 explained, “*I feel like a lot of other people... view that we’re the main clinician in the child’s care when really... our service here is very consultative, and we don’t have that much capacity to see children regularly or ongoing.*” This consultative role was closely tied to processes that aimed to ensure COC, as cleft team SLPs provided guidance to help local therapists manage cleft-related speech issues effectively. They also reported they often acted as mentors or informal supervisors, sharing their expertise to try to build the confidence and skills of local clinicians. As P8 described, their role was “*almost like a bit of a mentor coach, (an) informal supervision arrangement.*” Another SLP highlighted the importance of their advisory role, saying, “*My role has largely been an advisory role, so I advise speech therapists out in the field*” (P5). This process included offering tailored advice on therapy strategies, troubleshooting challenges, and sharing specialized knowledge that might not otherwise be available in the local setting. “*I think it’s really having that maybe extra level of knowledge and experience to have a bit more of a consultative role and to help guide community therapists and parents,*” P9 explained.

### Internal Consultants

Internally, SLPs perceived themselves as integral to hospital-based discussions regarding intervention planning, particularly in guiding surgical decision-making within the multidisciplinary cleft care team at the hospital. They explained that their involvement is key in determining appropriate interventions at different stages of care. As P9 stated, *“I think that’s a big part of our role... helping with decision making around intervention at different time points.”* They saw their role as particularly significant in guiding decisions related to surgical interventions. P9 highlighted this role by explaining, *“I find, in our hospital anyway, they (surgeons) are relying hugely on us to guide them around decision making for surgical intervention for secondary speech surgery.”*

**We are Navigators.** SLPs described themselves as navigators, guiding families, and coordinating care, and ensuring CoC between families, community SLPs, and other professionals involved in the cleft care journey. Communication with parents was a key aspect of this navigational role, with SLPs describing they often served as the primary point of contact for families for the multidisciplinary team. P3 explained, *“We find we speak to a lot of that coordination. And part of that is because of that relationship we have. Parents speak to us, and they open up about other things.”* This relationship facilitated a sense of trust and support, enabling cleft team SLPs to act as liaisons between families and the wider care team. The respondents mentioned they also assist in navigating complex systems such as the (Australian) National Disability Insurance Scheme (NDIS). As P7 explained, *“A lot of that has been NDIS... Helping manage with NDIS and helping them navigate these kinds of really tricky pathways.”*

**We are Advocates.** Many SLPs saw advocacy as integral to their role, ensuring that children with cleft palate receive the care and support they need, even in complex situations. This advocacy often required effective communication and collaboration with and between families, community SLPs, and multidisciplinary teams, aligning with processes that promote CoC. P9 highlighted this role, stating, *“I think that’s a big part of our role... advocacy, and helping to steer or making helping with decision making around intervention at different time points.”* This advocacy included working closely with families to ensure their voices were heard and that the child’s best interests were prioritized. P6 highlighted, *“Are they getting the right kind of therapy or not, and then trying to, in a politically correct way, help the parents advocate for... improving the focus of therapy.”* SLPs also found themselves in a position where they needed to advocate for children whose families may not be fully engaged in their care. P6 explained, *“If families are not engaged... but the child does need help, then looking at how can we advocate for that child.”* In these situations, SLPs reported seeking alternative ways to support the child, such as through school-based therapies or through other agencies.

In addition to working with families, SLPs also reported advocating for children within multidisciplinary teams. They saw themselves as pivotal in raising concerns and communicating with the team and family, particularly when coordinating care across different providers. As P3 stated, *“I think we are pivotal in raising concerns to the whole team, first of all to our whole team, and to the family too if they then have other providers.”* This advocacy aimed to ensure that all aspects of the child’s care, from speech to hearing and beyond, are addressed in a coordinated way. *“I think we kind of reach across (the team) a little bit...with the hearing and everything else and try and keep everything in place to advocate for these kids”* (P7).

### Global Theme Two: Ways we Communicate and Collaborate

Respondents used a variety of communication methods to collaborate with community SLPs and parents, ensuring CoC. These methods included both real-time communication, such as phone and video calls, and asynchronous communication, such as emails and written reports.

**Real-Time Communication is “Best Practice”.** Real-time communication, including phone calls, video calls, and face-to-face meetings, was valued for its immediacy and ability to foster collaborative discussions. SLPs used phone and video calls to discuss assessment findings, treatment plans, and shared goals. P5 explained, *“I either do phone call or a zoom call or they come in and see me with the patient.”* These direct interactions allowed for immediate clarification, problem-solving, and relationship-building. For more complex cleft-related speech issues, real-time collaboration was seen as particularly beneficial. SLPs reported facilitating joint sessions where community SLPs attended therapy or assessment appointments, either in person or remotely. P8 highlighted the importance of this approach: *“Having them joining in via Teams for a joint session... that’s... best practice for some of that complex cleft speech... errors.”* However, coordinating schedules for real-time communication could be challenging. SLPs acknowledged that time constraints and conflicting commitments sometimes made it difficult to arrange phone calls or joint sessions, particularly when community SLPs had busy caseloads or worked in different time zones.

**Asynchronous Communication: “Day-to-Day It’s Lots of Emails”.** Due to scheduling difficulties, emails and written reports were often the default mode of communication between cleft and community SLPs. These asynchronous methods provided flexibility and ensured that all clinicians had access to the same clinical information. P8 acknowledged this reality: *“All that other stuff I’ve talked about takes time and it takes everyone’s diaries lining up. To be honest, it probably looks day-to-day like lots of emails.”*

SLPs highlighted the importance of sharing written reports with community clinicians to ensure that therapy recommendations were clear and accessible. P2 explained, *“If it’s a child that we’re reviewing as part of routine... processes, I would always be sending a copy of my correspondence or report... sent to the family and cc’ing the community speech pathologist.”* Recognizing that written reports alone might be insufficient for complex cases, cleft team SLPs sometimes reported taking a proactive approach to follow-up communication. P2 described their method, saying, *“If there’s additional complexity and I really would like to discuss that, I’ll usually follow that (the report) up with a phone call or an email to that child’s (community) speech pathologist.”* This ensured that any areas of uncertainty or concern could be addressed collaboratively.

To further facilitate communication, many SLPs provided direct contact details to parents and encouraged local SLPs to reach out when needed. P2 shared, *“I’ll often say to parents, here’s my card. If your speech pathologist has any questions, please, please get them to give me a call or email me.”*

### Global Theme Three: Our Relationships

**Relationships Matter.** In their work with children with cleft palate, SLPs consistently emphasized the importance of fostering strong, respectful relationships. They worked to create a “non-threatening” environment, where they could share knowledge without appearing to assert authority. P2 explained, *“Usually once you’ve broken those walls down and you’re non-threatening in sharing of your knowledge, people (community SLPs) are usually really happy to collaborate.”* SLPs explained that relationships with community SLPs and families should be built on trust and mutual respect, where all parties felt free to discuss successes as well as difficulties. P8 noted, *“I need to make a connection with this family before they take on anything I say.”* Once these relationships were established, respondents said that openness and honesty flourished. P2 shared, *“And once you build that relationship, people are quite happy to be... fairly candid... So, it’s just about building the relationship where you feel comfortable to make mistakes together and to learn together.”* This sense of mutual learning and support helped to create a collaborative environment where both SLPs and families could work towards the child’s progress without fear of judgment.

**When Relationships Exist, Collaboration Works – When They Don’t, “We Don’t Hear Back”.** SLPs recognized that effective communication with community SLPs was essential for CoC, and when strong relationships existed, communication tended to be two-way and collaborative. Many described positive experiences where community SLPs reached out regularly to discuss cases, ask questions, and share progress. These successful exchanges often occurred with community SLPs who managed a higher volume of cleft cases and felt more comfortable contacting specialists: *“They probably have contacted a few times and know that it’s not so scary once they do.”*

When these relationships were in place, the communication was two-way, collaborative, and helped ensure everyone—including the family—was on the same page.

However, when relationships were not well established, SLPs frequently reported communication breakdown. Many expressed frustrations at the lack of follow-up, despite their efforts to provide handovers and support. P4 noted, *“We very rarely hear back from them, which is a big frustration. So it tends to be one way.”* This issue was particularly evident with private therapists, as opposed to those who worked in public health, who might be constrained by time pressures or the demands of a fee-for-service model. P7 explained, *“I think I’m less likely to hear back from private (therapists). I don’t know the reason. P3 described their efforts, stating, “For them to actually share back is hard and I’m working hard at that... By communicating outwards, I’m hoping I get inwards.”*

**“Big Gold Castle on the Hill That Nobody Can Come Into”.** A barrier to CoC identified by cleft-team SLPs was the perception that specialized cleft services were often viewed as being in a “big gold castle on the hill” (P8). This perception represented a divide between cleft team SLPs and community SLPs, which appeared to impact effective collaboration. P8 captured this sentiment, explaining, *“There’s this perception that (hospital) is this big gold castle on the hill that nobody can come into, that’s not approachable. And I think if you do call us, we’re gonna tell you you’re doing a bad job or you’re not skilled enough to be doing the job.”* The SLPs perception was that this belief discouraged community SLPs from reaching out for support, creating a barrier that made it difficult to ensure consistent and collaborative care for children with cleft palate.

SLPs recognized that this traditional medical model where specialists are seen as the sole experts, was not conducive to building strong, collaborative relationships. P3 rejected this approach, stating, *“We take this medical model of ‘we’re an expert, come to me and I shall lay hands.’ No, we can’t do that anymore for so many reasons...”*

The perception of a hierarchical dynamic also impacted families, who respondents thought sometimes saw hospital-based cleft teams as superior to their local therapists. P2 explained, *“I think it’s really important that families understand and respect what their local speech pathologist is giving... there can be that ‘Oh, they’re the experts at the hospital and they know better, and my speechie is just implementing.”* This mindset appeared to undermine the crucial role and skillset of community SLPs in delivering therapy and supporting families.

**“Sharing Knowledge Rather Than Giving Knowledge”.** SLPs advocated for a collaborative approach to knowledge exchange, emphasizing the importance of “sharing knowledge rather than giving knowledge” (P8). This perspective highlighted the idea that knowledge transfer should be two-way and highlights that community SLPs and parents also bring valuable knowledge to the team. They consistently mentioned avoiding

presenting themselves as the “experts” who held all the answers and instead emphasized a “partnership.” P2 emphasized this, “that sort of concept that the hospital is the experts and actually letting the families know we’re very much a partnership, in partnership with their local clinician.”

### Global Theme Three: Community SLPs are Central

**Community SLPs are Critical.** Community SLPs were also recognized as pivotal in ensuring CoC for children with cleft palate. Respondents said they saw community SLPs as integral members of the care team, often having more consistent and long-term interactions with the child and their family. P9 explained, “I think they’re (community clinicians) probably one of the two most important people in their cleft team along with their parents... because they’re going to have that degree of frequency that the tertiary cleft team are not going to have.” SLPs acknowledged that community therapists provided essential support between specialized cleft team visits, often managing the bulk of day-to-day therapy. P4 elaborated, “I think that they, in the end, are more important than us. If they get it together with the child and with the parent, they’re a very significant person in that child’s life, trying to improve their speech.” P7 stated, “Decisions are made on that child’s progress in therapy,” highlighting how community SLPs’ observations and feedback informed the overall care plan and surgical decisions.

Community SLPs were seen as essential for maintaining CoC through regular therapy and following through with recommendations from cleft team SLPs. P8 described the process, saying, “We’ll see kids for therapy for diagnostic purposes to see what’s their capacity like, stimulability-wise... Often that then involves going back to a local therapist to have that repetition and that practice and then coming back to us.” This collaborative approach ensured that children received consistent therapy and that their progress was monitored and supported across different settings.

**Community SLPs Lack Knowledge and Confidence.** SLPs highlighted a barrier to CoC: the perception of limited knowledge and experience in some community SLPs in managing cleft-related speech issues. While acknowledging that some community therapists were highly skilled, participants noted that these clinicians were “few and far between.” P3 reflected on this disparity, explaining, “We have some very talented long-term cleft specialists in the community, but as I said, they are few and far between.” This inconsistency in expertise created challenges for ensuring consistent and effective care for children with cleft palate.

Respondents went on to describe they perceived many community SLPs as not feeling confident addressing cleft-related issues, even when they had the necessary skills. P7 remarked, “They do have the therapy, they do have the knowledge. They’re not quite sure where to start or what to do, but they actually do know what they’re doing.” SLPs also observed that while some community therapists were open to

collaboration, more experienced clinicians sometimes hesitated to seek support. P3 explained, “The more experienced the therapist is, the less likely they are to actually want to go, ‘Hey, I’m doing this, it’s not really working.’” This reported reluctance to ask for guidance or engage in collaborative problem-solving may pose as a barrier to effective communication and collaboration.

Despite their importance, respondents recognized they perceived that community SLPs sometimes felt disconnected from the broader cleft team. P10 reflected, “I don’t think they feel as though they’re part of the team. But they are critical to the team.” This perceived disconnect was identified as a barrier to CoC, and cleft team SLPs stressed the need to actively include and support community therapists in the care process. Facilitating communication through regular contact, joint sessions, and sharing resources were seen as ways to bridge this gap and reinforce their role as key team members. P6 explained, “We’re all a part of that team. I don’t see anyone as being any more important... the plastic surgeon is as important in that team as the community speechie.”

### Demystifying Cleft by Supporting and Reassuring Community SLPs

SLPs saw an essential part of their role as breaking down the complexities of cleft speech therapy to make it more accessible to community speech therapists. They recognized that the unique challenges of cleft speech could feel daunting to clinicians without specialized training. P5 explained, “Unless you work in the field, you don’t understand quite the quantity and complexity of the speech that we have to work with.” To address this, SLPs focused on “demystifying” (P8) cleft care, as they shared strategies and insights that made cleft-related speech goals achievable for community therapists.

For cleft team SLPs, empowering community clinicians was about building confidence and breaking down perceived barriers. P9 reflected on her own early experiences, recalling the uncertainty she once felt: “I remember feeling like that myself thinking, I have no idea... but I think when you can break it down... it makes it a lot easier for them.” By guiding therapists through specific cleft techniques and reinforcing that these were extensions of skills they already had, SLPs helped to reinforce the idea that cleft therapy was not “rocket science” (P2). P7 shared that their goal was “just going through it and showing them what they do know, and how you’ve done this a hundred times but we’re just targeting this instead.” They acknowledged that this capacity-building was essential to providing consistent cleft care in the community. As P3 stated, “While I’m not going to say anyone can do it, I think with our support we need anyone to do it, because that’s our capacity building.”

### Global Theme Five: Parents are Key

**Families are Core.** SLPs emphasized the core role parents had in the care and management of children with cleft palate, describing them as integral to every step of the care process including

holding critical information, facilitating interventions, and driving decision-making. P6 illustrated this by describing a conceptual framework: *“The picture that I always use is like a circular picture. We have the child and their family in the middle of a wheel and the whole team around them.”* P2 echoed this sentiment, stating, *“I would like to think of the team as the child and the family are the core people at the centre and the heart of what we do.”* Parents were described as the ongoing holders of information, maintaining continuity across years of therapy, surgical procedures, and interactions with various specialists. P1 noted, *“They’re like the ongoing person that is holding all the information... they’ve been there since the beginning...”* This continuity was seen as essential, particularly in cases where children were not yet able to take on that responsibility themselves. Parents were viewed as the primary point of connection, bridging gaps between the child, the multidisciplinary team, and community services.

Empowering parents and supporting their involvement were described as essential processes for promoting CoC and overcoming barriers. P3 stated, *“Ideally, I would want parents to be liaising with us and being a true partner in that care. And knowing that the door is always open.”* Respondents emphasized the importance of facilitating parents’ understanding and engagement, ensuring they had the tools and confidence to act as advocates and collaborators. P7 summarized, *“I think the parents are just absolutely key in every step that happens. And we just need to help ensure they’ve got the support and the understanding to... come into those situations and those decisions with what they need.”*

SLPs also emphasized the pivotal role of parents as both decision-makers and therapists in their child’s care. SLPs viewed parents as integral to the success of speech therapy itself, emphasizing the importance of their active involvement in home practice and the generalization of therapy outcomes to daily life. P3 explained, *“Parents are ultimately their child’s therapist. We are merely the people with the expertise to go, try this.”*

**Some Parents “Find it Really Hard”.** Collaboration reportedly broke down when families struggled to process the complexity of cleft care. Some parents arrived at appointments without fully understanding their purpose or the role of the cleft team SLP. P8 explained, *“You’ve got families that kind of come in, don’t really know why they’re there. Don’t really know what your job is.”* This lack of understanding apparently led to misinterpretations, with parents finding it difficult to understand the complexities. P8 shared, *“They find it really hard to process that... pulling apart speech versus VPD versus language versus hearing versus all of that,”* which often required SLPs to provide repeated explanations and additional guidance: *“You feel like you’re constantly having to over explain what you’re doing and why” (P8).* For these families, SLPs acknowledged the importance of breaking down information clearly and supporting parents in managing the many elements of cleft care.

SLPs noted that parents often relied heavily on clinicians for guidance, with some deferring decisions to the “experts.” P9 reflected on this dynamic, sharing, *“mum has said on every single occasion... ‘You’re the experts, whatever you say.’ And you know, really, I kind of want to say, well, actually, you know your child the best... you need to feel like you’re making a decision in this, too”.* This sentiment underscored the need for cleft team SLPs to empower parents to feel as though they are an integral team member.

The burden of care also played a significant role in the quality of communication and collaboration. For parents juggling work, after-school care, and other responsibilities, engaging in therapy and supporting home practice was challenging. P3 empathized with these families, stating, *“They get home, the kids in after school care, they meet their kids at 6 o’clock at night, when are they meant to do therapy?”* P5 acknowledged this tension, stating, *“Parents have got limitations in that they have other kids at home. They have other roles to play, and sometimes being the therapist as well as a parent can be really... detrimental on their relationship.”* SLPs acknowledged that not all families were able to take on an advocacy role due to various barriers. Some parents lacked the confidence, time, or knowledge to advocate effectively. P6 noted, *“Not all families are going to be able to advocate for their child and, you know, have that level of interest or time to spend.”*

### Global Theme Six: The Landscape of Healthcare is Not Working

SLPs described a healthcare system across Australia and New Zealand that was often disjointed, inconsistent, and difficult to navigate. A combination of structural issues, funding models, and workforce limitations contributed to gaps in service delivery, leading to fragmented care and limited collaboration.

**The System Isn’t Working.** Respondents identified significant barriers to CoC due to issues within the current healthcare and funding models, particularly with the NDIS in Australia. Many SLPs noted that the NDIS model, while beneficial in increasing access to services, often appeared to lead to fragmented care and reduced parental involvement. P8 explained, *“I know that NDIS has changed things for the better, but it’s also made it really challenging for some of these families. They just go and see somebody, the first person they can get into, not necessarily the person that’s got the best skill set for them.”* This lack of specialist care in community settings was reported to create gaps in service quality and effectiveness.

The structure of NDIS funding was also seen as undermining the perceived value of therapy. SLPs reported that they perceived when families did not have to pay directly for therapy, their engagement decreased. P10 observed, *“The parents who pay for something, value it.”* This diminished sense of

ownership led to challenges in achieving therapeutic outcomes. P2 added, “Parents often aren’t present for the therapy... they’ll come into (the cleft) review and say, ‘Oh, are you still seeing that lady? What are you working on with her? (to their child)’” This lack of involvement appeared to hinder collaboration.

SLPs found that public health SLPs were generally easier to collaborate with compared to private therapists. P10 noted, “The community health therapists are easy to deal with... they are committed to helping.” This perceived commitment appeared to translate into more effective collaboration. In contrast, private therapists were perceived as harder to contact, because their time was billable, which discouraged collaboration. As P3 explained, “Private therapists are possibly some of the hardest to contact because parents are paying from their own pocket.” This financial structure sometimes created barriers to collaboration, as private therapists faced competing demands on their time and resources, possibly making it more challenging to engage in open and frequent communication.

**Our Resources are Limited.** SLPs identified numerous systemic challenges within the current healthcare landscape that hindered CoC for children with cleft palate. One major barrier was geographical distance, which limited access to specialist services. As P5 noted, “Because we’re spread out, we don’t have a lot of (children) who can travel to us for speech therapy.” The vast geographical areas meant that many children worked with local therapists for intervention. Another participant highlighted the difficulty, stating, “In the country region they have to go to the country therapists for intervention because... (the state) is huge” (P1).

Staffing shortages and limited resources further compounded these challenges. P1 explained, “if we were to be implementing gold standard evidence-based practice, we would need a lot more staff. I think at this stage we rely on our community services to provide that.” The lack of capacity to deliver ideal services, such as language programs for toddlers, was a significant barrier. Another participant expressed frustration at these limitations, saying, “There’s not enough hours in the day... issues with staffing, (P5)” while another described their service as being “pulled in lots of different directions” (P9). These constraints made it difficult for SLPs to engage in hands-on therapy, collaboration, and follow-up care as frequently as needed. P10 explained, “With the two days a week we have, we can’t do enough therapy, and that impacts our ability to provide ongoing support and advice.”

The challenge of coordinating care across different organizations was another obstacle. As P1 pointed out, “You can’t co-provide (air quotes) from two health organisations at the same time.” This organizational divide made it difficult to provide joint therapy or mentorship to community SLPs. Furthermore, the logistics of arranging time for communication were problematic, with P2 stating, “The biggest challenge to all of this obviously is time and finding mutual time.” These barriers may disrupt the flow of information and delayed timely interventions, impacting CoC. P2 elaborated, “If your

speech pathologist has any questions, please, please get them to give me a call or email me. But the reality is, it’s hard to find time that matches up.”

