# Facilitators and barriers to delivering an optimal specialist service: an example from cleft lip and/or palate care

Nicola Marie Stock<sup>1</sup>
Fabio Zucchelli<sup>1</sup>

Vanessa Hammond<sup>2</sup>

Nichola Hudson<sup>3</sup>

Debbie Sell<sup>4</sup>

Author details can be found at the end of this article

Correspondence to:

Nicola Marie Stock; nicola2.Stock@uwe.ac.uk

# **Abstract**

**Background/Aims** Despite published standards of care, inequities and variations in specialist care delivery in the UK have been identified. Using cleft lip and palate services as an example, this study aims to identify potential facilitators and common barriers to delivering an optimal specialist service.

**Methods** Individual interviews were conducted with 50 specialist clinicians, representing all 16 NHS cleft lip and palate services in the UK. Responses were analysed thematically.

**Results** A range of barriers to optimal care were identified, including working within a restrictive medical model, declining resources and an insufficient evidence base. To facilitate optimal care delivery, participants described a need to share best practice, partner with academics to demonstrate service effectiveness, use technology in clinic and authentically integrate patient-centred care.

**Conclusions** Commissioners need to work more closely with specialist teams to ensure that resources are allocated based on need, with the view of optimising service delivery and patient outcomes.

Key words: Commissioning; Multidisciplinary; Optimisation; Patient-centred care; Specialisation

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# Introduction

A cleft in the lip and/or the palate is one of the most common congenital conditions in the world, affecting approximately 1 in every 600 children born in the UK (Cleft Registry and Audit NEtwork, 2020). Although surgery to repair the cleft is usually performed during the first year of life, children born with a cleft lip and/or palate (CL/P) and their families often engage in a multidisciplinary treatment pathway throughout childhood and into adulthood (Berkowitz, 2013). In addition to surgery and orthodontics, this pathway includes support from clinical nurse specialists, specialist clinical psychologists, and specialist speech and language therapists, who are involved in the entire pathway from prenatal consultation to maturity.

In the UK, CL/P care is delivered by 12 centralised networks, comprising 16 NHS regional teams. Commissioners for these services are responsible for the allocation of resources and are guided by the Cleft Development Group, a national independent body of clinicians, researchers, charitable organisations and patient or parent representatives (Cleft Registry and Audit NEtwork, 2020). The UK's CL/P service was designed using a 'hub and spoke' model, with all cleft surgery and key assessments taking place at specialist centres and all other core services being delivered at the centre or by outreach services in collaboration with community services.

Despite largely positive reports of care from healthcare professionals and patients (Scott et al, 2015; Searle et al, 2015; Stock et al, 2018), significant variations in care delivery across teams are still common (Scott et al, 2015; Stock et al, 2020a), as are inequities in the way services are funded (Searle et al, 2015; Lead SLT Group for the Craniofacial Society of Great Britain and Ireland, 2016). Ongoing evaluation of service configuration and performance is crucial for the continued development of CL/P teams and for achieving optimal patient outcomes (Fox and Stone, 2013). Specialist healthcare professionals are ideally placed to assess the ongoing state of care provision, yet data offering their perspective

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Stock NM, Zucchelli F, Hammond V et al. Facilitators and barriers to delivering an optimal specialist service: an example from cleft lip and/ or palate care. British Journal of Healthcare Management. 2022. https://doi. org/10.12968/bjhc.2021.0051 remains relatively scarce (Stock et al, 2020a). Furthermore, the views of non-surgical specialists (such as nurses, psychologists and speech and language therapists) are rarely presented in research (Scott et al, 2015). While quantitative data are available and can be useful for evaluating service delivery, qualitative investigation can offer a richer insight into the realities of delivering a highly complex and specialist service.

This study explored variations in specialist care from a qualitative perspective, using CL/P services as an example, looking specifically at common facilitators for and barriers to the optimal delivery of CL/P services from a non-surgical multidisciplinary perspective.

#### **Methods**

Individual, semi-structured telephone interviews were conducted with 50 participants who were either currently working in or had recently retired (<2 years) from a specialist CL/P centre. Participants included 17 specialist nurses, 19 clinical psychologists and 14 speech and language therapists, with all 16 CL/P services in the UK represented. All but two participants were women. The nurses reported an average of 15.5 years working in specialist CL/P services (range 4–31 years), clinical psychologists reported an average of 7.4 years (range <1–20 years), and speech and language therapists reported an average of 11.8 years (range <1–28 years). Interviews were conducted between September 2016 and March 2017, with an average length of 58 minutes each.