## Discussion

This study explored the experiences of specialist cleft team SLPs in their communication and collaboration with community SLPs and parents. The cleft team SLPs described multiple ways in which they communicate and collaborate to maintain CoC, as well as the barriers and facilitators that influence these processes. The findings align with Haggerty and colleagues’ framework for CoC encompassing informational continuity, focusing on communication and knowledge-sharing; management continuity, relating to coordinated service provision and role clarity; and relational continuity, which emphasizes trust, professional rapport, and relationships between cleft teams, community SLPs and families.<sup>6</sup>

### *Informational and Relational Continuity: Building Relationships Beyond Broadcasting*

Effective CoC relies not only on the seamless transfer of information but also on the strength of relationships that support collaboration. Informational continuity ensures that critical knowledge about a child’s care is consistently shared between professionals and families, while relational continuity fosters trust, mutual respect, and long-term partnerships that enhance the quality and consistency of care. Both elements are essential in cleft speech therapy, as they enable community SLPs, cleft teams, and families to work together effectively. However, findings from this study suggest that while cleft team SLPs were committed to sharing information, communication often remained one-directional, highlighting an opportunity to strengthen engagement through more reciprocal and interactive approaches. Respondents consistently highlighted the importance of strong relationships in ensuring CoC for children with cleft palate. They emphasized that effective partnerships with community SLPs and families facilitated trust, collaboration, and knowledge-sharing, ultimately benefiting the child’s therapy journey. While cleft team SLPs recognized that “relationships matter” and reported they were committed to sharing information and supporting community clinicians, the data suggested that much of this communication was one-directional, with a focus on providing reports, email, and educational resources. There was less discussion on how ongoing, two-way communication and collaboration were actively fostered over time. This highlights an opportunity to strengthen engagement by exploring more interactive and reciprocal approaches to relationship-building.

While respondents frequently reported providing education and resources to community clinicians, there was little discussion on whether they actively sought feedback from these therapists about what support they needed or how they preferred to engage in collaboration. Instead, communication was often

structured around reports and professional development, which, while valuable, may not have encouraged true partnership-building. The focus on knowledge dissemination over reciprocal exchange may have reinforced the reported hierarchical dynamic, where cleft team SLPs were positioned as the experts “giving” knowledge rather than collaborating on equal footing. While respondents spoke about wanting to integrate community SLPs more seamlessly into the care pathway, there was little mention of direct efforts to understand how these clinicians worked, what barriers they faced, or what type of support they needed. Without mechanisms for soliciting feedback and adapting their support accordingly, cleft team SLPs risked reinforcing the very divide they sought to overcome.

Cleft team SLPs also recognized the power of language in shaping professional relationships. Simple shifts in how emails, reports, and letters are worded could foster a more welcoming and collaborative tone. Instead of passive phrases like “Please contact me if needed,” stronger invitations such as “I’d love to discuss this case with you—please let me know a time that works” could encourage more reciprocal communication. These small but intentional adjustments could help reposition interactions as collaborative exchanges rather than top-down directives, fostering more engagement from community clinicians.

Moving forward, more intentional efforts could be explored to build relationships beyond information-sharing in order to facilitate collaboration. Strategies such as joint sessions, structured follow-up after reports, regular case discussions, and shifting language in communications to invite more engagement could create more sustainable, two-way partnerships. Without deliberate relationship-building efforts, the risk remains that cleft team SLPs will continue to broadcast information rather than cultivate lasting, collaborative connections that promote CoC. By expanding their approaches to communication and collaboration, cleft team SLPs could bridge the gaps in CoC and strengthen the partnerships that underpin high-quality care for children with cleft palate.

### *Management Continuity: Moving Beyond the Consultative Model*

Management continuity refers to the coordination of care and service delivery across multiple providers to ensure that interventions are aligned and consistent. Cleft team SLPs have traditionally operated within a consultative model, providing advice, assessments, and recommendations to community SLPs who then implement therapy. While this model ensures that children with cleft palate receive specialized input, it can also reinforce a hierarchical dynamic, where community SLPs may feel they are simply receiving directives rather than being active partners in care. Many respondents expressed frustration over the lack of response from community SLPs, but the data suggested that limited two-way engagement may have contributed to these challenges.

Moving beyond a purely consultative role requires shifting towards a collaborative partnership model, where cleft team

and community SLPs co-design treatment plans, share decision-making, and engage in structured mentoring. Grames et al.’s collaborative treatment model offers an innovative approach, promoting joint goal-setting, knowledge-sharing, and ongoing case discussions rather than isolated consultations. Implementing peer mentoring programs and co-treatment opportunities would allow cleft team SLPs to work alongside community clinicians, supporting skill development and ensuring therapy remains consistent across settings.<sup>9</sup> By redefining their role as facilitators of shared care, rather than just consultants, cleft team SLPs can foster stronger, more sustainable partnerships. This shift would not only enhance CoC but also empower community clinicians to feel more confident and engaged in cleft therapy, ultimately improving outcomes for children with cleft palate. Ultimately, this research should inform policy, practice, and education in cleft care, emphasizing the importance of cohesive care for improved patient outcomes and quality of life.

### **Limitations**

A limitation of this study is its focus on specialist cleft team SLPs working within established cleft services in Australia and New Zealand. The findings may not fully capture the experiences of cleft team SLPs in other healthcare systems or resource-limited settings, including low and middle-income countries. Additionally, the participants in this study were highly experienced clinicians which may limit the applicability to less experienced clinicians in the same or similar settings. Finally, there is the potential influence of pre-existing professional relationships between the researchers and the participants which was managed through the inclusion of researchers without these relationships and through reflexive practice as described in the method.

### **Conclusion**

This study explored the experiences of cleft team SLPs in communicating and collaborating with community SLPs and parents to facilitate CoC for children with cleft palate. Respondents consistently emphasized the importance of relationships in ensuring effective care, recognizing that strong partnerships facilitated trust, collaboration, and knowledge sharing. While cleft team SLPs demonstrated a strong commitment to education and supporting families and community clinicians, their engagement often took the form of information dissemination rather than interactive, two-way relationship-building. Although some community SLPs actively sought guidance and maintained open lines of communication, cleft team SLPs expressed frustration at the lack of engagement from others, suggesting that communication gaps persisted.

Despite these challenges, cleft team SLPs remained dedicated to fostering collaboration and enhancing the capacity of community clinicians through education and knowledge-sharing. Moving forward, a shift towards a co-facilitative role rather than a purely consultative model may strengthen

relationships and improve CoC. Rather than positioning themselves as the primary experts directing care, cleft team SLPs could work alongside community clinicians in a more interactive, shared capacity, encouraging reciprocal learning and collaborative problem-solving. Strategies such as joint sessions, interdisciplinary meetings, structured mentoring, and more intentional follow-up processes could help foster this approach. Additionally, cleft team SLPs may benefit from refining the way they frame communication—using language that encourages reciprocal dialogue and ensures that community clinicians and parents feel empowered to contribute to the care process.

Further research is needed to explore the perspectives of community SLPs and parents to gain a more comprehensive understanding of their experiences and expectations in CoC within cleft speech pathology services. Ultimately, fostering a culture of shared learning, mutual respect, and equal partnership between cleft team and community SLPs, alongside active parental involvement, will be essential in improving CoC for children with cleft palate.

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### Data Availability

The data that supports the findings of this study is available in the supplemental material.

### Declaration of Conflicting Interests

The authors declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

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Written informed consent for publication was obtained from all participants included in this study.

### ORCID iDs

Mikaela Bow  <https://orcid.org/0009-0007-0569-5189>

Patricia McCabe  <https://orcid.org/0000-0002-5182-1007>

Alison Purcell  <https://orcid.org/0000-0002-4623-4086>

### Supplemental Material

Supplemental material for this article is available online.

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**Chapter 4: Collaboration begins with connection:  
Experiences of community-based speech-language  
pathologists in cleft palate continuity of care**

## **Chapter 4: Collaboration begins with connection: Experiences of community-based speech-language pathologists in cleft palate continuity of care**

This chapter consists of a manuscript that has been submitted for review:

Bow, M., McCabe, P., Sutherland, R., & Purcell, A. (2026). Collaboration begins with connection: Experiences of community-based speech-language pathologists in cleft palate continuity of care. *International Journal of Speech-Language Pathology*. 1-12.  
<https://doi.org/10.1080/17549507.2026.2622405>

This paper contributes to the overall aim of the thesis by examining how continuity of care is realised from the perspective of community speech-language pathologists (SLPs). Community SLPs are central to delivering ongoing intervention for children with cleft palate across Australia and New Zealand. Building on insights from the scoping review and prior chapter on cleft team SLPs, this study explores how community clinicians experience and enact informational, management, and relational continuity in their clinical practice. It also investigates the challenges and enablers of collaboration with cleft team SLS and parents.

### **Statement of Contribution to Co-Authored Published Paper**

This study was designed and written in collaboration with my supervisors, Prof Patricia McCabe, Dr Rebecca Sutherland and Prof Alison Purcell.

**Collaboration begins with connection: Experiences of community-based speech-language pathologists in cleft palate continuity of care**

Mikaela Bow

Patricia McCabe

Rebecca Sutherland

Alison Purcell

Correspondence concerning this article should be addressed to Ms. Mikaela Bow, Faculty of  
Medicine and Health, The University of Sydney, Camperdown, NSW 2006, Australia.

[mikaela.bow@sydney.edu.au](mailto:mikaela.bow@sydney.edu.au)



## Collaboration begins with connection: Experiences of community-based speech- language pathologists in cleft palate continuity of care

Mikaela Bow, Patricia McCabe, Rebecca Sutherland & Alison Purcell

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# Collaboration begins with connection: Experiences of community-based speech-language pathologists in cleft palate continuity of care

MIKAELA BOW<sup>1</sup> , PATRICIA MCCABE<sup>1</sup> , REBECCA SUTHERLAND<sup>1</sup>  & ALISON PURCELL<sup>2</sup> 

<sup>1</sup>Faculty of Medicine and Health, The University of Sydney, New South Wales, Australia, and <sup>2</sup>Faculty of Health, Western Sydney University, Australia

## Abstract

**Purpose:** Little is known about how community-based speech-language pathologists experience continuity of care when working with children with cleft palate. This study explored how continuity of care is promoted, the barriers and facilitators encountered, and the nature of collaboration with cleft team clinicians and families.

**Method:** Twelve community-based speech-language pathologists from Australia and New Zealand participated in semi-structured interviews. Participants worked across private practices, schools, hospitals, and community health. Reflexive thematic analysis was used to interpret the data.

**Result:** Three global themes were developed: (1) Navigating roles and relationships, (2) communication and collaboration, and (3) I need help – and I have some ideas. Participants valued collaborative care, but described variable communication, and limited access to cleft team support. Trusting relationships and clear, timely information were key facilitators in continuity of care.

**Conclusion:** Community speech-language pathologists play a central role in cleft care and demonstrate a strong commitment to engage in collaborative care yet face barriers to inclusion and collaboration. Findings point to the need for clearer communication pathways, shared planning, and inclusive, team-based models that better facilitate collaboration between community clinicians, cleft team clinicians, and parents.

**History:** Received 12 August 2025; Accepted 21 January 2026

**Keywords:** Words: cleft palate; continuity of care; cleft speech therapy


## Introduction

Children born with cleft palate with or without cleft lip (CP ± L) require complex, long-term care from multiple healthcare providers (American Cleft Palate Craniofacial Association, 2024). Speech-language pathologists (SLPs) are essential members of the cleft care team, supporting feeding and communication development from infancy through adolescence (Kummer & Bow, 2022; Sommer & Wombacher, 2025). In Australia and New Zealand, cleft care is delivered within mixed public and private funding models. This can add a layer of complexity to achieving continuity of care across providers and settings.

Specialist cleft-team SLPs are typically embedded within multidisciplinary, hospital-based cleft teams that include surgeons, nurses, audiologists, orthodontists, and other health professionals. Within this model, specialist SLPs focus on cleft-specific assessment, monitoring language development and structural impacts on speech and resonance, advising on surgical intervention, and providing consultative recommendations to families and other providers.

In contrast, community-based or generalist SLPs usually work in private practice, community health, hospitals or educational settings such as schools. In working with children with cleft, they deliver majority of ongoing, day-to-day therapy, support generalisation

Correspondence: Mikaela Bow [mikaela.bow@sydney.edu.au](mailto:mikaela.bow@sydney.edu.au) Faculty of Medicine and Health, The University of Sydney, Camperdown, NSW 2006, Australia.

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across environments, liaise with families and educators, and often coordinate broader communication goals alongside other developmental priorities (Bedwinek *et al.*, 2010; Grames, 2004, 2024; Grames & Stahl, 2017).

Continuity of care (CoC) is critical to the effective management of cleft-related speech disorders, particularly given the need for coordinated, consistent, and collaborative intervention across time and settings. Haggerty *et al.* (2003) outline three core domains of CoC: Informational continuity (i.e. ensuring key clinical information is shared between providers), management continuity (i.e. aligning services and roles to maintain cohesive care), and relational continuity (i.e. developing sustained, trusting relationships between families and professionals and between professionals themselves). Each of these elements is particularly relevant in cleft care, where treatment decisions are informed by shared clinical data, regular follow-up, and collaborative input from multiple professions and the child's family (Gulliford *et al.*, 2006).

A recent qualitative study explored the perspectives of specialist cleft SLPs on CoC and identified several challenges to collaboration, particularly with community clinicians (Bow *et al.*, 2025). Specialist cleft SLPs described their efforts to support CoC through educational outreach, consultation, and written communication; however, much of this communication was perceived as one-directional. While specialist cleft team SLPs valued collaboration, they also noted barriers including role ambiguity, limited feedback from community clinicians and systemic constraints such as staffing shortages and funding models. Importantly, cleft SLPs acknowledged that community SLPs play a pivotal role in maintaining therapeutic continuity, given their more frequent contact with children and families.

Despite recognition of the importance of community-based SLPs in the cleft care pathway, limited research has examined their perspectives on CoC (Bow *et al.*, 2024). Existing studies do, however, suggest that community clinicians may feel underprepared to manage cleft-related speech disorders (Alighieri *et al.*, 2021; Bedwinek *et al.*, 2010) and may face challenges in accessing support or collaborating effectively with cleft teams. Understanding how community SLPs perceive their role, experience collaboration, and navigate the complexities of delivering care is essential for improving continuity, ensuring quality outcomes, and informing best practice models.

This study builds upon this previous research by shifting focus to community-based SLPs and their experiences of CoC in providing cleft palate speech services. Through semi-structured interviews with Australian and New Zealand clinicians working in private practice, schools, and community health, the study aimed to explore how these professionals promote continuity, the barriers and facilitators they encounter, and their perspectives on collaboration

with specialist cleft team SLPs and parents. Using the CoC framework proposed by Haggerty *et al.* (2003), this study sought to provide a more comprehensive understanding of continuity from the viewpoint of those delivering day-to-day care.

The research questions guiding this study were:

- (1) What does communication and collaboration currently look like between the community SLPs, cleft SLPs, and parents from the perspective of community SLPs?
- (2) What processes are currently being used by community SLPs to ensure CoC with cleft SLPs and parents?
- (3) What are the barriers impacting continuity of care?
- (4) What are the facilitators for promoting continuity of care?

## Method

### Study design

This study employed a qualitative methodology using reflexive thematic analysis (Braun & Clarke, 2022), underpinned by grounded theory principles, to explore the experiences of community-based SLPs in promoting continuity of care for children with cleft palate. Ethical approval was obtained from the Human Research Ethics Committee at The University of Sydney (Protocol: 2023/105).

Eligible participants were SLPs working in private practice, hospital or community health, or school-based settings in Australia or New Zealand who had provided therapy to at least one child with a cleft palate in the preceding 12 months. No upper or lower age limit was specified for children, provided that the participant had supported at least one child with cleft palate in the past year. Recruitment was conducted via email through professional networks and social media. Of the 14 who expressed interest, 13 met eligibility criteria and were enrolled in the study and one was deemed to have withdrawn as they were unable to be reached.

Data collection was conducted via Zoom, allowing participation from clinicians across geographically diverse regions. Semi-structured interviews were guided by a piloted interview schedule (see Appendix 1) that was developed from the study aims, existing literature on continuity of care, and findings from our previous study with cleft-team SLPs (Bow *et al.*, 2025). The schedule was piloted with a community-based SLP who had experience working with children with cleft palate. Minor wording and sequencing changes were made to improve clarity, but not substantive changes to content were required. The final interview guide explored topics including interprofessional collaboration, communication with cleft teams and families, and perceived facilitators and barriers to CoC. Interviews were audio and video-recorded and transcribed verbatim. Field notes were taken to document contextual information and researcher

reflections. No repeat interviews were conducted. Interviews ranged from 24 to 36 minutes, with an average duration of 30 minutes. Recruitment continued until the target sample of 12 participants was achieved, informed by previous interviews with specialist cleft SLPs (Bow et al., 2025) and guided by the goal of reaching code saturation and focused research objectives (Hennink & Kaiser, 2022).

### **Research team and reflexivity**

All interviews were conducted by the first author, a female mid-career SLP and PhD candidate with clinical experience in both cleft team and private practice settings. At the time of the study, she was actively working in clinical and academic roles. The broader research team consisted of three additional female researchers: Two senior academics with PhDs and expertise in cleft-related speech pathology and speech disorders across the lifespan, and one senior researcher with a PhD and background in disability and neurodiversity. The team brought diverse clinical and research perspectives, which supported robust interpretation of the data.

An existing professional relationship between the interviewer and six participants was noted, although none of these participants were directly recruited. Participants were aware that the interviewer was conducting the research as part of her PhD and that the study aimed to improve CoC in cleft speech services. To mitigate potential bias associated with these existing relationships, the first author maintained a reflective journal throughout the study.

Researcher triangulation was used to enhance credibility. The first and third authors conducted initial coding together, and the second and fourth authors independently coded this same data. The first author led initial theme development, which was then reviewed and discussed with the wider team. Each member contributed a distinct interpretive lens, and differences in perspective were explored through iterative discussion until a shared, coherent thematic framework was reached. Consistent with reflexive thematic analysis, reliability was conceptualised in terms of depth, reflexivity, and transparency of interpretation.

### **Result**

Twelve community-based SLPs participated in this study, including 11 based in Australia and one participant based in New Zealand. Further geographical information is not included to ensure participant confidentiality. Their years of clinical experience ranged from 1 to 40 years, with a mean of 15 years. Highest educational qualifications included a Bachelor's degree ( $n=8$ ), Master's degree ( $n=3$ ), and PhD ( $n=1$ ). Ten participants reported receiving some cleft-related training during their university education, and five had engaged in further professional development related to cleft care, including seminars,

observation days in cleft clinics, and postgraduate coursework. Participants reported working across various settings including private practice ( $n=8$ ), community health ( $n=3$ ), schools ( $n=3$ ), and hospitals ( $n=2$ ); with five participants working across more than one setting. Two participants had prior experience working in a hospital-based cleft team. Across their careers, participants reported treating between 1 and 150 children with cleft palate, including between 1 and 25 children in the past five years.

### **Themes**

Thematic analyses of the interviews generated three themes: These global themes were comprised of 14 subthemes. A summary of themes and subthemes can be seen in Figure 1.

#### **Global theme one: Roles and relationships**

##### *Community SLPs are the “doers” and advocates*

Community SLPs often described themselves as the ones “on the ground”, “doing the work”. This included conducting therapy and taking on multiple roles that included being advocates and coordinators to support the child and family. While cleft services were often viewed as consultative, community SLPs positioned themselves as the consistent presence. “I’m the one that’s actually doing the therapy with him weekly”, said P11. Similarly, P4 reflected, “we are really important because we are delivering the therapy week to week”, highlighting the frequency and continuity they provide. “We’re the ones that are building the rapport... the ones who are in their homes often... who are seeing them regularly”, said P7. “I see these clients two times a week, and they (cleft SLP) see them once every six months”, explained P2.

But their role extended well beyond therapy. Many described taking on case coordination, system navigation, and parent support. “We’re the ones who will see them in multiple environments... help their daycares”, explained P7. “They come to us with everything”, P6 noted, “we’re kind of their case manager... the main point of communication”. While P1 added, “we’re training up the adults around the child... supporting the family alongside the cleft team”.

This ‘doing’ often involved stepping into advocacy roles on behalf of the parent and child, “I’m the one who has to advocate, initiate all the conversations (with cleft SLP), really... seek that information”, said P2. P3 said that she often guided parents and helped them understand what was going on, “I’m educating them up as much as I can... empowering them to communicate effectively”.

##### *Tiers or team?*

Participants offered differing perspectives of the dynamic of the child’s cleft speech team. Some described a hierarchy with the cleft SLPs as the

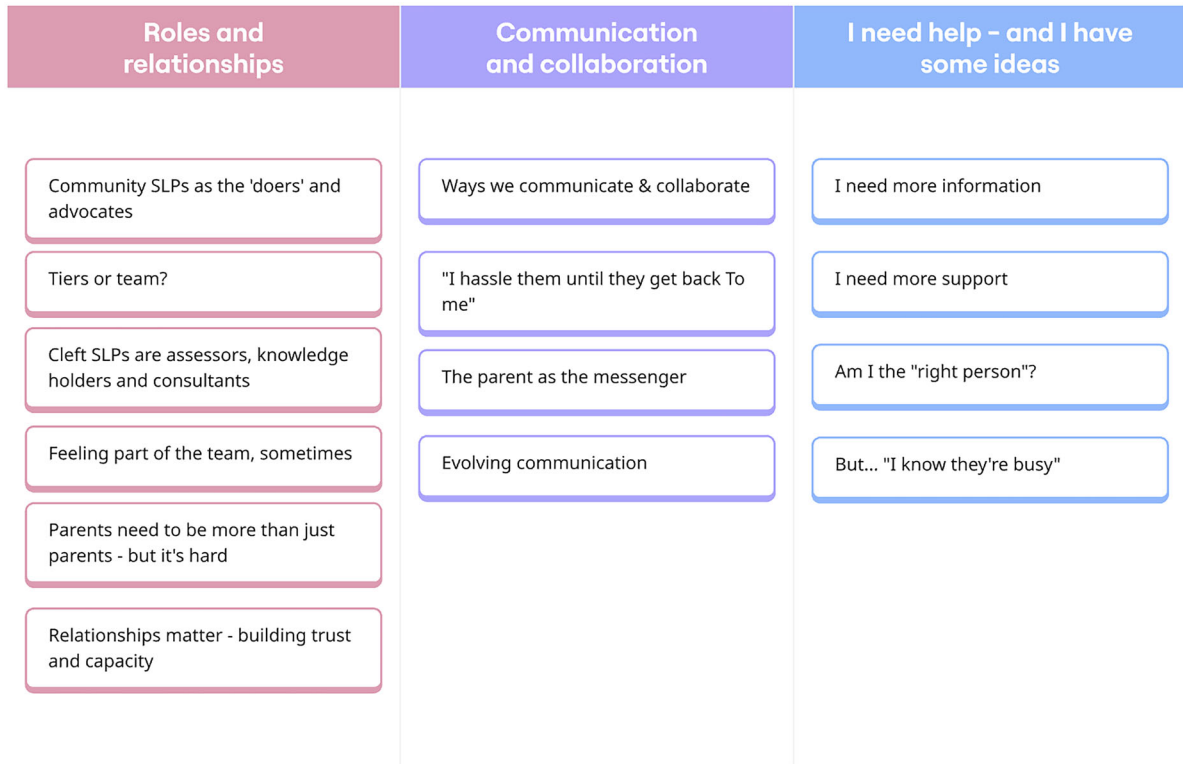


Figure 1. Global themes and subthemes.

central, expert authority who led, diagnosed, and directed care. “They’re the wizards”, described P2, adding, “they have the answers to the questions that we don’t know”. Similarly, P1 reflected that she followed instructions, “from my perspective, the cleft team is kind of the most important one, and then we’re just kind of doing the things that they tell us to do”. P4 described cleft SLPs as, “almost the leaders and the guide of the child’s whole journey” and P5 stated, “they’re top level.”

In contrast, other participants challenged this hierarchy and discussed more inclusive, collaborative models of care. “It’s got to be recognised that we’re a team and that the cleft team isn’t at the top”, said P12, who advocated for putting egos aside to ensure “we’re on an equal playing field”. P8 echoed this sentiment, “I would probably consider them (cleft SLPs and parents) to be relatively equal members of the team... perhaps with slightly different roles or responsibilities”. The role of parents in this dynamic was particularly significant. Many participants acknowledged that parents are central members of the team. “Parents are the most important part of the team”, stated P8, while P7 emphasised, “the child and the family are first and foremost”. However, this importance wasn’t always reflected in practice as will be shown in later themes.

*Cleft SLPs are assessors, knowledge holders and consultants*

Community SLPs viewed cleft SLPs as assessors and diagnosticians with cleft-related speech difficulties,

especially in identifying structural impacts and determining whether surgery or therapy is required. As P3 explained, their role is “to mostly diagnose what’s going on in terms of nasality ... whether they might need surgery”. Others described them as having “the expertise in assessment and teasing out the structural impact” (P8) and being responsible for “assessment and diagnos(is) for those more structural difficulties” (P5), before they “get in touch with us” to guide next steps (P1). They were also often described as clinical consultants, with community SLPs noting, “I definitely would treat them as like the consulting the person who I would go to with the questions” (P2). Participants also highlighted the key role cleft SLPs play in goal setting and using their specialised knowledge to guide therapy direction for community clinicians. As P8 noted, they are “absolutely guiding or suggesting therapy goals”, while others appreciated “a bit of guidance in the goals for each client” (P10) to ensure alignment with structural and clinical priorities. Cleft SLPs were viewed as the central source of specialised knowledge within the team, described as “the ones who know all the lingo ... the next step ... the research” (P7) and as “the leaders and the guide of the child’s whole journey (who) set the tone” for cleft care (P4). Cleft SLPs were also expected to communicate, responsible for “provid(ing) some kind of feedback to the rest of the team” (P11), “comprehensive handover to the community speechie” (P6), and “liaising with whoever they work with” (P9), to ensure CoC across settings.

*Feeling part of the team, sometimes*

Community SLPs described mixed experiences of inclusion within the cleft care team with some reporting feeling valued and included, while others described a more peripheral or inconsistent sense of involvement. For many, feeling like part of the team depended on prior relationships, proactive communication, and being “kept in the loop”. “I definitely feel a part of the team”, said P8, “because we spend so much time working together ... and over time, I’ve built some rapport with the specialist teams”. Similarly, P12 shared, “I have to say that I have never been treated like anything but a team member”. However, this sense of belonging was not universal. P6 contrasted two cases on their caseload: “With one client, I got a handover - it felt like a team. The other... I wouldn’t call that a team”. Specific interactional features were described as helping community SLPs to feel part of the team, including being copied into reports and emails, receiving direct handovers, and being invited to attend cleft appointments (in person or telehealth). When these behaviours were absent, community SLPs were more likely to feel peripheral, uninformed, or disconnected from the team.

*Parents need to be more than just parents – but it’s hard*

Parents were consistently described as having a key and multifaceted role in their child’s cleft care journey, often stepping beyond typical parental responsibilities. These roles included implementing therapy, advocating for the child and being ‘case managers’. As P1 summarised, “they’re kind of the main players in it”. P8 reiterated this, “they’re sort of the key component to any sort of therapy really being successful”. One of the most consistently described roles for parents was that they are responsible for carrying out therapy at home. P4 noted, “they’re the ones reinforcing the homework ... every day”. P9 added, “their role is facilitating that generalisation of strategies in their home environment, on top of all the other things they need to do”. P10 reiterated this, “their role is to help with speech intelligibility ... they have their homework to do”. They also noted that a parent’s role is to “support the child to the best of their ability” (P9).

Parents were also seen as key advocates, however, community SLPs recognised that this role often came with significant challenges. As P2 reflected, “it’s really hard for them to be that ... really strong advocate, that they need to be, because it’s really challenging in the medical system”. This was also reported to depend on a parent’s capacity to advocate, “they (parents) don’t always have that capacity to do that (advocate)”, acknowledged P2. Some families were seen as driving forces behind their child’s progress, “it’s usually a parent who’s behind the impetus to get the best for their child”, said P12. Yet others

struggled to keep up with the demands of a complex and fragmented system. “I just feel like it’s all up to them”, said P7. “To contact, recontact, get the hearing tests done again ... Parents have become the case worker”.

Many parents were described as highly informed and committed, as P10 highlighted, “the parents are really involved and want to learn and do their own research”. P2 noted, “my parents of children with cleft lip and/or palate are way more committed to the cause ... they always attend their appointments”. However, participants also reported that parents were juggling multiple services, diagnoses, and appointments. “They’ve got 5,000 other things going on”, said P2.

Importantly, community SLPs noted there was variability in parental engagement and capacity with some parents described as “really engaged” and others less responsive “I never get a response ... I don’t even know if she’s reading the emails” (P1). Health literacy and familiarity with medical systems were seen as a factor impacting this. “The ones that don’t know the system, or don’t know the language, don’t feel like they can take the leadership role in the team”, said P3. Meanwhile, parents with health backgrounds such as a mother who was a nurse was “very well ... versed ... in the medical side of things as well” (P11).

*Relationships matter – building trust and capacity*

Strong relationships between community and cleft SLPs were seen as important to the CoC. Participants consistently reflected that when a personal connection was present, communication flowed more easily, and support was more accessible. “I’ve only ever contacted the cleft palate clinic because of our established relationship”, said P11. “I guess I’m lucky in that I do have that”. P7 expressed a similar sentiment, “I’m lucky because I know the SLPs to contact ... I have a contact in the hospital I can email.”.

These relationships were not always immediate and often developed over time, often through repeat interactions, mutual problem-solving, and shared clients. “Over time, I guess I felt like I’ve built some rapport with the specialist teams”, said P8, “so yeah, I do feel like I’m part of the team”.

Relationships also served as powerful tools for capacity-building. Several participants described learning informally through these connections, in a way that felt more practical and tailored than formal training. “That time I speak to them – it is gold”, said P11, “it makes such a difference”. P6 echoed this, stating, “I benefit from conversation more than just emails”.

By contrast, in the absence of relationship, collaboration was more difficult to initiate and less effective. “If you don’t feel confident enough to be like, ‘Can we have an hour chat?’ you probably just won’t do it”, said P1. Others highlighted that when cleft team

members changed or contact points were unclear, existing rapport disappeared, and communication suffered. “They go on maternity leave... and you don’t have that relationship with the new person”, noted P9.

### ***Global theme two: Communication and collaboration***

#### *Ways we communicate and collaborate*

*Communication and collaboration with cleft SLPs.* Community SLPs used a variety of asynchronous communication methods to connect with cleft SLPs, with email being the most common. “Honestly, emails work really well for me”, said P8; with P3 reiterating this, “via email mostly or sometimes by phone”. Others received written reports following assessments or reviews, or indirect updates delivered through parents. “It’s been a lot of parents communicating with them, and then they might get in touch with me, or the parents send me, like the notes or a report or something”, noted P9. In some cases, videos were uploaded or exchanged, “I’ve uploaded videos online that (cleft SLP) then watched and then given feedback on. So that has worked really well” (P8).

When it came to synchronous communication, participants described using phone calls and online meetings. “They will just pick up the phone and call me” (P11). “You just get so much more out of a conversation than back-and-forth emails”. A small number of clinicians reported attending hospital appointments or sitting in on cleft sessions, which helped deepen collaboration. P8 shared, “we did a joint session... and that probably helped foster that feeling that I was part of the team”.

#### *Communication and collaboration with parents.*

Communication with parents was described as primarily in person, typically during therapy sessions. These moments were used to set goals, model strategies, and provide emotional support. “Most of the time the parents are in here, and it’s a lot of education, obviously, making sure that they do understand what’s happening and explaining to them”, said P3. This was reiterated by P11, “I’m in constant communication with them... I see him at home... so the parents are always present”. In addition to face-to-face interaction, community SLPs often used emails and text messages to stay in touch. “I’d email her if she wasn’t in the session and give an update – she’d ask for resources”, said P1.

*Collaboration as a team.* Despite individual relationships with either cleft SLPs or parents, very few participants described genuine three-way collaboration. One notable example involved a joint Zoom session:

At the cleft clinic... I was able to Zoom in on it and participate in the session, offer some feedback on

what’s happening... and how he’s going. And (cleft SLP) assessed him and shared with me the findings, and then said, ‘I think we should work on X, Y, and Z. This is where he’s at’. So couldn’t have asked for a better off... and then (cleft SLP) followed up again.

While such joint sessions did occur on occasion, most communication tended to remain dyadic, between the community SLP and the parent, or the community and cleft SLP, but not all three. Being copied into emails was mentioned as one strategy to bridge the gap, with P2 sharing, “parents often rely on me to find the phone number, find the email, send the email, cc them into the email, do all that stuff...”

#### *“I Hassle them until they get back to me”*

Many community SLPs described the process of contacting cleft SLPs as inconsistent and effortful often requiring persistence, follow-up, and repeated attempts before receiving a response. “I would just ring them and hassle them until they get back to me”, said P2. A common theme was that community SLPs were almost always the ones initiating contact, with little to no proactive outreach from the cleft team. P9 noted, “It’s more that I’m reaching out to them... they don’t usually reach out to me”. P4 echoed this, stating, “they don’t initiate any contact with us”.

#### *The parent as the messenger*

In the absence of direct communication between cleft and community SLPs, parents were frequently described as a messenger for relaying information between services. While this dynamic sometimes enabled timely updates, it also introduced gaps, delays, and inaccuracies. “Parents sometimes can be the relayer (sic) of information”, said P2, who also acknowledged that “it can often get mixed”. Several SLPs expressed concern that critical clinical details could be lost or miscommunicated when filtered through a parent. P10 cautioned, “take it with a grain of salt, basically what the parents say”, noting that parents may not have the clinical background to accurately interpret or convey information.

#### *Evolving communication*

Community SLPs described how their communication needs and preferences evolved over time, particularly as they gained experience with cleft cases and developed relationships with cleft SLPs. In the early stages of their careers, or when encountering cleft for the first time, relational communication, such as phone calls, Zoom discussions, and informal check-ins, was especially important. “When you’re in that early career freak-out... I had no clue what I was doing. A phone call was everything” (P2). Another added, “at the start when I was picking up a new client, I would... spend half an hour on the phone going through everything that I needed to know. Maybe phone at start then email” (P2).

As confidence increased and working relationships with cleft teams became more established, transactional communication, such as emails, reports, and written updates, became not only sufficient but preferred. This shift reflected both growing self-assurance and the realities of time pressure in busy clinical roles. “It’s more convenient for them, also for me ... every 10 minutes of my time must be accounted for. So, it’s easier just to flick them an email” (P2). Another participant appreciated the practical benefits: “Honestly, emails work really well for me ... there is that sort of written record ... I can go back and check on” (P8).

### ***Global theme three: i need help – and i have some ideas***

#### *I need more information*

Community SLPs described breakdowns in informational continuity and expressed a desire for information regarding the child’s cleft history and recommendations, the cleft pathway, team roles, and who to contact. Many reported feelings of uncertainty about what had already been done, what was recommended, and what they were expected to focus on. A clear handover, ideally initiated by the cleft SLP, was described as needed at the beginning of working with the child. P6 described, “I guess that point of referral, just ensuring we have all the information, the reports, any intervention they’ve already started, or strategies they’ve provided Mum, so just kind of an ISBAR (Identify-Situation-Background-Assessment-Recommendations) handover”. P2 reiterated this point, “in an ideal world ... when we receive the referral ... a bit of a round table ... to sit down and say, ‘Okay, this is where they are at’”. There was also a desire for more informal information, such as access to progress notes, “it would be amazing to see progress notes,” said P6.

Community SLPs also expressed a strong need for greater clarity around the cleft care pathway, including the timing of interventions, who to contact, and how roles are shared between the cleft and community teams. Understanding the different roles and responsibilities of the cleft SLP versus community SLP was desired: “But maybe even in that initial ‘Hey, you’re taking on this client. I’ve done their cleft assessment. This is where they’re at. Your responsibility is, you need to contact me,’ like there’s no discussion of those roles and relationships” (P2).

For some, even the basics such as knowing who to reach out to were unclear. “I didn’t know who to contact” said P6, noting the uncertainty around who to contact for follow-up. Others suggested practical solutions to bridge the gap, such as, “a handout on who to contact if we have questions” (P6) or “a fact sheet ... or if it was included in the professional development” (P8), to explain the typical stages and timing of cleft-related care. P6 reflected, “and knowing the pathway, because I realised, I don’t know the

pathway”, highlighting how lack of system knowledge can impact continuity.

#### *I need more support*

Community clinicians described a desire for more than just information—they expressed a desire for early, intentional, clinical, and relational collaboration as well as ongoing support, particularly when they had less experience working with children with cleft palate. Many clinicians likened the ideal relationship with cleft SLPs to that of a supervisor or mentor. “It’s kind of like a supervisor at uni ... (I’d like) some validation for me” (P2). Others sought access to someone who could help them troubleshoot clinical issues. “Pie in the sky dreams, but a clinician that can answer your questions” (P3). Timely replies were considered invaluable: “Every time I emailed with a relevant question ... they responded, I would be so happy with that” (P2).

Many community SLPs expressed a desire for more support in goal-setting, particularly in the early stages of working with cleft cases or when structural concerns were present. While they often took responsibility for ongoing therapy, participants wanted clearer direction around where to begin. “There’s gotta be a bit of guidance in the goals for each client” (P10). This was further supported by P2, “I think it works really well where they give goals, then I work on it, and then we check in, in a predetermined period of time”.

Community SLPs were clear in their desire to move beyond simply being informed or instructed. They wanted to be included as active collaborators in a shared care model. Several noted that current communication was often one-way, with little opportunity to engage in decision-making: “It would help if we were invited to join sessions. If they empowered us and trained us, we would probably be more comfortable taking on clients with cleft” (P4) and “we’re working together, not separate ... so it’s easier to show the parents ... we’re on the same page” (P3).

Participants also identified telehealth as an underutilised but powerful strategy for inclusion. Virtual check-ins, shared review sessions, and live therapy input were seen as feasible and effective. “Having a telehealth session where (cleft SLPs) are present ... we can do it in real time” (P8). One participant reflected, “we haven’t taken advantage of Zoom interviews or calls, and that’s really something that I could have done” (P12). Others suggested simply “dropping in” to hospital reviews via telehealth (P6). These ideas speak to a broader theme: Community SLPs don’t just want to be told what to do, they want to feel included, supported, and part of the care team.

Finally, SLPs emphasised the importance of ongoing learning. They requested informal supervision, short online Q&As, and small, bite-sized education. “Just like that ad hoc kind of supervision ... even like a case discussion” (P6), and “those little ...

lunchtime Zoom ... a 10-minute opportunity to ask questions ... I think that's a really good" (P10).

#### *Am I the "right person"?*

Community SLPs shared a sense of professional inadequacy when supporting children with cleft palate, often describing feelings of fear, uncertainty, or being underqualified. These feelings were especially strong for clinicians with limited exposure to cleft, those working in smaller or regional settings, and early-career clinicians. "Sometimes you feel like it's the parent taking the child to the specialist, and you're just the one who doesn't know anything. And that's not a nice feeling" (P3). For some, the complexity of cleft care and its association with surgery and specialist knowledge appeared to amplify the pressure. "There's a lot of fear around because it is cleft, it does feel different and it is different" (P11). Several participants described how the perceived expertise gap contributed to hesitation, avoidance, or reliance on others to lead care decisions. "I think a lot of clinicians, sometimes, including myself, don't feel like we have the expertise to manage it, because we're not in a specific cleft role" (P8). This was reiterated by P7, "it (goal setting) should be led by the tertiary clinic, because a lot of community SLPs get fear and overwhelmed (from) the minute they're in this". Even more experienced clinicians reflected on past uncertainty, as P2 shared: "Sometimes, it seems really obvious now ... but it really wasn't obvious to me when I was new".

Feelings of intimidation were not only internal but also reportedly influenced interactions with families and cleft teams. "They (new graduates) probably honestly feel intimidated by calling the expert to ask for advice" (P8), one clinician explained, while another noted the reputational pressure: "Not knowing the answers ... makes us (in) smaller settings, the community health and regional settings, look really bad in the family's eyes" (P8). This sense of inadequacy was reported to deter some SLPs from accepting referrals. "If a kid comes up on the wait list, they go, 'nope, not doing it ... I can't'", said P1. Lack of confidence interpreting reports was another barrier: "Getting the reports from the cleft team and interpreting them ... I think people are really not confident about" (P1).

#### *But ... "I know they're busy"*

Community SLPs frequently acknowledged and expressed empathy for the workload and limited availability of cleft SLPs. While they often wished for more communication or support, they were highly respectful of the cleft team's capacity and hesitant to overburden them. "It's hard to get in touch with busy people, and I've never had a bad experience with anybody speech pathology wise" (P12), one clinician shared, capturing a common tone of understanding. Others were quick to point out that communication delays or limited access were not personal. "It's just

(their) time ... (they're) so swamped ... that's by no means a reflection on them" (P11).

Many described cleft SLPs as dedicated but overwhelmed, juggling large caseloads and expansive regions. "She'd have to go drive six hours ... so it's a massive area. So, she's quite overworked" (P1). Even when community clinicians wanted to ask questions, they often refrained. "I would definitely feel that I would be putting pressure on that clinician, because I know how busy they are" (P5), and "If I didn't need to ... I would try and find information from my supervisor or my peers" (P5). Some felt guilty reaching out, "I don't want to burden her with extra work ... but she's like, no, no, seriously, just anytime" (P1).

Others highlighted systemic challenges, "I know that's not their communication, but it's the systems, just make it happen quicker, respond to my emails" (P2). This subtheme highlights not only the high regard in which cleft SLPs are held, but also the impact of perceived systemic capacity limits on timely collaboration. While community clinicians want connection, many hold back out of concern that they are asking too much.

## **Discussion**

This study forms part of a broader research series investigating CoC in cleft speech services. While prior research (Bow *et al.*, 2025) explored the experiences of specialist cleft team SLPs, this paper shares the voices of community-based SLPs who deliver the majority of day-to-day therapy for children with CP ± L (Grames, 2004).

Three global themes were identified: Navigating roles and relationships, communication and collaboration, and I need help – and I have some ideas. Collectively, these themes reflect a strong commitment by community SLPs to engage in collaborative, high-quality care for children with CP ± L; yet also reveal gaps in information flow, team integration, and professional support. Participants valued strong relationships and reported proactive efforts to communicate, advocate, and coordinate care. However, variability in access to cleft team input, limited clarity around roles, and fragmented communication systems created barriers to consistent CoC.

When contrasted with the perspectives of cleft SLPs in Bow *et al.* (2025), a clear mismatch emerges: Cleft team SLPs often express frustration about limited feedback from community clinicians; while community SLPs described delayed or lack of responses, inconsistent access to information, and reluctance to reach out due to perceived hierarchies or cleft team workload. These perspectives suggest that both groups are motivated to collaborate but report being disconnected by systemic and relational barriers.

A consistent message across the two clinician groups is that relationships matter. When strong, trusting relationships existed between clinicians, and

between families and clinicians, communication was easier, collaboration more efficient, and shared care more achievable. In contrast, when relationships were absent or unformed, communication was delayed or absent altogether. This reinforces the idea that CoC is not only operational but deeply relational, dependent on the quality of interactions as much as the flow of information. Using Haggerty et al. (2003) three-domain model (informational, management, and relational continuity), this study offers new insight into how community SLPs promote and experience continuity in cleft care, and where breakdowns occur.

***Informational continuity: timely, relevant and accessible Information***

*Informational continuity*, defined as the availability and transfer of relevant clinical information across providers (Haggerty et al., 2003), was identified as both essential and inconsistently realised. Community SLPs emphasised the need for timely access to background information, reports, and recommended therapy goals when commencing work with children with cleft. Many reported feeling underprepared to begin therapy without understanding the child's cleft history, including past and planned surgeries, and reported that such information was often delayed, incomplete, or filtered through parents. This finding is echoed in primary care literature, where incomplete transfer of patient data is a common disruption to continuity and has been associated with poorer health outcomes and clinician dissatisfaction (Kripalani et al., 2007).

Moreover, community SLPs expressed a strong preference for time and case-specific, practical resources, rather than generic materials. This differs from cleft teams who reported sharing both reports and educational materials (Bow et al., 2025). This research shows these efforts do not always meet the timing, specificity, or format needs of community clinicians. This misalignment highlights a known challenge in CoC: Information sharing must be not only available, but contextually relevant and accessible at the point of care.

Notably, both cleft and community clinicians acknowledged the limitations of relying on parents to bridge the information gap, yet this was still commonly reported as a mode of information transfer. This shared concern reinforces the importance of establishing direct and reliable communication pathways between clinicians. Together, these findings point to a core challenge in achieving informational continuity. It is not enough to simply provide information—it must be timely, relevant, and easily accessible.

***Management continuity: calls for early collaboration***

*Management continuity*, refers to the consistency and coordination of care across providers and over time (Haggerty et al., 2003). In this study, community

SLPs viewed themselves as central coordinators “on the ground”, embedded in the child's daily context. They described managing therapy, advocating for services, liaising with families and schools, and guiding parents navigating complex health systems. Cleft SLPs (Bow et al., 2025) also reported being coordinators, advocates, and family liaisons.

Community SLPs expressed a desire for shared goal setting with cleft teams and clearer role delineation. When guidance was received from cleft SLPs, particularly around goal setting, it helped align therapy and enhanced confidence. However, this guidance was not reliably available. Participants called for structured handovers, early contact at the point of referral, and joint care planning conversations to support collaborative care.

Similarly, based on interviews with cleft SLPs, the authors argued for a shift from a purely consultative role towards a collaborative partnership model, where cleft and community SLPs share responsibility for goal setting, engage in structured mentoring, and co-design therapy plans (Bow et al., 2025). The perspectives of community clinicians in the current study strongly supports this recommendation. Comparable patterns have been described in other specialised speech-language pathology contexts, such as head and neck cancer (Foley et al., 2023) and paediatric feeding disorders (Clawson et al., 2008; Raatz et al., 2023). In these populations, breakdowns in coordination similarly undermine outcomes, underscoring that the challenges identified here are not unique to cleft care but reflect broader issues in specialised, team-based speech-language pathology practice where hospital- and community-based clinicians need to systematically and repeatedly interact for best CoC.

These findings are echoed in the broader health-care literature. A systematic review of communication and information transfer between hospital-based and primary care physicians found that breakdowns during transitions of care, particularly hospital discharge, led to missed follow-up, reduced clinician satisfaction, and poorer continuity across services (Kripalani et al., 2007). They argue for standardised, timely summaries and proactive planning between teams to ensure information is not delayed or lost. Though set in a medical context, these recommendations are directly applicable to cleft care transitions and underscore the value of implementing consistent handover processes between cleft and community SLPs.

***Relational continuity: hierarchies and the power of relationships***

*Relational continuity*, the ongoing therapeutic relationship between provider and patient or between providers (Haggerty et al., 2003), is widely recognised as a cornerstone of quality care. In this study, community SLPs described how trust, familiarity, and repeat contact with cleft SLPs

facilitated easier communication and learning. Informal but sustained relationships often enabled capacity-building and gave community clinicians the confidence to ask questions and troubleshoot therapy decisions.

Conversely, when no relationship was established, collaboration was described as effortful, inconsistent, or absent. Community SLPs sometimes refrained from reaching out, even when support was needed, due to concern about burdening cleft teams, whom they viewed as overworked. While cleft SLPs acknowledged capacity constraints (Bow *et al.*, 2025), the impact on community clinicians such as delayed outreach, reliance on parents for updates, or complete disengagement, speaks to the critical role of relational continuity in enabling continuing practical collaboration.

Importantly, both studies converged on a key message: Relationships matter. Across the study with cleft clinicians (Bow *et al.*, 2025) and the current study, strong interpersonal relationships were repeatedly identified as a facilitator for successful collaboration, while their absence made communication slower, less effective, and more transactional. This shared recognition highlights relational continuity not only as a practical enabler of teamwork, but as a protective factor against disengagement, role confusion, and fragmented care planning.

The importance of this finding is echoed in broader continuity literature. A systematic review, exploring the association between CoC and patient outcomes, found that increased provider continuity was significantly associated with both improved patient outcomes and satisfaction in a range of healthcare settings (Van Walraven *et al.*, 2010). While much of this research has focused on provider-patient relationships, the findings also reinforce the value of sustained interprofessional relationships in supporting effective and confident care delivery.

Perceptions of hierarchy also influenced relational dynamics. Some community clinicians described cleft SLPs as “wizards” or positioned them “at the top of the pyramid”. While these labels were often meant with admiration, they risk reinforcing disempowering dynamics that hinder equal partnership. In Bow *et al.* (2025), cleft SLPs acknowledged these perceptions, referencing the image of being “the big gold castle on the hill that nobody can come into”. They mentioned avoiding presenting themselves as the experts who held all the answers and instead emphasised a partnership.

This pattern reflects the broader healthcare literature, where hierarchical professional cultures have been shown to restrict collaborative working, reduce help-seeking behaviours, and perpetuate unequal team roles (Crampton *et al.*, 2023). As highlighted in the UK-based review of teamwork enablers and barriers, professionals often felt undervalued when working within rigidly hierarchical environments ultimately

leading to siloed practice and reluctance to share concerns or contribute ideas across roles (Crampton *et al.*, 2023). Actively dismantling perceived hierarchies and promoting psychological safety are therefore essential steps for cultivating genuine interprofessional and intraprofessional collaboration in cleft care. Together, these findings highlight relational continuity, not only as a facilitator of care, but as a protective factor against disengagement, role confusion, and fragmented decision-making in cleft services.

### Implications for practice and future research

This study highlights that CoC in speech-language pathology cleft care cannot rely on goodwill or informal communication alone; it requires intentional systems that enable shared understanding, role clarity, and real-time collaboration. Community SLPs are not passive implementers of external recommendations; they are central to the success of cleft therapy. Their ability to deliver high-quality, consistent care depends on accessible information, respectful partnerships, and clear pathways for engagement. Parents emerged as active coordinators of care, frequently bridging gaps between services, advocating for their child, and implementing therapy in everyday contexts. However, relying on parents to compensate for system-level shortcomings is seen by SLPs as placing a heavy burden on families and risks inconsistent or incomplete information transfer.

Alongside structural systems, this research aligns with growing evidence that relationship-centred communication is a core clinical skill; one that supports trust, improves outcomes, and reduces clinician burnout (Chou & Cooley, Chou 2018). Effective communication is not innate; it must be taught, practised, and refined through feedback. These principles apply not only to interactions with families but also to the professional relationships between cleft and community SLPs. Promoting CoC in cleft services, therefore, requires both operational frameworks and the deliberate cultivation of interpersonal and communication skills.

In addition to system-level changes, practical tools that proactively connect cleft and community SLPs may help operationalise collaborative care. For example, letters or structured communication templates from the cleft SLP to the community or school-based SLP, such as those described by Lynn Marty Grames and incorporated in Sommer and Wombacher (2025), provide a simple mechanism to initiate contact, clarify roles, and outline key recommendations. Adapting and implementing similar resources within local services could support more consistent, triadic communication between cleft SLPs, community SLPs, and parents.

The next paper in this series will explore the perspectives of parents, with an emphasis on how families experience and contribute to continuity of care. This future work will incorporate tailored

recommendations for parents and outline how all stakeholders including community SLPs, cleft team SLPs, and families can work together more effectively to support truly integrated, collaborative cleft care.

### Limitations

The community SLPs who participated in this study may reflect a more motivated or experienced subgroup, potentially skewing results towards clinicians with an interest in cleft care. In addition, while participants were drawn from both Australia and New Zealand, only one clinician from New Zealand took part possibly limiting the generalisability of findings across this context. To protect participant confidentiality, further detailed demographic information could not be reported. Similarly, data on participants' broader caseload profiles (e.g. whether the clinicians predominately worked with speech, language, or generalist caseloads) were not collected, which limits the ability to examine whether experiences of continuity differ according to caseload composition or service settings. Moreover, while this discussion draws on published findings from cleft team SLPs, perspectives from parents remain underexplored. Their inclusion will be essential for a truly comprehensive understanding of continuity in cleft speech services.

### Conclusion

This study amplifies the perspectives of community-based SLPs and sheds light on the challenges and opportunities they face in delivering care to children with cleft palate. These findings reveal that while many values are shared with cleft team SLPs including commitment to families, the importance of communication and relationships, and recognition of systemic constraints, their experience of collaboration is inconsistent and often fragmented. Community SLPs described themselves as “on the ground”, delivering therapy while also acting as advocates and coordinators to support children and families, yet their access to timely information, clinical support, and shared decision-making was often limited.

Through the lens of Haggerty et al.'s (2003) framework, this study sheds light on facilitators and barriers in informational, management and relational continuity, while also identifying promising pathways for more continuous, coordinated, and collaborative, team-based models of care. Community SLPs expressed a strong desire for early communication, structured handovers, joint goal-setting, and flexible professional development.

By highlighting the voices of community clinicians, this study contributes a deeper, more nuanced understanding of where continuity succeeds and where it falters. When read alongside companion research on cleft team SLPs (Bow et al., 2025), it presents a more complete picture of the collaborative landscape in cleft care. It also paves the way for future research to

include parent perspectives and explore triadic care models that engage all stakeholders in shaping systems that are inclusive, integrated, and responsive to the real-world needs of children with cleft palate and their families.

### Ethics approval statement

The study was approved by the Human Research Ethics Committee of The University of Sydney (2023/105).

### Participant consent statement

Written informed consent for publication was obtained from all participants included in this study.

### Disclosure statement

No potential conflict of interest was reported by the authors.

### ORCID

Mikaela Bow  <http://orcid.org/0009-0007-0569-5189>

Patricia McCabe  <http://orcid.org/0000-0002-5182-1087>

Rebecca Sutherland  <http://orcid.org/0000-0002-4522-058X>

Alison Purcell  <http://orcid.org/0000-0002-4623-4086>

### Data availability statement

The data that supports the findings of this study is available in the supplementary material.

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**Chapter 5: “I Have to Be My Child’s Voice”: Parents’  
Experiences of Continuity of Care in Cleft Speech Services**

## **Chapter 5: “I Have to Be My Child’s Voice”: Parents’ Experiences of Continuity of Care in Cleft Speech Services**

This chapter consists of a manuscript that has been submitted for review:

Bow, M., McCabe, P., Sutherland, R., Delzotto, A., & Purcell, A. (n.d.). “I Have to Be My Child’s Voice”: Parents’ Experiences of Continuity of Care in Cleft Speech Services. *Disability and Rehabilitation* (Manuscript submitted for publication).

This chapter advances the overall aim of the thesis by exploring how continuity of care is experienced by parents, who are typically the one constant presence across their child’s cleft care journey. Drawing on the findings of the three previous chapters, this study examines how parents perceive informational, management, and relational continuity throughout their child’s journey. It investigates the challenges families face in communication and collaboration, as well as the facilitators of effective continuity. By centring the voices of parents, this chapter provides a critical consumer perspective that complements the experiences of cleft team and community SLPs. Together, these insights offer a more complete understanding of continuity of care in cleft speech services and inform the development of more collaborative, family-centred models of practice.

### **Statement of Contribution to Co-Authored Published Paper**

This study was designed and written in collaboration with my supervisors, Prof Patricia McCabe, Dr Rebecca Sutherland and Prof Alison Purcell, with input from parent advisor Ms Alison

Delzotto, who contributed to the interpretation of findings and review of the manuscript to ensure parent perspectives were accurately represented.

Bow, M., McCabe, P., Sutherland, R., Delzotto, A., & Purcell, A. (n.d.). *“I Have to Be My Child’s Voice”*: Parents’ Experiences of Continuity of Care in Cleft Speech Services (Manuscript submitted for publication).

Mikaela Bow

Patricia McCabe

Rebecca Sutherland

Alison Delzotto

Alison Purcell

Correspondence concerning this article should be addressed to Ms. Mikaela Bow, Faculty of Medicine and Health, The University of Sydney, Camperdown, NSW 2006, Australia.  
[mikaela.bow@sydney.edu.au](mailto:mikaela.bow@sydney.edu.au)

# **“I Have to Be My Child’s Voice”: Parents’ Experiences of Continuity of Care in Cleft Speech Services**

Mikaela Bow<sup>1</sup>, Patricia McCabe<sup>1</sup>, Rebecca Sutherland<sup>1</sup>, Alison Delzotto<sup>2</sup> and Alison Purcell<sup>3</sup>

<sup>1</sup>Faculty of Medicine and Health, The University of Sydney

<sup>2</sup>Parent Co-Researcher

<sup>3</sup>Faculty of Health, Western Sydney University

## **Author Note**

Correspondence concerning this article should be addressed to Ms. Mikaela Bow, Faculty of Medicine and Health, The University of Sydney, Camperdown, NSW 2006, Australia.

[mikaela.bow@sydney.edu.au](mailto:mikaela.bow@sydney.edu.au) (ORCID ID: <https://orcid.org/0009-0007-0569-5189>)

Co-authors details include:

Professor Patricia McCabe: [tricia.mccabe@sydney.edu.au](mailto:tricia.mccabe@sydney.edu.au) (ORCID ID: <https://orcid.org/0000-0002-5182-1007>)

Doctor Rebecca Sutherland: [rebecca.sutherland@sydney.edu.au](mailto:rebecca.sutherland@sydney.edu.au) (ORCID ID: <https://orcid.org/0000-0002-4522-058X>)

Alison Delzotto: [a.delzotto@hotmail.com](mailto:a.delzotto@hotmail.com) (ORCID ID: <https://orcid.org/0009-0001-2734-1230>)

Professor Alison Purcell: [a.purcell@westernsydney.edu.au](mailto:a.purcell@westernsydney.edu.au) (ORCID ID: <https://orcid.org/0000-0002-4623-4086>)

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## **Abstract**

*Purpose:* This study explored parents' experiences of continuity of care in cleft speech services, focusing on their interactions with cleft team and community speech-language pathologists.

*Method:* Thirteen parents from Australia and New Zealand participated in semi-structured interviews.

*Results:* 5 global themes and 15 subthemes were developed.

The global themes developed were: (1) relationships matter, (2) navigating a long and overwhelming journey, (3) communication that connects (or disconnects) care, (4) shared goal, different roles, and (5) barriers and solutions. Parents valued trusting relationships, accessible information, and coordinated management across services. However, limited three-way collaboration, inconsistent communication, and restricted access to cleft team SLPs left many parents acting as the intermediary between professionals. Parents identified early collaboration, accessible information, and clearer communication pathways as key enablers of continuity.

*Conclusions:* Effective CoC relies on systems and relationships that are coordinated, transparent, and inclusive of families. Strengthening shared communication pathways and co-facilitative models of care could reduce the burden currently carried by parents and enhance cohesion for children with cleft palate.

*Keywords:* cleft palate; speech-language pathology; continuity of care; parent experiences; collaboration; family-centred practice; qualitative research

## Introduction

Parents of children with cleft palate (with or without cleft lip; CP±L) are the one constant presence in their child's long and complex cleft care journey. They play a pivotal role in advocating for their child, coordinating services, supporting therapy at home, and bridging communication between multiple professionals and services (Bow et al., 2025; Bow et al., 2026). Attending speech therapy frequently spans multiple care settings including specialist cleft teams in tertiary centres and community-based SLPs who provide therapy closer to home (American Cleft Palate Craniofacial Association, 2024; Bow et al., 2024). The effectiveness of this model is dependent upon high quality continuity of care (CoC) to allow for speech therapy, which is continuous, coordinated, and responsive to the needs of both the child and family (Bow et al., 2024, 2025; Bow et al., 2026).

Continuity of care (Haggerty et al., 2003) has been conceptualised as encompassing three interrelated domains: informational continuity, which refers to the timely and accurate transfer of relevant information between providers and across settings; management continuity, which involves the consistency and coherence of care plans and therapeutic goals; and relational continuity, which refers to ongoing, trusting relationships between care recipients and providers. In cleft speech care, where children often transition between different therapists over time and across locations, maintaining these domains is both essential and challenging.

Parents play a critical role in sustaining continuity of care as they are the consistent link across the many transitions children with cleft experience. They are recognised as having unique and expert knowledge of their child's development, interests, and day-to-day impact of their communication difficulties (McCormack et al., 2010), making them valuable collaborators in family-centred practice (Espe-Sherwindt, 2008). Unlike professionals who may be involved for only part of the child's care pathway, parents accompany their child across multiple services. For

this reason, alongside others, professional organisations internationally emphasise collaboration with parents as a core element of best practice (American Speech-Language-Hearing Association, 2016; Speech Pathology Australia, 2022). Importantly, research has begun to capture parents' perspectives highlighting their expectations and priorities within cleft speech therapy (Alighieri et al., 2020).

Parents of children with cleft have shared that they expect clear communication between the different disciplines involved in their child's care and wanted community SLPs to liaise directly with the cleft team to be kept informed about their child's plan (Alighieri, 2020). They also valued SLPs who were knowledgeable and experienced in treating cleft and emphasised the importance of receiving both written and oral information. Specifically, parents wanted information about treatment progress, prognosis, and strategies for transferring learned skills into the home environment. Beyond information exchange, parents underscored the importance of a positive and trusting connection between themselves, their child, and the SLP (Alighieri et al., 2020). Importantly, when parents felt informed and supported, they described a stronger sense of trust and connection with their clinician. Evidence also suggests that parents can play an active and meaningful role in therapy when provided with adequate training and support. Sell et al. (2023) demonstrated that parents were able to successfully undertake direct therapy following in-depth training, reporting growth in their knowledge and confidence and describing themselves as empowered when supported by specialist SLPs. Together, these studies show that when parents are actively engaged, adequately informed, and supported, they can be powerful facilitators of continuity in cleft speech care.

These findings align with the broader cleft literature exploring parent experiences in multidisciplinary care. Nelson and Kirk (2013) reported that parents often felt a lack of information concerning future treatment and emphasised the need for better coordination,

including a key professional to act as a consistent point of contact across the treatment pathway. Similarly Myhre et al. (2019) described parents' experiences of multidisciplinary craniofacial consultations as both reassuring and overwhelming, with satisfaction closely linked to professionals' communication skills and the clarity of information provided. Parents who felt well-informed and listened to reported higher satisfaction, while inadequate communication contributed to feelings of being objectified or excluded from the process. The Eurocleft study also highlighted that one-third of parents desired more information from speech therapists specifically, underlining the significance parents place on communication about speech development (Semb et al., 2005). Importantly, parents have consistently identified speech outcomes as a key concern for their child's quality of life, with poor intelligibility discouraging the child from communicating with others and contributing to psychosocial challenges when difficulties are not adequately addressed (Zeraatkar et al., 2019).

Beyond cleft-specific contexts, studies of SLP services for children with speech, language and communication needs (SLCN) similarly show that parents want more consistent therapy, clearer communication, and clarification of their role within intervention (Carroll, 2010). These findings reinforce that parents across clinical populations value being seen as knowledgeable partners and expect to be included in decision-making and therapy processes. This aligns with evidence that SLPs working with children with SLCN also value parent involvement. For example, a survey of 288 Australian SLPs reported 96.4% involving parents in phonology-based speech sound disorder intervention (Sugden, 2018),

Despite this growing recognition of the importance of parent engagement, much of the cleft literature on continuity of care has focused on the perspectives of health professionals rather than families. For instance, recent studies by (Bow et al., 2025; Bow et al., 2026) have demonstrated that cleft team and community SLPs value collaboration but often experience

fragmented communication, unclear role boundaries, limited access to shared documentation, and variability in cleft-specific training and clinical confidence. These studies also highlighted that relationships, both between professionals and with families, are central to continuity but can become points of vulnerability when time, access, or clarity is limited. Together, this work underscores the need to foreground parent experiences, as they reveal how these professional challenges translate into real impacts on continuity across the care pathway.

Consumer engagement research further underscores the importance of incorporating the perspectives of families into healthcare and research processes. Frameworks such as the United Kingdom's Health Research Authority Guidance on Public Involvement in Research and the National Health and Medical Research Council Statement on Consumer Involvement in Health and Medical Research in Australia advocate for meaningful partnerships with consumers in research (Health Research Authority, 2025; National Health Medical Research Council, 2016). Parents of children with complex health needs bring unique experiential knowledge that can complement professional expertise and ensure that research outputs are relevant, accessible, and responsive to the realities of family life. In cleft care, embedding consumer voices is particularly valuable given the long-term, multidisciplinary nature of treatment and the central role of parents in navigating and sustaining continuity of care.

As the one constant across their child's cleft care journey, parents have a vantage point that no single clinician of service can hold. They are uniquely positioned to observe and experience the realities of continuity, or lack thereof, of care. Parents are the ones who must interpret and act upon specialist advice, facilitate referrals and appointments, and support their child's engagement in therapy. In doing so, they are not just passive recipients of care on behalf of their children but active participants, advocates, and decision-makers and are seen as such by

their clinicians (Bow et al., 2025; Bow et al., 2026). Understanding their experiences is critical to improving how cleft speech services are delivered, coordinated, and supported across sectors.

Building on previous studies that examined the experiences of cleft team (Bow et al., 2025) and community-based SLPs (Bow et al., 2026), this study focuses on the perspectives of parents to complete a triangulated understanding of the care continuum.

This study aimed to explore the experiences of parents regarding continuity of care in cleft speech services. The research questions guiding this phase were:

1. What does communication and collaboration currently look like between parents, community SLPs, and cleft team SLPs from the parents' perspective in cleft care?
2. What processes are currently being used by parents to ensure continuity of care for their children with CP±L?
3. What are the barriers impacting continuity of care?
4. What are the facilitators for promoting continuity of care?

By amplifying the voices of parents, this study contributes to a more holistic understanding of continuity in cleft services and highlights opportunities to strengthen partnerships across clinical settings.

## **Methods**

### **Study design**

This study used a qualitative methodology guided by reflexive thematic analysis (Braun & Clarke, 2022), and informed by grounded theory principles to examine parents' experiences of CoC for children with CP±L. Ethical approval was granted by The University of Sydney Human Research Ethics Committee (Protocol: 2023/105), and all participants provided written informed consent before taking part.

### **Consumer involvement**

In alignment with principles of consumer and community involvement in research (Health Research Authority, 2025; National Health Medical Research Council, 2016), this study included active consumer participation across numerous phases of the project. The Smits et al. (2020) Involvement Matrix was used to guide, document, and reflect on the nature and extent of involvement, defining the parent co-researcher's roles as advisor, co-thinker, and partner throughout the execution and implementation phases. A parent of a child with a cleft, external to the participant sample, was invited to contribute as a consumer co-researcher. During the execution phase, she contributed as a co-thinker and partner, independently reviewing de-identified transcripts, noting preliminary reflections, and participating in team discussions during data analysis meetings. Her feedback helped to ensure that the emerging codes and themes reflected the realities of navigating cleft care and that parent voice remained central to interpretation. During the implementation phase, she served as an advisor and partner in refining theme names and reviewing draft and final manuscripts for accuracy, clarity, and resonance with lived experience.

### **Participants**

Participants were eligible if they were a parent or caregiver of a child with cleft palate who had received services from both a cleft team SLP and a community-based SLP within the past 12 months. Eligible participants were required to reside in Australia or New Zealand. Purposive sampling was employed to ensure variation in participant backgrounds, including geographic distribution across urban, regional, and rural settings.

Recruitment was conducted via advertisements disseminated through parent support groups such as CleftPALS and Cleft NZ, as well as targeted Australian and New Zealand Facebook communities. Interested parents could express interest by contacting the research team via email or completing a secure Qualtrics survey. The survey included a Participant Information

Statement, Consent Form, and a short demographic questionnaire. No incentives were offered for participation. Recruitment continued until data saturation was reached, defined as the point when no new themes were identified in successive interviews (Hennink & Kaiser, 2022). No participants declined participation or withdrew from the study.

### **Research Team and Reflexivity**

The research team comprised five female researchers with complementary expertise. All interviews were completed by the first author, a female mid-career SLP and doctoral candidate with clinical experience in both cleft team settings and private practice settings. At the time of data collection, she was working in academic and clinical roles. Two researchers were senior academics with PhDs and clinical-research backgrounds in cleft-related speech disorders and speech pathology across the lifespan. Another was a senior researcher with a PhD and a background in disability and neurodiversity. The fifth was a registered nurse and parent of a child with a cleft palate, who contributed as a parent co-researcher and offered valuable lived-experience perspectives. This diverse team composition enhanced the depth and credibility of data analysis and interpretation.

### **Data Collection and Analysis**

Semi-structured interviews were conducted via Zoom to accommodate participants from a wide geographical range. Interviews took place in settings chosen by participants, typically within their own home. A collaboratively developed and piloted interview guide (see Appendix A), informed by findings from the first three papers in this research series, was used to support consistency across interviews. All interviews were audio and video-recorded using Zoom's secure platform and transcribed verbatim. Field notes were taken during and immediately after each interview to capture relevant contextual and non-verbal information. These field notes documented contextual observations, early analytic reflections, and potential patterns emerging

across interviews, which were later revisited during the coding and theme development stages. No repeat interviews were conducted. Interview durations ranged from 24 to 59 minutes, with a mean of 30 minutes.

Transcripts were de-identified and data were analysed using reflexive thematic analysis in accordance with Braun and Clarke (2022) six-phase framework. First, all authors familiarised themselves with the transcripts through repeated reading. Initial coding was conducted by the first author and third author, followed by one team member independently reviewing the entire dataset to enhance analytic depth. The team then collaboratively reviewed and refined the codes into candidate themes. Themes were iteratively developed through team discussions, allowing for continual re-engagement with the data and evolving interpretations. Throughout this process, the research team revisited transcripts to ensure that candidate themes were strongly grounded in participants' accounts and reflected the breadth and complexity of the dataset.

### **Trustworthiness**

To support the trustworthiness of the data, several strategies were employed. Member checking was offered, whereby participants could review their transcripts and suggest amendments. Nine participants opted to review their transcripts, with one requesting changes such as the omission of fillers and minor grammatical adjustments. Researcher triangulation further enhanced credibility: the five researchers brought diverse perspectives, including clinical, academic, and lived-experience expertise. The inclusion of a parent co-researcher added an additional layer of interpretive depth, ensuring that emerging codes and themes resonated with lived experiences of navigating cleft services and that parent perspectives remained central throughout the analytic process.

An existing professional relationship between the interviewer and two participants was noted, although none of these participants were directly recruited. Participants were aware that

the interviewer was conducting the research as part of her PhD and that the study aimed to improve CoC in cleft speech services. To mitigate potential bias associated with these existing relationships, the first author maintained a reflective journal throughout the study. This journal documented assumptions, reactions to interview content, and evolving interpretations, enabling ongoing reflexive consideration of how the researcher's clinical experience and professional relationships might shape the analytic process.

Researcher triangulation was used to enhance credibility, with each team member contributing a distinct lens to data analysis and interpretation. Differences in interpretation were discussed collaboratively during analysis meetings, supporting transparency and reflexivity in theme development and strengthening confidence in the final analytic framework.

## **Results**

### **Participants**

A total of 13 parents participated in 12 interviews. One interview included two parents, and all participants were female. Participants represented diverse family and service contexts across urban, regional, and rural areas in Australia and New Zealand, with one parent residing in New Zealand. The children of these parents ranged in age from 1 to 12 years, with an average age of 4.6 years. Five of the 12 children had an additional diagnosis beyond their cleft palate.

The speech therapy experiences of these families reflected the complexity of cleft care pathways with seven of the children currently receiving therapy from more than one local speech pathologist, with one child seeing three different community SLPs. Frequency of therapy sessions varied considerably, ranging from twice weekly to monthly, or even less in one instance. See table 1 for demographic information.

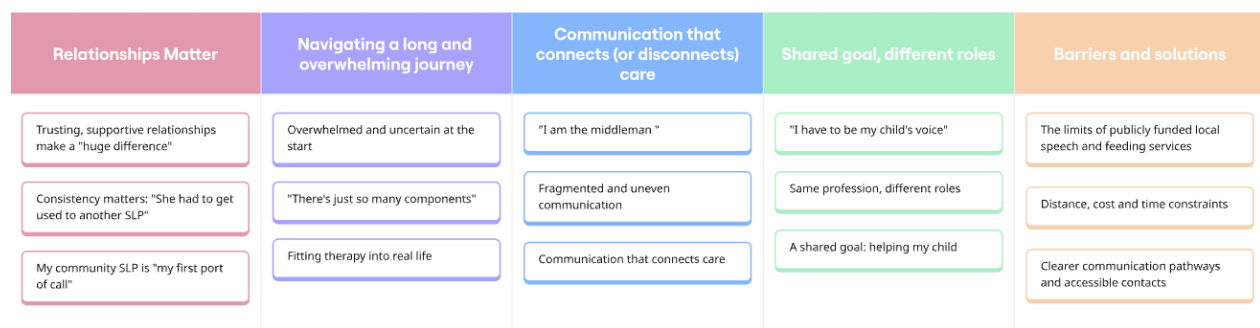
Table 1. Demographic Information.

Participant number	Relationship to child	Age of child (in years)	Other diagnoses	No. of local SLPs	Intervention frequency
1	Mother	12	No	1	Fortnightly - monthly
2	Mother	3	Yes	2	Fortnightly
3	Mother	2	No	1	Monthly
4	Mother	3	No	2	Fortnightly
5	Mother	1	Yes	2	Monthly
6	Mother + Mother	1	No	2	Monthly
7	Mother	10	Yes	3	Weekly x 1 Fortnightly x 1 Monthly x 1
8	Mother	12	No	1	Recent review. Will recommence sessions soon.
9	Mother	2	Yes	2	2 x weekly
10	Mother	3	Yes	2	1 x weekly 1 x monthly
11	Mother	3	No	1	Weekly
12	Mother	3	No	1	Fortnightly

## Themes

Thematic analysis yielded 5 overarching themes and 15 subthemes.

A summary of themes and subthemes can be seen in figure 1.



### Theme one: Relationships matter

Parents repeatedly emphasised that the quality of their relationships with both community and cleft SLPs shaped their experience of care.

*Trusting, supportive relationships make a "huge difference"*

Parents described how trusting, supportive relationships with their SLPs made a “huge difference” (P10) to their child’s care and their own confidence on the process. Existing relationships between community and cleft SLPs were seen as particularly valuable, enabling smoother communication and coordinated plans. For some, knowing their community SLP already had ties with the cleft team reassured them that information would be shared. As one parent explained, “because I think they (community SLP) know the teams as well, I felt like they took more interest and would go and talk to the teams” (P1),

Established links between professionals also eased transitions and reduced the need for parents to act as the go-between. Familiarity with the cleft system was seen as a strength: “she had been in (cleft hospital) where my daughter was primarily looked after for 20 or so odd years... And then when I mentioned to her, this is the person she was seeing, she knew who that was” (P5). This trust in professional relationships was highly valued, with one parent reflecting, “I think they trust each other (community SLP and cleft SLP)” (P5). Similarly, another parent emphasised the benefit of continuity, noting that “history with the cleft clinic and everything sort of helped make that decision to go with her as well... And I think the communication has been really good between...it really seems that everyone knows each other as well” (P6).

Parents frequently used highly positive language such as “amazing,” “wonderful,” “incredible,” “blessed,” “lucky” to describe both community and cleft SLPs (P1, P6, P9, P10, P11) but with particular emphasis on their community SLP. This language conveyed not just satisfaction but deep gratitude and emotional reassurance, reinforcing how much positive relationships shaped their journey. As one parent reflected, “She’s fantastic. We love (community SLP)” (P6). Another explained, “my speech pathologist (cleft SLP), she’s amazing, the local one as well” (P9).

***Consistency matters: “She had to get used to another SLP”***

Parents emphasised that consistency in both relationships and appointments with speech pathologists was central to their child’s progress and their own sense of reassurance. Having one speech pathologist who knew the child well was described as highly valuable: “she's been with (child) throughout his whole journey. So having that history, knowing who he is, what he's capable of, you know what might set him off and what might make him feel comfortable... she has been really valuable” (P4). Others echoed the stability this brought, with one parent reflecting, “With our local speechie, it's been very consistent. We've been well supported” (P4).

By contrast, when therapy was interrupted or clinicians changed, families described disruption and uncertainty. One parent recalled, “we haven't seen them for 18 months prior to that, and then we were like, smack bang with like this information, of like, she's delayed, she's delayed, she's delayed” (P12). Another explained, “So (child) had to get used to a new speechie again” (P7).

***My community SLP is “my first port of call”***

Parents consistently highlighted the central role of their community SLPs as the person they turned to first. Community SLPs were described as the most accessible and familiar supports, with regular contact making them the natural “first port of call” (P3). As one parent put it, “I see that the speech team here (local) is like my first point of call... I kind of see the cleft team in (city), like their speech team as, if it can't be fixed here, or it's something that is beyond the services that are offered in (town). It's kind of like it gets escalated up to (cleft team)” (P3). Similarly, P4 explained, “I’d say definitely the local speechie (is the main person I communicate with).” This sentiment was reiterated by P11: “It’s really just been our speech therapist that’s been kind of holding our hand every step of the way”.

While parents recognised the expertise of cleft team SLPs, they described feeling more comfortable approaching local therapists for day-to-day concerns: “I probably feel more

comfortable asking my local one... than asking (cleft SLP)” (P12). For some, this sense of security came from the confidence that their local therapist could interpret or pass on concerns: “I think without the help of my local speechie, I wouldn't have got the reassurance and the answers that I needed to feel like things were okay” (P4).

### **Theme two: Navigating a long and overwhelming journey**

Parents described the cleft journey as long, confusing, and at times exhausting, especially in the early years.

#### ***Overwhelmed and uncertain at the start***

The early stages of the cleft journey were described as overwhelming and confusing. Parents often entered appointments with large teams of professionals without a clear understanding of who each person was or why speech pathology was involved so early. As one parent recalled, “that initial appointment or two, it was very overwhelming, and I had no idea what anyone was doing or where anyone stood in (child's) journey” (P2). Others echoed this sense of uncertainty, with P9 reflecting, “I didn't know what a speech pathologist was. I thought it was only speech, nothing really with feeding,” while P2 admitted, “She was a tiny baby then I was like why the hell would I need a speech therapist for a baby.”

Many parents also described feeling unprepared for the length and complexity of the journey. P3 explained, “the whole thing is daunting at the start... It's just a long road, like it's not going to end now,” while another parent reflected, “I didn't realise how long of a journey it was going to be with speech” (P2). For some, this sense of overwhelm was compounded by receiving conflicting advice in the early stages. P6 recalled being told different things by the cleft team and the community service: “we were being told one thing by the cleft team, yeah, where (child) should be at feeding wise. And then the speechie we were seeing through the (local public health

service) ... just was telling us a completely different thing, and we didn't know who was right or what we should be doing.”

Parents also highlighted the emotional toll of these early experiences including the loneliness of navigating the first 18 months largely on their own, “No one really prepared us for the journey of like, the struggles of it... It can be a very lonely journey” (P12). Practical challenges such as appointment fatigue were also noted, with P7 explaining, “appointment fatigue, yeah? Is something that you don't realise happens until suddenly she's getting the appointments at school.”

Despite these difficulties, parents described a shift over time as they became more familiar with the system and “learned as they went”, gaining confidence through experience. P1 reflected, “I probably didn't know the questions to ask back when she was younger. Now that we've seen different ways, different speech pathologists work, I feel more confident in asking.” Similarly, P2 noted that what once felt overwhelming is now seen differently: “walking into that cleft team, there's just so many people in the one spot, and you kind of, it was a big eye opener... now I find it the most well-oiled machine in the world.” This illustrates how confidence often grows with time and experience but also highlights the challenges families face at the beginning of their child’s cleft journey.

***“There’s just so many components”***

Parents described the complexity of navigating speech services over time, often beginning with feeding support in hospital before transitioning into community health, private clinics, or NDIS-funded therapy as their child’s needs developed. As P1 explained, “We were seeing a speech pathologist, initially for feeding. Obviously, it was (cleft SLP), and initially through (hospital)... We then linked in with our local community health at (town), and we had two blocks there.” For others, the shift from one service to another was ongoing, with P5 reflecting, “she

started off being in (local hospital), and then (cleft hospital), so was using the therapists that were on site, and then we ventured out independently when we got NDIS (National Disability Insurance Scheme) and other supports and found private therapists to help her with her feeding journey.”

Parents described confusion around who is responsible for what, particularly when care was split between cleft teams and community providers. As P3 described, “it just can be sometimes a bit confusing occasionally to know who just to go to,” while P7 asked, “is the (cleft SLP) supposed to check in monthly with the speechie? Like, I don’t know the process on that.” This uncertainty sometimes resulted in gaps in care or delayed follow-up, as families waited for services to reach out as P3 explained, “I was considering looking for private speech therapy, because I wasn’t sure whether the clinic was going to reach out to us.” For many, navigating multiple providers without clear communication or defined responsibilities compounded the sense that, as P3 put it, “there’s just so many components.”

### ***Fitting therapy into real life***

Parents described the challenge of fitting therapy into already busy family lives. School, work, pregnancy, and everyday routines often limited what was possible. As one parent explained, “we haven't been able to fit it in this year... at the moment, we're just doing intensive during school holidays” (P1). Others admitted to feeling tired or inconsistent: “Sometimes I try and just sit back and let (community SLP) take over and I'm tired. I'm like, yep, over it” (P2); “there are some weeks that... we might not be as good as we should be (at homework), yeah, because of life” (P3).

Families valued when therapists adapted expectations to fit real life, offering reassurance and flexibility. P3 reflected that being told to “just focus on two or three” tasks during a busy week made therapy feel achievable. Parents also appreciated supportive, family-centred

approaches: “She wants to work with us as a family... She’s so supportive” (P10). In contrast, others found rigid systems less helpful: “I just found that that wasn't our experience in our local hospital. It was just very much this is this is our approach” (P10).

### **Theme three: Communication that connects (or disconnects) care**

Parents repeatedly emphasised that communication and collaboration between cleft and community SLPs shaped the quality of their child’s care. When information flowed directly between professionals, supported by practical tools like emails, reports, or videos, families felt confident and less burdened. However, when communication was absent or left to parents to manage, continuity of care was disrupted, leaving families feeling like “the middleman.” Three-way communication between parents, community SLPs, and cleft teams was rare, and while some parents were pragmatic about this, others described it as a clear gap.

#### ***“I am the middleman”***

Parents consistently described being the “middleman” between cleft teams and community SLPs, responsible for relaying updates, transferring reports, and ensuring everyone was informed. This was often seen as burdensome and inefficient. As one parent explained, “because there's no communication from the private speech pathologist back to the hospital, I need to give them that update when I go to clinic with (child)... Without that, they would have no idea what she's doing outside of visiting once a year at the (cleft hospital)” (P1). Others spoke of the challenge of juggling correspondence from multiple services, with P3 noting, “I sometimes get correspondence from (town), and then I get correspondence from (cleft hospital), and, like, I’ve got to keep track of it all.”

Parents highlighted both the practical strain and the risks of this role, from repeatedly handing over summaries at new appointments (P7, P6) to gaps in care when communication did not occur. For example, P8 reflected, “if that woman on the (area) had been in touch with... the

speechies in (cleft hospital), maybe we could have worked out that (child)'s palate was too short to make a 'p' and a 'b', and we couldn't have spent all that time trying to get him to do it.” While some acknowledged moments when their efforts helped link services together (P4, P11), most expressed a clear preference for direct professional-to-professional communication, rather than parents carrying the responsibility.

### ***Fragmented and uneven communication***

Parents described a mixed picture of how information flowed within and between services, with day-to-day communication often accessible in the community, episodic in the cleft clinics, and inconsistently shared across providers leaving families to pull the pieces together themselves.

### **Communication with community SLPs**

With community SLPs, contact was mostly immediate and practical. Parents highlighted routine face-to-face updates and verbal check-ins: “Probably, mostly it’s just verbal communication. When I see them, and they will then give me feedback at the end of each session of what (child’s) done” (P1). This was reiterated by others: “Our sessions are face to face every month” (P12). Many valued emails beyond the session: “We mainly deal via email if we’re not in an appointment. But yeah, I think communication is really great. She provides a follow up summary of all of our appointments” (P4), and “we’ve messaged quite a few times as well, but primarily it’s been through email, just because it’s easier to remember things”. Others appreciated responsiveness and reliability: “I felt like I emailed her on Monday night and said that (child) is doing incredible after his surgery, and we want to get back into it. I get a reply at 6am the next morning” (P6). Few participants identified the need for more consistent between-session feedback: “Even just a text after each appointment saying (child) did great today. This is what we’re working on. See you in a fortnight” (P2).

### **Communication with cleft-team SLPs**

In contrast, communication with cleft SLPs was commonly described as concentrated around clinic appointments. Parents valued the structure and documentation. “They (cleft SLP) would communicate with us while we are there. They would get (child) to do exercises, and then do a summary of how her speech is going, and give recommendations on whether she needs to” (P1). Some found access straightforward and appreciated direct contact. “The clinic has always been very easy to access, so I can easily ring them... I can get in contact with someone” (P3). Others described long intervals between reviews and limited communication outside of appointments. “We don’t have a lot of contact with them, apart from when he’s due for an appointment with the cleft clinic” (P3). “We don’t have a lot of interaction anymore with the cleft team speech pathologist besides our once or we’re not even going back for another two years now to see them which, to me, is a little bit concerning” (P1). Some described communication as brief and clinic-based. “It’s good when you’re there... but it’s all done, I guess, in the session” and “It’s not as easy if you’ve got a follow up question, because they don’t always work full time in the clinic, and they’re busy” (P8). For some families, experiences were overwhelmingly positive. “I could never say a bad word about the cleft clinic and what they have done” (P10).

### **Communication between SLPs**

Professional-to-professional communication ranged from excellent to absent. Some parents only inferred contact through letters or updates. “I believe they do (community and cleft SLP) talk. ... like, a letter gets drawn up after a cleft clinic visit, of their assessment of (child), and then that gets communicated back to the (community) team” (P3). “I know for a fact, (community SLP) has (cleft SLP) details, so she’ll send (cleft SLP) stuff that she needs to” (P2). Others described clear, two-way exchanges that reassured them care was aligned. “She’ll email her and say, “What should she do?” She even had...training” and “then (cleft SLP) emails, my

local one at local speech, and then they communicate and see what else, what other structures that strategies they have to do” (P9). Yet uncertainty persisted. “I don’t know that there was any (communication between cleft SLP and community SLP). Maybe there was, but I didn’t know about it” (P1).

### **Three-way communication**

Triadic or “three-way” communication was rare. ““There is none” (P3). For some, this absence was viewed pragmatically. “I don’t think there’s been a joint appointment with us, but I don’t feel that there needs to be... it takes a lot of organisation to get three people in the same place at the same time” (P2). “I could say to (community SLP)... when you’re talking to (cleft SLP), could you make sure that I can just drop in and talk on the Zoom.” (P7). Others saw missed opportunities for coordination. “I don’t think I probably ever had collaboration between a private speechie and a public one, so I guess it’s something that probably does make sense, especially in those early years” (P8). Even when professionals connected directly, parents were often positioned at the edges. “It was more between, the speech pathologists, not so much us. Trying to work out what could work for (child) and, like, it was kind of just back and forth of strategies, I think” (P6).

Taken together, these accounts depict fragmented and uneven communication. Parents experienced accessible, relationship-based exchanges in the community, structured but episodic communication in cleft clinics, variable coordination between professionals, and very little routine three-way dialogue. Families experienced the benefits when the pieces connected and the burden when they did not.

### ***Communication that connects care***

Parents highlighted that communication was most effective when it was practical, collaborative, and aligned. Written and retrievable formats such as emails were frequently

described as the easiest and most reliable way to stay updated: “At the moment, yeah, the emails seem to be the go. And I guess the most effective form of communication ...between all the parties” (P6). For some, receiving resources in accessible formats made a tangible difference at home: “I’ve got videos of her doing stuff in the session, and so then I could look at them at home and say, this is what we’re meant to be doing. That was the best way” (P8).

When communication extended beyond updates and became collaborative, parents felt reassured that everyone was “on the same page” (P11). They valued professionals sharing observations and strategies directly: “So she (community SLP) has any questions... she videos (child), and she sends it to (cleft SLP) and says, Am I doing a good process? What do I have to do next?” (P9). Similarly, P11 valued when her SLPs worked together: “They’ve had maybe three or four phone calls, ... having the communication between the two of them to work on a solution... has been brilliant”. Parents described how this reduced their burden as the middleman and ensured more coordinated care: “To have them both (community and cleft SLP) then communicate with each other and say what they’ve both noticed has been pretty amazing” (P11). For these families, effective communication was not only practical but also confidence-building, giving them reassurance that therapy was connected, consistent, and responsive to their child’s needs.

#### **Theme four: Our roles and goals**

##### ***“I have to be my child’s voice”***

Parents repeatedly described advocacy as one of their most important and persistent roles. Almost every parent emphasised that they had to act as their child’s voice, ensuring their needs were recognised and acted upon. As one parent explained, “I just have to advocate, like I just have to be (child’s) voice, because she doesn't know what she needs and she doesn't know what's

wrong with her” (P2). Others echoed this sentiment, saying, “you're your child's only advocate” (P7).

This advocacy extended beyond simply speaking up in appointments. Parents described following up with providers, chasing communication, and holding the system together when links were missing. One parent reflected, “you've really sort of got to be that cog to keep things moving and everything connected” (P4). Another described, “I've had to advocate for even that communication to happen, rather than just being standard across the board” (P5). Many parents accepted this as part of their role but also expressed frustration that the responsibility fell so heavily on them rather than being supported by established processes.

For many, being their child’s voice also meant understanding enough to advocate effectively. Parents described a strong drive to seek knowledge about therapy goals, progress, and what each activity was targeting. “The why kind of helps me understand the kind of activities that I need to do” (P3). Others emphasised the need to build their own expertise: “There’s no point in doing speech therapy once a week with a therapist. I need to understand how it needs to be done, so that I can do it properly at home” (P8). Parents described investing time in researching, clarifying approaches, and monitoring progress: “I’ve spent countless hours figuring out these things that are going to help (child) and then also communicating them with the local speech therapist” (P4). This pursuit of understanding was often tied to managing uncertainty. As P12 reflected, “being educated on what’s to come... the unknown is also kind of fearful as well.”

This understanding translated into action, as parents positioned themselves as extensions of therapy. They took on the responsibility of practising, reinforcing, and embedding strategies in everyday life. Many described “continuing that work outside of clinic” (P4) and ensuring that what was introduced in sessions was not “lost in weeks” (P2). For some, this involved managing structured homework or creating resources from scratch. “I sweated blood over it (speech

therapy). I would make all these resources at home for all the sounds, and I'd laminate them, and we do it twice a day" (P8). Others described integrating therapy into family routines: "She (community SLP) kind of gives us the tools and we put stuff into practice" (P6).

### ***Same profession, different roles***

Parents recognised that while community and cleft SLPs share the same profession, their roles in the cleft care journey were distinct.

### **On the ground: community SLPs doing the hard work**

Across interviews, community SLPs were positioned as central to ongoing care, often described as "on the ground" (P3) and responsible for practical progress. "Community SLPs are doing all the therapy, all the hard work" (P12). Parents valued their consistency and responsiveness, describing the role as "pretty massive... from helping these kids to use bottles, to eating safely, to then learning how to use their speech sounds" (P4).

Beyond therapy, community SLPs were seen as monitors, advocates, and connectors. "If something was worrying or anything, she would, she'd be honest" (P6). "Her role, I guess, having those appointments and then doing those NDIS reviews for us is more than enough" (P2). Some shared notes or contacted cleft teams when needed (P8, P12). Overall, families viewed community SLPs as carrying the weight of implementation, valuing their reliability and supportiveness.

### **Specialist oversight: cleft SLPs as assessors and guides**

Cleft SLPs were seen as specialists who "specialise in the cleft speech kind of stuff" (P2). Parents described their role as supporting the community SLP to ensure care aligned with cleft-specific expertise: "Working with (community SLP), ensuring... they're both aligning in what (hospital) wants and what we're working with" (P12). As one parent reflected, "The cleft team should be... giving some guidance to the private one to make sure they know what they're doing"

(P8). Families valued this partnership between the specialist and local providers but noted that access and contact varied considerably.

### **Bridging the knowledge gap: willingness to learn and collaborate**

Parents did not expect community SLPs to have specialist cleft knowledge, but they valued honesty and initiative when expertise was limited. “My private speechie, whether she understands something or not, she tells me honestly... how we're going to pursue it. Or let me ask my colleague, or let me get back to you on that” (P5). “She wants to learn.” (P10).

Many described community SLPs who sought advice or collaborated directly with cleft teams: “She actually emailed (cleft SLP) to find out more information” (P9). “She will say, I'm not sure. I'm going to consult with (cleft SLP)... to get us the right answer. And she always does” (P10).

### **Access and assumptions: I love my community SLP, but am I missing out?**

While most families expressed high satisfaction with their community SLPs, some questioned whether they were missing out on more regular or specialist input from cleft teams. “I do feel that they are not very proactive in reaching out to us to see how we're going. Maybe that's because I've said we're seeing a private speech pathologist, so they just let it be” (P1). Parents also perceived inequities between city and regional families: “The assumption is that they probably get more regular appointments with the cleft team at the hospital in (city)... whereas for us, we basically only use the speech team out there for a review” (P3).

Several parents felt that cleft teams assumed regional families would not travel for therapy. “They really expect you to go locally to sort out anything... That's what I've always been told since the beginning” (P4). Others challenged this assumption: “We are happy to see you more frequently... not make an assumption that because we're in (town), an hour and a half

away, that we wouldn't make the effort to take (child) to a weekly speech session, if that's what's required" (P7).

### ***A shared goal: helping my child***

Parents emphasised that despite different roles, everyone involved was ultimately working toward the same goal: helping their child succeed. As one parent put it, "I think we all have the one main goal, and that's just to better (child) and to help her" (P2). This was reiterated by P5, "I think the idea is that we all have a common goal at the end of the day is to kind of help fix this". Families recognised that each professional brought unique expertise, with local therapists managing the day-to-day and cleft SLPs providing specialist oversight: "(they) both specialise in certain things, so if (community SLP) feels that she has a lacking, then she's obviously reaching out and if (cleft SLP) feel that (cleft SLP) need to contact her, (cleft SLP is) contacting her" (P2).

At the same time, parents were acutely aware of gaps in the system. Although they felt "everybody's got (child)'s best interests" at heart, they felt "without having a parent that's pretty willing to advocate for your own kid, they don't really fit together as much" (P4). Some described themselves as the "cog to keep things moving and everything connected" (P4) and stepping in when the different parts did not "fit together" (P4).

### **Theme five: Barriers and solutions**

Parents described a range of systemic and practical barriers that disrupted continuity of care, from inconsistent local services and barriers of distance, cost, and unclear communication pathways. Yet across interviews, families also identified tangible solutions including clearer communication, accessible information, and better coordination between services.

### ***The limits of publicly funded local speech and feeding services***

Parents frequently contrasted their experiences in the public system with those in private therapy, describing, across jurisdictions, public services as inconsistent, harder to contact, and less family centred. “I just did find there was not a lot of consistency between who was seeing (child) often, and then they would leave, and would have to catch them up on (child’s) background” (P1). High turnover, limited appointments, and a lack of flexibility were common frustrations. “We weren't able to get a decent amount of appointments with them, which, I mean, I understand is the public system, and I know that they're overwhelmed” (P10). Parents noted that community health clinicians were often difficult to reach: “Community health - I wouldn't have got an email from them” (P1), and contrasted this with the responsiveness of private therapists: “Now being with (community SLP 1) and (community SLP 2), the communication is miles above anything we ever got from our local hospital, and just very responsive to emails, very responsive to texts, very easy to get in contact with” (P10). Private services were described as more flexible and accessible: “It's (private therapy) always better than the public system... I guess they're more local, and you can pick your time and your day that suits you” (P8).

### ***Distance, cost, and time constraints***

Parents also described the practical barriers of geography, scheduling, and affordability that shaped access to care. “It was hard to get in (to speech therapy), and then managing school and school hours, we couldn't get a block that was outside of school time” (P1). For many, cost determined therapy frequency: “It is also financial issue, I can't afford to send her weekly, fortnightly is all we can afford... It is hard, because as a parent, I'm left to make these decisions without sort of any guidance from the cleft team” (P1).

Families in regional or rural areas reported that location itself was a major barrier. “There are just certain things, like, when you live regionally, that are just a bit harder” (P3). “We've got a massive population on the (area), and we don't have those resources for our kids, like they are

going to (city) or (city) to get anything decent” (P10). Another parent summarised, “Where we are (is a barrier). I think location is the hardest part” (P11).

### *Clearer communication pathways and accessible contacts*

A strong theme across interviews was the desire for clearer, more proactive communication between cleft and community SLPs, with parents informed but not responsible for coordinating it. “It would just be good for them to communicate that rather than relying on me giving them that information” (P1). “It’d be better if it was just a clear, communication, like, they sort out their stuff and then give it to me” (P3). Parents wanted routine sharing of reports and updates. “I think it would be great that the hospital could ask the speech pathologist that they’re seeing for a bit of a more detailed report on what’s happening... and whether the cleft team can help with any of that” (P1).

Many proposed practical solutions: “It would be really helpful to have them communicate more often, or even just having, like, a clinical note pass on if they’re noticing something in a local session” (P11). “Even just an email once every six months, just between the three of us, just an update, like a CC for me, because I’m obviously in it every day” (P11). Others suggested shared databases or regular check-ins: “Even like a Zoom meeting like this would be really great... just so that the cleft speech therapist can actually see how he’s progressing” (P11).

Clear contact points were also critical. “We have to go through outpatients to make bookings for cleft clinic. I wouldn’t know who to ask on the speech cleft team... I don’t have any contact on the cleft team directly” (P1). Parents often struggled to know whom to contact for questions or updates: “You don’t always get an email address when you’re in the public system... I guess, I’d go through the cleft coordinator, but then she’d have to forward it on” (P8).

Across interviews, parents’ reflections balanced frustration with constructive ideas. They recognised systemic limitations but proposed straightforward, realistic solutions including better

resourced public services, clearer written information, direct communication between providers, and accessible contact pathways to bridge gaps and support genuine continuity of care.

### **Discussion**

This study explored parents' experiences of continuity of care in cleft speech services, focusing on their interactions with both cleft team and community SLPs. It forms part of a broader research series investigating CoC from the perspectives of cleft team SLPs (Bow et al., 2025), community SLPs (Bow et al., 2026), and parents. Parents, situated at the centre of these interactions, offered accounts which reflected both the successes and shortcomings of working with speech pathologists. Their accounts reinforced the central message emerging across our research series, that continuity depends on relationships, communication, and collaboration, while also highlighting unique insights into the emotional, logistical, and communicative burden they carry. Some parents described deeply positive experiences such as feeling "lucky" to have supportive therapists, trusting relationships, and coordinated plans. Others recounted fragmented systems, unclear roles, and the weight of acting as the primary link between providers. The findings are discussed through the lens of informational, relational and management continuity (Haggerty et al., 2003).

#### **Informational continuity: what parents needed, when they needed it, and how it was delivered**

Parents consistently highlighted the need for clear, accessible information about the cleft care journey including who is involved, what happens when, and the roles of different SLPs. Early stages were described as "overwhelming", with parents seeking simple written summaries, named contacts on the cleft team, and practical formations such as brief emails, after-session summaries and short videos, that they could reference at home. Many felt they became the "middleman", responsible for transferring reports and updates between services.

These experiences help explain the mismatch evident across the research series: cleft team SLPs reported sharing information such as written summaries or review letters, believing this supported continuity. However, they also noted that feedback from community clinicians was infrequent, leaving them uncertain about how information was received or acted upon. In contrast, community SLPs described receiving little or delayed information, and noted that what was shared often lacked the detailed information they desired, such as the child's surgical history, the cleft care pathway, and who to contact within the team. Parents accounts show how information often travelled through families rather than directly between professionals.

Evidence from broader paediatric healthcare contexts suggests that these experiences are not unique to cleft care. Families of children with complex or chronic conditions frequently assume responsibility for coordinating communication and navigating fragmented services across multiple providers and settings (e.g., Miller, 2009). In these circumstances, parents often relay clinical recommendations, maintain records, and ensure that different professionals remain informed about changes in their child's care. Research examining continuity of care for children with complex health needs similarly emphasises the important of reliable information transfer across providers, including shared documentation, care plans, and clearly defined communication pathways to support coordinated decision-making (Boerkoel, 2025; Navein, 2023). When such systems are absent or inconsistently implemented, informational continuity becomes dependent on individual effort rather than reliable structures, increasing the likelihood that families assume responsibility for bridging communication gaps between services. These findings suggest that the challenges described by parents in cleft speech services reflect wider systemic issues in multidisciplinary care rather than concerns unique to cleft care alone.

These intersecting perspectives reveal a clear breakdown in informational continuity: what is being shared by cleft team SLPs, and what is needed by community clinicians and parents

are not aligned. The information that does circulate often travels through parents rather than directly amongst professionals, increasing the risk of miscommunication and reducing the opportunities for collaboration. Parents' accounts therefore underscore the need for coordinated, transparent systems of communication that support families rather than rely on them to carry the flow of information.

Similar challenges have been described internationally. Parents of children with cleft have long reported wanting clearer information about treatment timelines, surgical procedures, and who to contact within the multidisciplinary team (Alighieri et al., 2020; Nelson & Kirk, 2013). Likewise, in the broader speech sound disorder literature, parents of children with childhood apraxia of speech have described difficulty accessing reliable information about the disorder and available services, and the need to act as information brokers themselves by sharing this knowledge with other professionals and educators (Dawoud et al., 2025; Highman et al., 2025). For families in this study, informational continuity was strongest when communication extended beyond verbal updates, was retrievable, and proactively anticipated transitions.

**Management continuity: how families experienced coordination (or its absence) across settings**

Limited three-way collaboration between families, community SLPs, and cleft team SLPs was described across all perspectives (Bow et al., 2025; Bow et al., 2026). Parents noted that while communication occasionally occurred between professionals, this was often informal rather than embedded within routine practice. Some were pragmatic, recognising the challenge of coordinating busy clinicians across multiple services, whereas others felt that joint discussions would be valuable but had simply never been presented as an option. These reflections suggest that collaborative models of care are not yet routinely visible or accessible to families. Both parents and community SLPs report difficulty in accessing cleft team SLPs between review

appointments. They understood the cleft team's workload and limited capacity but emphasised the value of more regular communication and feedback through the therapy process. Parents wanted reassurance that their child's community-based therapy aligned with cleft team recommendations, while community SLPs sought timely opportunities to clarify goals, share progress, and confirm treatment plans.

Across the series, there has been a consistent call to move beyond a consultative model – where the cleft SLP provides advice and the community SLP implements therapy – toward a co-facilitative treatment model in which both SLPs share responsibility for planning, monitoring and adjusting intervention. Comparable coordination challenges have been documented across paediatric healthcare systems where care is distributed across specialist and community providers. The involvement of numerous professionals across health, social, and educational services can complicate care coordination, often resulting in caregivers assuming a central role in organising communication and aligning care across providers (Boerkoel, 2025). Studies of children with complex health needs similarly highlight that when structured coordination mechanisms are lacking, families frequently assume informal responsibility for linking services and maintaining continuity between appointments (Miller, 2009). These findings suggest that the absence of clear collaborative processes can shift the burden of coordination onto families. In contrast, systems that implement structured communication routines, shared care planning, and clearly defined points of contact are more likely to support coordinated and coherent care across settings.

To help build more collaborative treatment models the parents' offered several practical solutions that were modest and actionable. These were: brief scheduled check-ins (e.g. 6 monthly triage emails), named contacts, shared notes and occasional joint telehealth appointments. Such

steps would distribute the coordination load away from families and operationalise cofacilitation across settings.

**Relational continuity: why connection and consistency made a “huge difference”**

Across all perspectives in this research series, one message was unequivocal: relationships mattered. Parents emphasised the quality of their relationships with both cleft and community SLPs shared their overall experience of care. Trust, familiarity and feeling genuinely supported were described as making a “huge difference” to their journey. Consistent, caring relationships provided reassurance while turnover or infrequent review disrupted trust and progress. Parents highlighted the disruption and emotional fatigue accompanied with changing therapists and this finding was echoed in the childhood apraxia of speech research (Highman et al., 2025). Community SLPs were typically the accessible first port of call for day-to-day needs, with parents feeling more comfortable asking them questions. They also felt reassured when community SLP to cleft links were visible. Existing relationships between community and cleft SLPs eased transitions, reassured families that information would be shared, and reduced parents’ go-between burden.

Across the research series, our interpretive analysis emphasised building relationships beyond broadcasting information (i.e. two-way engagement rather than one-way advice), while the community SLP study highlighted that collaboration begins with connection (trust and rapport as prerequisites for honest dialogue and shared problem solving). For parents in this study, relationships therefore represented the interpersonal foundation upon which information sharing and coordinated management rest. Across all papers in this series, parents, community SLPs and cleft team SLPs all recognised that collaboration depends not only on clear systems and shared plans, but on the human relationships that make collaboration possible.

The importance placed on relationships by parents in this study is also reflected in broader continuity-of-care literature. Families managing complex paediatric conditions consistently highlight the value of sustained relationships with clinicians who understand their child's history, needs, and family context (Miller, 2009). Recent work examining continuity of care for children with medical complexity similarly emphasises that effective coordination depends not only on structural processes but also on the quality of relationships between families and healthcare providers, which support trust, communication, and shared understanding across services (Boerkoel, 2025; Navein, 2023). When clinicians develop ongoing partnerships with families and other providers, communication tends to be more efficient and management decisions more coherent across services. These findings reinforce the role of relational continuity as a mechanism through which informational and management continuity are enacted, supporting coordinated care across complex service systems.

### **Closing the loop: centring parents and strengthening continuity across domains**

Across informational, management, and relational continuity, parents' accounts converge on a simple proposition: Continuity is most effective when clear, retrievable information, early and sustained co-facilitation, and trusting, consistent relationships operate together. Where any one domain faltered, parents absorbed the gap – carrying information, joining the dots, and advocating to keep care on track.

A strength of this study is the involvement of a parent co-researcher across analysis and manuscript development. Their lived experienced sharpened the interpretation of themes, ensured the salience of recommendations, and helped keep parents, not just services, at the centre of what continuity should look and feel like in cleft speech therapy care.

### **Limitations**

This study may reflect the perspectives of more engaged parents, as those who participated were likely to already be active in their child's care. The sample also included only mothers, meaning fathers' and other caregivers' perspectives were not captured. Finally, only one parent from New Zealand participated, limiting the ability to explore potential differences in service delivery and continuity across the broader Australasian context.

### **Conclusion**

This study explored parents' perspectives on continuity of care within cleft speech services across Australia and New Zealand, offering insight into how families experience communication and collaboration between themselves, cleft team SLPs and community SLPs. Parents' accounts revealed that while goodwill and professional expertise are strong within the system, true continuity depends on consistent information flow, coordinated management and trusting relationships. Through the lens of Haggerty et al. (2003) model, informational, relational and management continuity were shown to be interdependent and when one faltered, the others were affected.

Parents valued both cleft team and community SLPs and recognised their complementary roles, but they also described fragmented systems that relied heavily on them to bridge communication gaps. Their reflections reinforced that effective collaboration must move beyond a consultative model towards co-facilitative partnerships where families, community clinicians, and cleft team SLPs share responsibility for communication, goal setting, and care coordination. Early, proactive contact and clear communication pathways were seen as critical to building trust, consistency, and confidence across the care journey.

By centring the experiences of those who live this process daily, this study highlights the need to design cleft speech services that are relationally driven, communicatively transparent, and structurally supportive of shared care. Strengthening continuity across all three domains would

not only reduce the practical and emotional burden currently carried by parents but also enhance the cohesiveness and quality of cleft speech care for children and families.

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Appendix A. Interview Guide.

- Tell us about your child's journey with speech pathologists so far including your cleft speech pathologists and any local therapists.
- What does communication look like with your local / cleft-team SLP?
- How do they work together?
- Can you think of a time where communication worked well?
- Can you think of a time where communication didn't work so well?
- In your opinion, what would you like to happen in terms of your communication with both of your SLPs?

**Chapter 6: Connecting the team: The Tri-Care Cleft Speech  
Pathology Model for supporting continuity in cleft speech  
services**

## **Chapter 6: Connecting the team: The Tri-Care Cleft Speech Pathology Model for supporting continuity in cleft speech services**

Chapter 6: Connecting the team: The Tri-Care Cleft Speech Pathology Model for supporting continuity in cleft speech services

This chapter consists of a manuscript that has been submitted for review:

Bow, M., McCabe, P., Sutherland, R., Delzotto, A., & Purcell, A. (n.d.). *Connecting the team: The Tri-Care Cleft Speech Pathology Model for continuity in cleft speech services* (Manuscript submitted for publication).

Chapter 6 brings together the findings of the preceding studies to develop an integrated understanding of continuity of care within cleft speech services. While each earlier chapter examined continuity from the perspective of a single stakeholder groups including cleft-team SLPs, community SLPs, and parents, this synthesis analyses these perspectives collectively to identify shared challenges, points of divergence, and opportunities for improved collaboration. By examining how information, management, and relational continuity intersect across the triad, this chapter moves beyond stakeholder-specific insights to describe the systemic factors that shape continuity. The synthesis also provides the conceptual foundation for the Tri-Care Cleft Speech Pathology Model and its accompanying principles and recommendations, offering a coherent framework to guide more coordination, family-centred cleft speech services.

### **Statement of Contribution to Co-Authored Published Paper**

This study was designed and written in collaboration with my supervisors, Prof Patricia McCabe, Dr Rebecca Sutherland, Ms Alison Delzotto and Prof Alison Purcell.

## **Continuity of Care in Cleft Speech Services: Evidence-Based Recommendations**

Mikaela Bow

Patricia McCabe

Rebecca Sutherland

Alison Delzotto

Alison Purcell

Correspondence concerning this article should be addressed to Ms. Mikaela Bow, Faculty of  
Medicine and Health, The University of Sydney, Camperdown, NSW 2006, Australia.

[mikaela.bow@sydney.edu.au](mailto:mikaela.bow@sydney.edu.au)

**Connecting the team: The Tri-Care Cleft Speech Pathology Model for supporting continuity in cleft speech services**

Mikaela Bow<sup>1</sup>, Patricia McCabe<sup>1</sup>, Rebecca Sutherland<sup>1</sup>, Alison Delzotto<sup>2</sup> and Alison Purcell<sup>3</sup>

<sup>1</sup>Faculty of Medicine and Health, The University of Sydney

<sup>2</sup> Parent Co-Researcher

<sup>3</sup> Faculty of Health, Western Sydney University

**Author Note**

Correspondence concerning this article should be addressed to Ms. Mikaela Bow, Faculty of Medicine and Health, The University of Sydney, Camperdown, NSW 2006, Australia.

[mikaela.bow@sydney.edu.au](mailto:mikaela.bow@sydney.edu.au) (ORCID ID: <https://orcid.org/0009-0007-0569-5189>)

Co-authors details include:

Professor Patricia McCabe: [tricia.mccabe@sydney.edu.au](mailto:tricia.mccabe@sydney.edu.au) (ORCID ID:

<https://orcid.org/0000-0002-5182-1007>)

Doctor Rebecca Sutherland: [rebecca.sutherland@sydney.edu.au](mailto:rebecca.sutherland@sydney.edu.au) (ORCID ID:

<https://orcid.org/0000-0002-4522-058X>)

Ms Alison Delzotto: [a.delzotto@hotmail.com](mailto:a.delzotto@hotmail.com) (ORCID ID: <https://orcid.org/0009-0001-2734-1230>)

Professor Alison Purcell: [a.purcell@westernsydney.edu.au](mailto:a.purcell@westernsydney.edu.au) (ORCID ID:

<https://orcid.org/0000-0002-4623-4086>)

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## **Abstract**

*Purpose:* Continuity of care is critical in cleft speech services, yet communication and collaboration between specialist cleft-team speech-language pathologists (SLPs), community-based SLPs, and families is often fragmented. This study synthesizes findings from a multi-study research program to develop evidence-based recommendations and introduces the Tri-Care Cleft Speech Pathology Model – a triadic, collaborative framework designed to strengthen continuity of care.

*Method:* Findings from a scoping review and three qualitative studies exploring the experiences of cleft-team SLPs, community-based SLPs, and parents were synthesized and mapped using a continuity of care framework. Common barriers and facilitators were integrated into a set of practical recommendations and used to construct an operational model of triadic collaboration.

*Results:* The synthesis generated evidence-based recommendations across the domains of informational, management, and relational continuity and the development of the Tri-Care Cleft Speech Pathology Model. These outlined how parents, community clinicians, and cleft-team clinicians can collaborate through shared processes, communication routines, and reciprocal knowledge-building.

*Conclusions:* This synthesis offers an evidence-based set of recommendations and a clinically applicable model to support continuity of care in cleft speech services. The Tri-Care Cleft Speech Pathology Model offers a clear foundation for improving communication, coordination, and shared decision-making across settings. Future work should evaluate its feasibility and impact in clinical practice.

## **Background**

Cleft palate is associated with a range of speech and communication disorders that require ongoing and coordinated intervention across the lifespan (American Cleft Palate Craniofacial Association, 2024; Kummer, 2014). Speech-language pathology services for children with cleft palate are delivered by both cleft-team SLPs and community-based SLPs, with parents as active partners in this process (Bow et al., 2025; Bow, McCabe, Sutherland, Delzotto, et al., n.d.; Bow, McCabe, Sutherland, & Purcell, n.d.). High-quality services and optimal outcomes rely not only on clinical expertise and the quality of surgical interventions (Bearn et al., 2001), but also on the continuity of care experienced by the child and family between providers, settings, and life stages (Bow et al., 2025; Bow, McCabe, Sutherland, Delzotto, et al., n.d.; Bow, McCabe, Sutherland, & Purcell, n.d.). Continuity of care is defined as the degree to which health care services are experienced as connected and consistent over time, and is typically conceptualised through three interrelated domains: informational continuity, the availability and transfer of relevant clinical information; management continuity, the coordination of care delivery across providers; and relational continuity, the ongoing therapeutic relationship between patients, families, and providers (Bahr & Weiss, 2019; Haggerty et al., 2003; World Health Organisation, 2018).

For children with cleft palate, continuity of care is particularly critical given the involvement of specialist multidisciplinary cleft teams including speech-language pathologists (SLPs), community-based SLPs, and families. Each group brings unique expertise. Cleft team SLPs hold specialist knowledge of cleft-related speech disorders, knowledge of typical clinical pathways, as well as access to the surgical and medical teams. Community-based SLPs provide consistent local therapy and broader developmental expertise, and parents bring essential lived experience and knowledge of their child's daily communication.

Although this pathway is familiar to clinicians working in cleft care, it is important to make the typical structure explicit. In Australia and New Zealand, children with cleft palate are monitored and assessed by multidisciplinary cleft teams from birth. Although the support that is provided is unique to each team, it typically consists of early feeding support, periodical perceptual speech assessments / reviews, and periodical surgical, dental, and medical reviews. Outside these scheduled clinic appointments which often occur at key developmental or surgical milestones, ongoing speech therapy is delivered by community-based SLPs, who hold responsibility for regular therapy, progress monitoring, and supporting general communication development. Parents therefore navigate between specialist cleft clinic reviews and community therapy, often coordinating information flow between providers. While this distributed model ensures access to both specialist and local therapy, it relies heavily on effective communication and role alignment across settings for continuity of care to be maintained.

Despite this, research consistently highlights fragmentation in communication, unclear role expectations, and variable access to timely information across these groups, resulting in inefficiencies, stress for families, and potential impacts on therapy outcomes (Alighieri et al., 2021; Alighieri et al., 2020; Bedwinek et al., 2010; Bow et al., 2024, 2025; Bow, McCabe, Sutherland, Delzotto, et al., n.d.; Bow, McCabe, Sutherland, & Purcell, n.d.). Although continuity of care is recognized as essential in speech pathology services for children with cleft palate, existing literature offers little guidance on how collaboration should occur in practice. Studies tend to describe challenges, but stop short of outlining actionable processes, or evidence-informed structures to support communication across settings and collaboration across providers. As a result, clinicians rely on ad hoc strategies, and families experience inconsistent pathways depending on location, expertise of the local clinician, and communication practices of individual cleft teams or clinicians themselves. There is currently no cleft-specific, stakeholder-informed

framework to guide continuity in speech services, nor consensus around what effective collaboration should look like.

One existing attempt to formalise collaboration is the Innovative Collaborative Treatment Model (Grames & Stahl, 2017), which introduced joint sessions between cleft team and community SLPs. While conceptually valuable, the model was designed as a single-session, clinic-based continuing education program that positioned the cleft team SLP as the expert directing the community clinician through assessment and target setting. This largely one-directional, expert-to-novice structure does not reflect the reciprocal expertise, shared decision-making, or shared responsibility highlighted by stakeholders in contemporary research. The model also relies on in-person attendance, developed before widespread telehealth, which limits accessibility, particularly in geographically dispersed regions. Importantly, parents were not conceptualised as active partners, despite their central coordinating role in the pathways included in the study. As a result, the model does not provide mechanisms for ongoing communication, relationship-building, or shared responsibility across the care continuum.

These limitations underscore the need for a contemporary, flexible, triadic approach to collaboration that supports multiple modes of communication, centres parents as partners, and reflects the lived and professional experiences of all stakeholders. The current paper addresses this gap by integrating findings from a multi-phase research program, including the existing literature, a scoping review and three qualitative studies capturing the perspectives of cleft-team SLPs, community-based SLPs, and parents.

The aims of this paper are to:

1. Synthesize the key findings mapped to the domains of continuity
2. Present evidence-based recommendations for practice, and

3. Introduce a collaborative framework illustrating how continuity can be enacted through shared responsibility, flexible collaboration formats, and intentional relational practices.

### **Positionality and researcher reflexivity**

The research team comprised of five female researchers with diverse professional and lived expertise relevant to cleft speech services. The first author (MB) is a mid-career SLP and doctoral candidate with clinical experience in both multidisciplinary cleft teams and community private practice, which informed her understanding of the service interfaces discussed in this synthesis. The second author (PM) is a senior academic and clinical researcher with a PhD, whose work encompasses speech disorders across the lifespan and diverse methodological approaches. The third author (RS) is also a senior academic with doctoral training, drawing on a background in disability research and clinical practice. The fourth author (AD) participated as a parent co-researcher, contributing lived experience as a parent of a child with a cleft palate, and is also a registered nurse. The fifth author (AP) is a senior academic and clinical researcher with a PhD and specialist expertise in cleft-related speech disorders. Collectively, the senior clinical researchers brought extensive experience in qualitative research expertise, along with deep clinical and research experience in clinical pathways, service organization, and the translation of evidence into practice. Given the multi-study structure, reflexivity was central to this series of research studies. Data for each study and analysed sequentially. Interviews with cleft-team SLPs were conducted and partially analysed before data collection began with community SLPs. Similarly, the community SLP interviews were completed and data was partially analysed prior to commencing parent interviews. Although each study was designed, coded and interpreted independently, and multiple strategies were used to remain close to the data in each phase, the team acknowledges that insights gained from earlier phases inevitably shaped our evolving

understanding and informed the interpretive lens brought to later analyses. This cumulative meaning-making is consistent with iterative qualitative research, where understanding deepens over time. To mitigate undue influence, the team engaged in regular reflexive discussions, critically examining assumptions and professional perspectives. The involvement of a parent co-researcher further strengthened this process by grounding interpretation in lived experience. Importantly, the three studies generated distinct themes that reflected the perspectives of each participant group, giving confidence that the analyses remained faithful to the data and not overly shaped by what had emerged in previous phases.

### **Results from the multi-study findings**

This study represents the final stage of a multi-phase research program examining continuity of care in cleft speech services in Australia and New Zealand. The program comprised of (1) a scoping review of cleft speech services (Bow et al., 2024), (2) interviews with cleft team SLPs (Bow et al., 2025), (3) interviews with community-based SLPs (Bow, McCabe, Sutherland, & Purcell, n.d.), and (4) interviews with parents (Bow, McCabe, Sutherland, Delzotto, et al., n.d.). Each provide a distinct perspective on the structures, processes, and lived experiences shaping continuity in cleft speech services. Although conducted independently, the studies reveal interconnected themes that, when viewed, together, highlight shared areas of concern as well as unique pressures experienced by each group. While common research questions guided data collection across stakeholder groups and findings were interpreted through the shared lens of the continuity of care framework, each dataset was analysed independently and generated distinct themes grounded in the perspective of that group. Restating the theme of these studies allows the reader to see how they collectively underpin the recommendations and model presented later. A visual summary of all themes and subthemes across the four studies is provided in table 1.

Table 1. Themes and subthemes across the four studies.

<b>Stakeholder data source</b>	<b>Global themes</b>	<b>Subthemes</b>
Scoping review (Bow et al., 2024)	Continuity of care: Whose role is it?	<ul style="list-style-type: none"> <li>• That’s not my role, it’s yours</li> <li>• This is my role</li> </ul>
	Help: I’m a generalist	<ul style="list-style-type: none"> <li>• I don’t have the knowledge or experience</li> <li>• I need more information and support</li> <li>• I don't have the resources</li> </ul>
	The team: Who is on it?	<ul style="list-style-type: none"> <li>• Community SLPs</li> <li>• Parents</li> </ul>
Cleft team SLPs (Bow et al., 2025)	The multifaceted role of the cleft team SLP in continuity of care	<ul style="list-style-type: none"> <li>• We are educators</li> <li>• We are consultants</li> <li>• We are navigators</li> <li>• We are advocates</li> </ul>
	Ways we communicate and collaborate	<ul style="list-style-type: none"> <li>• Real time communication is best practice</li> <li>• Asynchronous communication: day to day it’s lots of email</li> </ul>
	Our relationships	<ul style="list-style-type: none"> <li>• Relationships matter</li> <li>• When relationships exist, communication works – when they don’t, “we don’t hear back”</li> <li>• “Big gold castle on the hill that nobody can come into”</li> <li>• “Sharing knowledge rather than giving knowledge”</li> </ul>
	Community SLPs are central	<ul style="list-style-type: none"> <li>• Community SLPs are critical</li> <li>• Community SLPs lack knowledge and confidence</li> <li>• Demystifying cleft by supporting and reassuring community SLPs</li> </ul>
	Parents are key:	<ul style="list-style-type: none"> <li>• Families are core</li> <li>• Some parents “find it really hard”</li> </ul>
	The landscape of healthcare is not working	<ul style="list-style-type: none"> <li>• The system isn’t working</li> <li>• Our resources are limited</li> </ul>
Community SLPs (Bow, McCabe, Sutherland, & Purcell, n.d.)	Roles and relationships	<ul style="list-style-type: none"> <li>• Community SLPs as the ‘doers’ and advocated</li> <li>• Tiers or team?</li> <li>• Cleft SLPs are assessors, knowledge holders, and consultants</li> <li>• Feeling part of the team, sometimes</li> <li>• Parents need to be more than just parents – but it’s hard</li> </ul>

		<ul style="list-style-type: none"> <li>• Relationships matter – building trust and capacity</li> </ul>
	Communication and collaboration	<ul style="list-style-type: none"> <li>• Ways we communicate and collaborate</li> <li>• “I hassle them until they get back to me”</li> <li>• The parent as the messenger</li> <li>• Evolving communication</li> </ul>
	I need help – and I have some ideas	<ul style="list-style-type: none"> <li>• I need more information</li> <li>• I need more support</li> <li>• Am I the “right person”?</li> <li>• But...”I know they’re busy”</li> </ul>
Parents (Bow, McCabe, Sutherland, Delzotto, et al., n.d.)	Relationships matter	<ul style="list-style-type: none"> <li>• Trusting, supportive relationships make a “huge difference”</li> <li>• Consistency matters: “she had to get used to another SLP”</li> <li>• My community SLP is “my first port of call”</li> </ul>
	Navigating a long and overwhelming journey	<ul style="list-style-type: none"> <li>• Overwhelmed and uncertain at the start</li> <li>• There’s just so many components</li> <li>• Fitting therapy into real life</li> </ul>
	Communication that connects (or disconnects) care	<ul style="list-style-type: none"> <li>• “I am the middleman”</li> <li>• Fragmented and uneven communication</li> <li>• Communication that connects care</li> </ul>
	Shared goal, different roles	<ul style="list-style-type: none"> <li>• “I have to be my child’s voice”</li> <li>• Same profession, different roles</li> <li>• A shared goal: helping my child</li> </ul>
	Barriers and solutions	<ul style="list-style-type: none"> <li>• The limits of publicly funded local speech and feeding services</li> <li>• Distance, cost, and time constraints</li> <li>• Clearer communication pathways and accessible contacts</li> </ul>

**Cleft team SLPS: Cleft expertise limited by structural constraints (Bow et al., 2025)**

Cleft-team SLPs described a strong commitment to sharing information and a high level of specialist knowledge in cleft-related speech disorders. They also emphasized that structural constraints such as competing clinician demands, large caseloads, and institutional pressures limited their ability to maintain consistent contact with community clinicians. They reported that communication tended to occur reactively rather than as part of routine practice. When relationships with community SLPs and parents were established, communication was effective,

but in the absence of pre-existing relationships, gaps and delays were common. Cleft clinicians also recognized that families were critical partners in achieving successful outcomes, although some parents faced challenges engaging due to competing demands and emotional load. Several cleft-team SLPs felt that community clinicians sometimes viewed the cleft service as a “castle on the hill”, indicating a sense of distance or inaccessibility. These findings highlight the need for systems that support more predictable, relationship-based collaboration.

**Community SLPs: Central providers operating on the periphery of the cleft system (Bow, McCabe, Sutherland, & Purcell, n.d.)**

Community clinicians reported being responsible for the majority of ongoing therapy but described limited and inconsistent access to the cleft team. Some reported needing to “chase” cleft clinicians for information or follow-up, reflecting unclear pathways for initiating communication. Community clinicians also expressed uncertainty about cleft-team processes, timelines, and expectations, relying heavily on parents to relay information between services. Strong relationships with both cleft SLPs and parents were identified as key facilitators that improved confidence, trust, and role clarity. While community SLPs viewed cleft-team SLPs as valuable specialists, they also felt that parents were often required to play a coordinating role that extended beyond typical family responsibilities. Some described feeling part of the child’s broader care team, but only inconsistently. These insights suggest that community clinicians are central but insufficiently integrated into cleft pathways, underscoring the need for clear communication structures and shared planning processes.

**Parents: Holding together a fragmented system (Bow, McCabe, Sutherland, Delzotto, et al., n.d.)**

Parents described playing an active role in holding together a fragmented system, often functioning as intermediaries between cleft and community services. Trusting, supportive

relationships were considered essential facilitators of continuity, yet many parents reported that the cleft pathway was overwhelming and unclear, particularly early in their child's journey. Families were required to navigate numerous appointments, services, and decisions, frequently acting as their child's "voice" and advocate. Parents recognized that cleft-team and community SLPs offered different kinds of expertise but shared a common goal of achieving the best outcome for their child. However, distance, time, travel demands, and financial costs created additional barriers to continuity for parents. Parents expressed a desire for clearer communication pathways, predictable points of contact, and more accessible avenues for seeking advice.

**Triangulated insight: Fragmentation is a system problem, not an individual one**

Across all stakeholders, a unified message emerged: all parties valued collaboration, all want continuity, and all describe similar gaps in communication, clarity, and coordination. Importantly, none attributed the gaps to unwillingness or incompetence. Instead, they cited structural constraints. This unified perspective reveals a critical insight; continuity in cleft speech pathology services is not undermined by clinician deficits, but by systemic barriers that impede triadic collaboration, shared responsibility, and joint planning.

**Synthesis of multi-study findings**

The synthesis of findings from the scoping review and three qualitative studies identified consistent strengths, gaps, and opportunities across stakeholder groups. These findings are presented according to the three domains of continuity.

**Informational continuity: inconsistent, parent-mediated, and systemically vulnerable**

Informational continuity emerged as one of the greatest vulnerabilities in the current cleft speech pathology services pathway. Parents in this study described routinely transferring information between clinicians. This increased the risk of omissions or miscommunications between parties. Community clinicians also reported concerns about information transfer and

accessibility. They often received limited information from the cleft-team unless they actively sought it out, and even then, there could be a significant delay in receiving the information.

Without direct communication, they were dependent on parents' reports about the child's surgical history and other information. Similarly, cleft clinicians also described informational blind spots. They were often unaware of the day-to-day therapy as they did not receive communication from the community SLPs prior to the child's clinic appointment and some parents had difficulty recalling speech goals. It was also difficult to obtain information regarding the child's progress, or contextual factors influencing performance. This resulted in both types of clinicians making clinical judgements without access to the full picture. Together, these patterns illustrated that informational continuity currently depends more on the individual efforts of parents and clinicians rather than on reliable systems and processes.

### **Management continuity: shared goals without shared pathways**

Management continuity, which includes coherent and coordinated care across settings and time, was often inconsistent or absent across the cleft speech pathway. Parents and community clinicians alike described uncertainty regarding next steps in the cleft pathway as well as the absence of shared planning structures. When guidance was provided, this was often in the form of a report rather than verbal communication, limiting opportunities for collaborative discussion. Cleft team SLPs described wanting to support community clinicians and collaborate more, but being constrained by time, or institutional priorities that emphasized direct clinical care over outreach care.

These findings demonstrate that management continuity requires more than periodic recommendations via email; it requires shared, ongoing planning and coordination across settings. Without structured mechanisms for joint goal-setting and unified intervention plans, or

routine feedback loops, continuity relies heavily on individuals, particularly parents, to manually connect each component of care.

### **Relational continuity: the foundation of collaborative care**

Relational continuity was described as the foundation upon which informational and management continuity is built upon (Bahr & Weiss, 2019). Strong relationships were most evidence between families and their community SLPs. Parents frequently described their community clinicians as central, trusted, and emotionally supportive figures in their child's journey. These clinicians, in turn, often held rich and nuanced information about the child's communication, temperament, family dynamics, and daily functioning. Community clinicians also spoke with genuine esteem for the families they worked with, recognizing the parents' commitment and expertise as integral to the process.

In contrast, relational continuity across settings was more fragile. While cleft team SLPs were committed to developing more meaningful relationships, their clinic structures which were characterized by large caseloads, infrequent review cycles, and limited opportunity for extended interaction, restricted ongoing relational engagement. Direct relationships between community SLPs and cleft team SLPs appeared to be rare and often dependent on chance encounters or the persistence of individual (community) clinicians. The absence of cross-setting relational continuity meant that parents frequently found themselves acting as the de-facto relationship-brokers, introducing one clinician's reasoning to another and attempting to align perspectives between services that had no direct communication.

### **Tri-Care Cleft Speech Pathology Model**

This multi-study research program demonstrates the need for a clear, flexible framework that supports collaboration across the entire triad. The Tri-Care Cleft Speech Pathology Model

conceptualizes cleft speech pathology care as a shared, triadic process where parents, community SLPs, and cleft-team SLPs each contribute essential expertise.

The three partners in Tri-Care include:

1. Parents – daily lived experience, contextual insights, real-world observations
2. Community-based SLPs – regular therapy contact, developmental expertise, local system knowledge (e.g., school)
3. Cleft-team SLPs – specialist cleft knowledge, access to medical/surgical team

The Tri-Care Cleft Speech Pathology Model positions all stakeholders as equal partners, distributing responsibility for continuity of care through shared communication structures, shared decision-making, and reciprocal knowledge-building. See figure 1 for a visual representation of the Tri-Care Cleft Speech Pathology Model.

While the Tri-Care Model conceptualizes parents, community SLPs, and cleft-team SLPs as the primary coordinating stakeholders, the child with cleft palate remains central to the continuity process. The model positions the child not as a passive recipient of coordinated care, but as the focal point around which relational, informational, and management continuity are constructed. Emerging research demonstrates that children with cleft palate are capable of reflecting meaningfully on therapy, participation, and communication experiences (Alighieri et al., 2025). Future refinement of the Tri-Care Model should therefore explicitly integrate developmentally appropriate mechanisms for incorporating children's perspectives into collaborative planning and decision-making processes.

Earlier work laid the foundation for this model. Alighieri et al. (2021) introduced the idea of collaboration in cleft care as a triangle involving parents and clinicians, and Grames (2025) expanded this into an early visual representation of collaborative practice. See Figure 1.

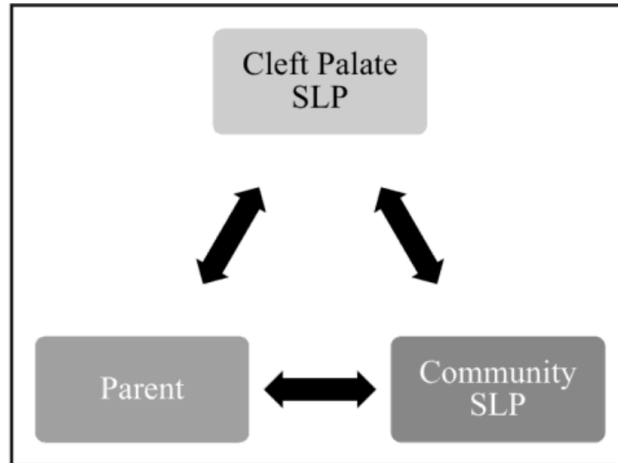


Figure 1. Representation of the "Triangle of Care" illustrating communication between the cleft palate SLP, community SLP, and parent. Concept adapted from Alighieri et al. (2021) as published in Grames (2025). Reprinted with permission.

The Tri-Care model advances this work by emphasizing triadic collaboration, as well as dyadic, and by explicitly positioning parents at the top of the triad. By reframing continuity of care as a shared, triadic process with parents as the pivot rather than a series of bilateral exchanges, the Tri-Care Model offers a practical, contemporary framework for relationship-centered and coordinated cleft speech services. See Figure 2.

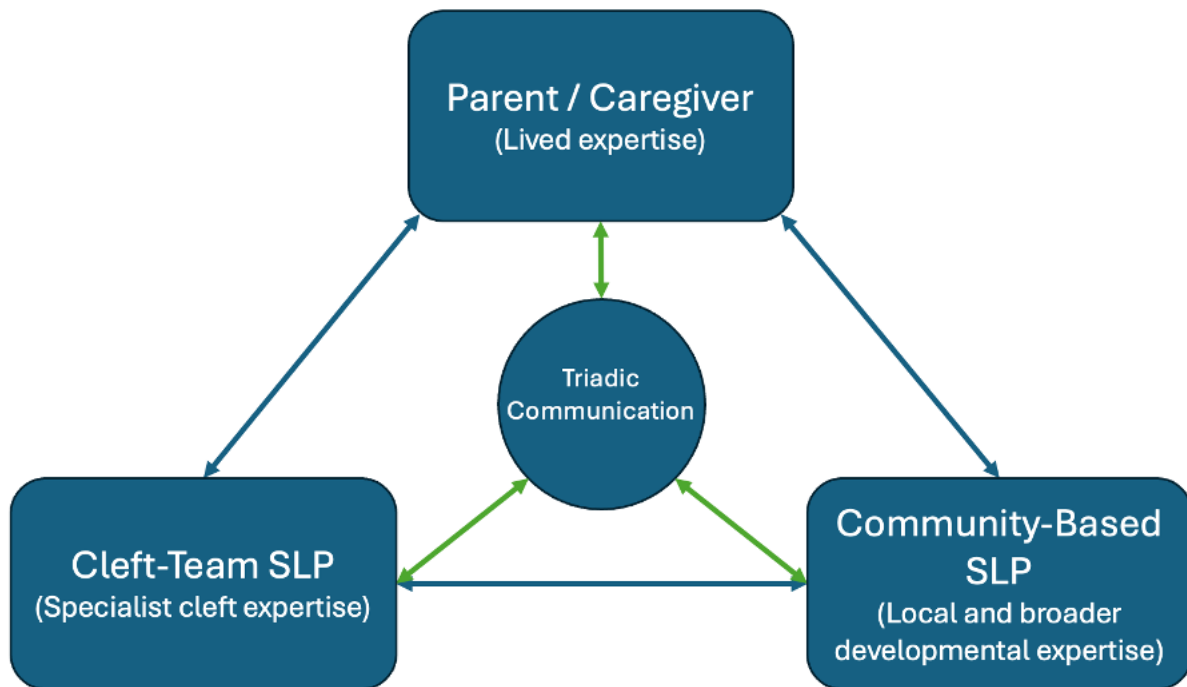


Figure 2. The Tri-Care Cleft Speech Pathology Model.

Legend:

Figure 1 visualizes the collaborative structure, with:

- Blue arrows = two-way communication between each dyad
- Green arrows = triadic communication, shared reasoning, and collective decision points

### **Principles of The Tri-Care Cleft Speech Pathology Model**

Together, these roles form the foundation of the Tri-Care Model, which emphasizes that continuity of care is most effective when expertise is shared, communication is intentional, and responsibility is distributed across the triad. To operationalize how this shared approach functions in practice, a set of guiding principles was developed. These principles were informed by professional and interprofessional standards (American Cleft Palate Craniofacial Association, 2023, 2024; Interprofessional Education Collaborative, 2016; Speech Pathology Australia, 2020; World Health Organisation, 2018). Drawing on these standards, the principles translate the core

features of the Tri-Care into actionable expectations for collaboration, outlining how parents, community SLPs, and cleft-team SLPs can work together in consistent, predictable, and mutually supportive ways. The principles include:

1. Mutual contribution: Each partner contributes essential, distinct expertise that shapes decision-making.
2. Shared responsibility for continuity: Coordination is distributed across all stakeholders rather than resting on one group.
3. Flexible modes of engagement: Collaboration occurs across various modalities to accommodate geography and availability.
4. Intentional relationship-building: Relationships are cultivated through predictable routines and respectful interactions.
5. Aligned roles and expectations: Role clarity is established early and reinforced across the pathway.

## **Operational components of The Tri-Care Cleft Speech Pathology Model**

### ***1. Structured entry point***

Goal: Establish early relationship, shared understanding, and readiness for collaboration.

A structured entry point is initiated when any partner identifies the need for coordinated support.

All stakeholders receive clear, accessible information outlining the child's history the roles of each partner and mutually agreed upon communication channels. A joint introductory session (in-person or virtual) brings all three partners together to begin collaboration on equal footing and establish shared expectations from the outset.

### ***2. Collaborative assessment and planning***

Goal: Develop a shared baseline and unified direction.

Assessment and planning are conducted collaboratively, with parents, community SLPs, and cleft-team SLPs contributing complementary expertise. Partners jointly interpret assessment findings (including recorded perceptual speech samples when appropriate), discuss clinical reasoning, and co-construct goals that reflect family priorities and functional needs. Parents are active contributors, offering lived expertise and participating in coaching and decision-making.

### ***3. Communication pathways and routines***

Goal: Maintain consistent, reliable, and predictable information flow across settings.

Communication routines are co-developed and shared across the triad. Community SLPs provide brief updates before clinic reviews; cleft-team SLPs share timely follow-up summaries; and parents contribute observation from daily contexts. Scheduled check-ins help sustain momentum and agreed escalation pathways guide how any partner can raise emerging concerns.

### ***4. Reciprocal knowledge building and mentorship***

Goal: Build shared understanding and strengthen capacity across all settings.

Knowledge-building occurs through reciprocal exchange rather than top-down instruction. Cleft team SLPs contribute specialist cleft expertise; community SLPs bring contextual knowledge and daily therapeutic insight; and parents provide lived, functional understanding of communication across environments. Joint case discussions, shared review of assessments or therapy clips, and problem-solving conversations enable partners to learn from one another. Continuing education resources and peer networks, such as special interest groups, further support mutual confidence and reduce isolation across the triad.

### ***5. Sustainability, system integration, and policy alignment***

Goal: Embed triadic collaboration into service structures for long-term impact.

Sustaining collaborative practice requires embedding shared processes, such as joint sessions, collaborative documentation, predictable communication routines, and structured follow-up, into

everyday workflows across settings. Mechanisms for ongoing feedback and continuous improvement help all partners refine these practices over time. Importantly, sustainability also depends on supportive policy structures where collaboration is recognized as legitimate clinician work, and shared information systems are needed to enable secure and timely communication, and continuity markers should be incorporated into service quality and accreditation frameworks. Integrating these policy elements ensure that triadic collaboration is upheld at the system level, rather than relying solely on individual initiative.

### **Recommendations for practice**

The insights generated across the research series point clearly to the need for practical, system-level strategies that strengthen continuity of care across informational, management, and relational domains. While stakeholders expressed a universal willingness to collaborate, they also identified consistent structural, procedural, and communication barriers that limited their ability to do so effectively. The following recommendations synthesize these shared priorities into actionable, evidence-informed practices that can be embedded into existing service models. They are designed to support cleft team SLPs, community SLPs, and families in working together more intentionally, predictably, and confidently across the cleft speech pathway. These recommendations are summarized in Table 2 and outline practical strategies for enacting more consistent and connected care across the Tri-Care team.

Table 2. Evidence-informed recommendations for strengthening continuity across the Tri-Care Model.

<b>Continuity Domain</b>	<b>Initiator</b>	<b>Recommendation</b>
Individual-Level Recommendations		
Informational	Community SLP	Provide pre-clinic updates summarising therapy goals, progress, concerns, and questions, with parent input.

	Community SLP and cleft-team SLP	Use shared information tools (e.g., recorded perceptual speech samples, stimulability probes, error classification summaries) to support common understanding of speech goals across settings.
	Cleft team SLP	Use accessible terminology where appropriate (e.g., reframing cleft speech characteristics using articulatory or phonological terminology) to support mutual understanding across providers.
	Cleft team SLP	Share cleft clinic outcomes promptly, sending recommendations, next steps, and clinical reasoning to parents and community SLPs.
	Parents	Share relevant observations or recordings that illustrate real-life communication, supporting decision-making and contextual understanding.
Management	All stakeholders	Initiate case discussions when progress is unclear, new concerns emerge, or therapy direction requires review.
	All stakeholders	Use flexible joint collaboration formats to accommodate family schedules, clinician availability, and geography, including: <ul style="list-style-type: none"> <li>- in-person joint sessions with child, parents, community SLP, and cleft-team SLP</li> <li>- telehealth sessions involving combinations of stakeholders (e.g., parent + community SLP + virtual cleft SLP).</li> </ul>
	Parent	Actively participate in shared planning discussions to ensure family priorities are represented.
	Cleft and community SLP	Adopt shared progress-update templates to align goals across settings and support consistent therapy direction.
	Cleft SLP	Invite community SLPs to scheduled cleft clinic review appointments, where possible giving sufficient notice.
Relational	All stakeholders	Promote a communication culture grounded in clarity, transparency, and respect, recognizing

		that relational continuity is co-constructed across the triad.
	All stakeholders	Facilitate early introductions between cleft-team SLPs, community SLPs, and parents to establish relationships from the outset.
	All stakeholders	Adopt warm, respectful communication that validates the complementary expertise of each stakeholder.
	Cleft SLPs	Use inviting language to encourage community clinicians and parents to collaborate (e.g., “I would love to discuss this further with you-let me know your availability”).
<b>Service-Level Recommendations</b>		
Informational	Cleft and Community SLP Services	Implement shared information systems or secure communication platforms enabling direct exchange between cleft teams and community SLPs.
	Cleft Service	Develop standardized templates for pre-clinic updates, shared reports, and therapy summaries.
	Cleft Service	Embed processes for timely release of clinic outcomes, ensuring community clinicians receive actionable information automatically.
	Cleft and Community SLP Services	Ensure contact information is accessible to all stakeholders.
Management	Cleft Service	Integrate routine joint consultation opportunities, either in-person or via telehealth, into cleft services.
	Cleft Service	Create structured escalation pathways, clearly outlining when re-review is required and who initiates contact.
	Cleft Service	Support community SLP attendance at key appointments through hybrid or asynchronous participation options.
	Community SLP Service	Community SLP services establish internal processes to provide pre-clinic updates and proactively confirm whether they will participate synchronously or asynchronously in upcoming cleft appointments.

	Cleft Service	Formalise the use of shared goal-setting tools, ensuring alignment across settings.
	Cleft and Community SLP Services	Create structured opportunities for joint decision-making and goal setting by all stakeholders (synchronously or asynchronously as appropriate).
Relational	Cleft Service	Embed early triadic introductions as a routine pathway step (e.g., initial “Meet the Team” joint orientation sessions).
	Cleft and Community SLP Services	Provide protected time for communication (e.g., billable consult time, scheduled triadic reviews).
	Cleft and Community SLP Services	Offer training in collaborative communication, recognizing that effective communication is a clinical skill that must be taught, practiced, and refined through feedback.
	Cleft and Community SLP Services	Recognize and resource collaboration as an essential component of cleft care, not an optional add-on.

### Discussion

This study synthesized findings from a multi-study program of research to develop recommendations aimed at strengthening continuity of care in cleft speech services. Organized under the domains of informational, management, and relational continuity, the recommendations provide all members of the Tri-Care team including cleft team SLPs, community-based SLPs and parents, with evidence-informed strategies to work together in more coordinated and predictable ways. Rather than positioning one stakeholder as the primary driver of the improvement, the recommendations are designed to promote shared responsibility and outline what effective collaborative care can look like when each partner contributes their expertise. Although this work was conducted in Australia and New Zealand, the structure and challenges of care described here closely mirror those reported in other high-income countries with centralized cleft services,

suggesting the Tri-Care Model offers internationally relevant guidance for strengthening continuity of care.

The proposed Tri-Care Model also warrants consideration alongside existing structural service configurations, such as the United Kingdom's Hub-and-Spoke model. While the Hub-and-Spoke model outlines how cleft services are geographically and administratively organised, the Tri-Care Model focuses on the processes that enable continuity of care across informational, management, and relational domains. It does not prescribe service structure but instead articulates how collaboration and coordination can be strengthened within and across existing systems. As such, the model is complementary to structural configurations like Hub-and-Spoke and may enhance continuity within those frameworks rather than replace them.

A key contribution of this work is the translation of stakeholder perspectives into actionable strategies. Previous studies have identified persistent gaps in communication and coordination between cleft and community providers (Bow et al., 2025; Bow, McCabe, Sutherland, & Purcell, n.d.), and parents have reported variable experiences, often assuming responsibility for transferring information between providers (Bow, McCabe, Sutherland, Delzotto, et al., n.d.). The current recommendations directly address these challenges by providing structures for proactive information sharing, shared decision-making, and intentional follow-up from all stakeholders.

The findings also highlight the importance of reciprocal knowledge-building. Consistent with the scoping review (Bow et al., 2024), community clinicians valued access to concise, cleft-specific professional development and opportunities for mentoring, while cleft team SLPs emphasized the importance of understanding the child's broader developmental and contextual needs as typically observed by community clinicians. By embedding structured opportunities for joint problem-solving, shared assessment review, and capacity-building, the recommendations

and operational components of the Tri-Care model aim to strengthen confidence and capability across settings. This has the potential to reduce parents' reliance on personal initiative to bridge service gaps and enhancing the sustainability of cleft care pathways.

Relational continuity emerged as foundational to effective collaboration. Strong relationships built on trust, mutual respect, and recognition of expertise enable information sharing and coordinated management to be realised more effectively. Importantly, communication was identified as a clinical skill that warrants deliberate practice across the triad. This aligns with the broader healthcare literature emphasizing the role of communication competencies in team-based care (Kripalani et al., 2007). Prioritising these skills within professional development for both cleft and community-based clinicians, as well as supporting parent empowerment, may represent a key opportunity for enhancing collaboration.

The recommendations presented here offer practical, immediately applicable strategies for strengthening continuity across settings. However, their broader impact depends on how effectively they are embedded within diverse service contexts. Successful implementation will require shared commitment from cleft teams, community services, and families, as well as integration of collaborative practices into existing protocols, training programs, and local workflows. Embedding these changes systemically, rather than relying on individual goodwill, will be essential for sustaining improvements in continuity. The authors recommend using Table 2 as a checklist for improving continuity of care in SLP work with children with cleft.

### **Limitations**

Some limitations should be acknowledged. First, the recommendations are derived from research conducted in Australia and New Zealand, which may limit their direct applicability to other health systems with different service structures. While the underlying principles are likely to be transferable, adaptation will be required to suit local contexts. Second, participants self-

selected into the studies, which may mean that those with stronger engagement with cleft services, or with a particular concern, may have been more likely to participate. Lastly, while the studies included diverse perspectives, some service contexts, such as very remote regions, and culturally and linguistically diverse populations, may be underrepresented).

### **Conclusion**

This study presents the first evidence-based recommendations specifically designed to strengthen continuity of care in cleft speech services. By addressing informational, management, and relational continuity, the recommendations outline actionable strategies that support shared, triadic collaboration between parents, community SLPs, and cleft-team SLPs. By promoting clearer communication pathways, aligned management practices, and intentional relationship-building, the recommendations have the potential to enhance coordination and, ultimately, improve the care experience for children with cleft palate and their families.

The model and recommendations developed here provide a foundation for more connected, predictable, and sustainable cleft speech care. They also offer services a practical framework against which to benchmark their current practices and identify opportunities for strengthening continuity of care. Future work should focus on validating these recommendations through stakeholder consensus processes, exploring the feasibility and acceptability across diverse service contexts, and evaluating their impact on continuity of care and child outcomes.

Future research should focus on implementation and evaluation of the Tri-Care Cleft Speech Pathology Model, including feasibility, acceptability, and impact studies across diverse service contexts.

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## **Chapter 7: Conclusion**

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This thesis set out to examine continuity of care in cleft speech services across Australia and New Zealand; a context where cleft-team speech-language pathologists (SLPs), community-based SLPs, and parents must work across settings, time points, and differing expectations to support the communication and feeding outcomes of children with cleft palate. Although continuity of care is widely acknowledged in healthcare literature as essential for achieving timely, coordinated, and effective intervention (World Health Organisation, 2018), this research has shown that continuity is not an inherent feature of current cleft care systems. Instead, it is something that must be deliberately constructed, supported, and maintained across information, management, and relational domains. Through a research series that included a scoping review, three qualitative studies, and a final synthesis culminating the Tri-Care Cleft Speech Pathology Model, this thesis provides a comprehensive, stakeholder-driven model for fostering continuity in cleft speech pathology services.

Each paper within this thesis makes a distinct contribution to the profession. The scoping review established the international evidence base and revealed a striking gap: while continuity of care is frequently assumed to underpin cleft services, it had not been systematically examined within cleft speech-language pathology. The qualitative study of cleft-team SLPs illuminated the systemic and relational tensions within tertiary services, highlighting how continuity efforts were often experienced as consultative and one-directional. The community SLP study shifted the lens to clinicians delivering day-to-day therapy and revealed barriers related to role clarity, access to expertise, and perceived hierarchies. The parent study placed families at the centre, demonstrating how continuity breakdowns are frequently absorbed by parents, who act as coordinators, advocates, and information brokers across services. Collectively, these papers

provide the first integrated, multi-stakeholder examination of continuity of care in cleft speech services.

There is a clear need for system-level change. Improving continuity of care requires more than goodwill or isolated efforts; it requires structural support, protected time for communication, shared expectations, and service models that recognise collaboration as essential clinical work. Future research should evaluate the implementation of the Tri-Care Model in real-world settings, examine its impact on therapy outcomes and family experience, and explore how digital tools or policy frameworks can further support sustained, improved continuity of care.

While this research is grounded in cleft speech services, the patterns identified across stakeholders mirror those described in broader speech-language pathology and healthcare contexts. Similar tensions between specialist and generalist clinicians, challenges in role clarity, reliance on families to coordinate care, and the influence of perceived hierarchies have been reported in multidisciplinary paediatric teams, school-health interfaces, and community-tertiary transitions. In this way, the experiences documented in this thesis are not unique to cleft care but reflect systemic features of cross-setting collaboration in contemporary service delivery models.

The findings therefore extend beyond cleft speech pathology. They contribute to a wider understanding of how SLPs working across health and education systems negotiate shared care, professional identity, and intra and interprofessional collaboration. The emphasis on informational, management, and relational continuity has relevance for SLPs working in multidisciplinary hospital teams, early intervention services, disability sectors, and educational settings, where continuity is similarly dependent on communication structures and sustained relationships rather than co-location alone. The Tri-Care Model may therefore serve as a conceptual template for other areas of speech-language pathology in which responsibility is distributed across settings and professionals.

An important future direction for the Tri-Care Model is the explicit inclusion of the child with cleft palate as an active stakeholder. While this thesis examined the perspectives of parents and clinicians, children themselves were not directly consulted in the continuity studies. Emerging research demonstrates that children with cleft palate can meaningfully reflect on therapy, participation, and communication rights (Alighieri et al., 2025). Integrating their perspectives would strengthen relational and management continuity by ensuring care reflects the lived experience of the child as well as parental priorities. Future research should incorporate developmentally appropriate, participatory methods to position children not only as recipients of coordinated care, but as contributors to it.

In conclusion, this thesis demonstrates that continuity of care is not merely a desirable feature of cleft speech services – it is fundamental to ensuring that children and families receive coordination, and effective support across their cleft journey. By highlighting the perspectives of parents, community clinicians, and cleft-team SLPs, and translating these insights into a unified, practical model, this thesis offers a pathway toward cleft services that are not only clinically robust but relationally grounded and genuinely collaborative.

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