The interview schedule was designed by the first and second authors based on a literature review (Stock and Feragen, 2016) and consultation with clinicians. Participants were asked about:

- Personal and professional information, such as year of qualification and main responsibilities
- Observations from working with patients and families, including common challenges faced by patients and common characteristics of those who cope well and those who struggle
- Current approaches to intervention, such as typical approaches used, format and comparison with other UK or international colleagues
- Barriers and facilitators to intervention, such as factors influencing intervention success and training needs
- Multidisciplinary teamworking, such as the benefits and challenges of the multidisciplinary approach and any perceived need for service improvement
- Audit and research, such as the current audit procedure and opportunities for research activity. Interviews were transcribed verbatim and subjected to inductive thematic analysis (Braun and Clarke, 2006), with themes chosen for their prevalence and/or importance in relation to the research question. Analysis was performed independently by the first and second authors, who are trained in qualitative methods. Findings were compared and any discrepancies discussed until full agreement was reached. Anonymised preliminary findings were presented to all members of the three clinical excellence networks at the annual meeting of the Craniofacial Society of Great Britain and Ireland in April 2017. A focus group discussion with each clinical excellence network was then facilitated by the authors to ensure the accuracy of the interpretative process and to discuss the implications of the findings.

Findings regarding the key challenges encountered by patients and families, and the types of non-surgical interventions used to address these challenges, were discussed in a previous article (Stock et al, 2020b). The present article uses the interview data with a focus on perceived facilitators and barriers to delivering an optimal specialist service. Institutional ethical approval for this study was obtained from the faculty research ethics committee at the University of the West of England. Participants were informed that their contribution to the study was voluntary, their data would be stored confidentially, they would not be identified during dissemination of the findings and they could withdraw their data from the study at any time before the completion of the analysis.

#### Results

#### Barriers to the delivery of optimal care

Thematic analysis identified several barriers to the delivery of optimal CL/P care (Table 1). Nurses and clinical psychologists discussed the negative impact of a poorly-delivered

diagnosis, the variable quality of online information and an increase in the uptake of private antenatal screening scans on new and expectant parents. Clinical psychologists and speech and language therapists highlighted how patients' and families' preconceptions of therapy and their level of engagement in therapy could be barriers to achieving optimal outcomes.

Working within services dominated by a medical model was identified by all three disciplines as a considerable challenge, with an imbalance in the priorities of care because of a focus on surgical outcomes. This resulted in a mismatch between optimal audit points, a desire to simplify complex issues and a misunderstanding among other clinicians of the benefits that the participants' disciplines offer. Clinicians from all three disciplines also discussed the challenges of delivering best practice in the context of declining resources, describing how ongoing disputes with their regional hospital managers surrounding cost-effectiveness, the importance of specialisation and general understaffing were a source of national inequity of care.

Participants from all disciplines described a weak evidence base for therapeutic interventions in CL/P care and the potential for this to impact their confidence as clinicians and their ability to demonstrate their value to others. However, participants also highlighted the challenges of collecting traditional 'higher level' evidence (such as

Table 1. Barriers to the delivery of optimal care as identified by cleft lip and palate specialist healthcare professionals (n=50)

nountion professionals (1–50)				
Theme (type of practitioner)	Barriers	Supporting quotes		
Managing misinformation (Nurse specialists and clinical psychologists)	Mixed level of knowledge among non-specialists	'The psychologists and the nurses, we spend a lot of time trying to undo the damage of a poorly-delivered diagnosis.' (Clinical psychologist 7)		
	Variability in the quality of online information	'There is a lot of misinformation online so if families are not directed to a trusted source the messages and the language are not helpful Antenatal visits can take anything from 1 hour to 3 hours depending on what the family has been reading.' (Nurse specialist 5)		
	Increase in the uptake of private scans	'The other thing we have to think about are the private companies. More and more people are going for gender scans at 16 weeks and it is just not handled properly and families are not referred.' (Nurse specialist 13)		
Patient engagement (Clinical psychologists and speech and language therapists)	Patients' and families' preconceptions	'There is definitely a stigma around mental health still Sometimes just a mention of the psychologistthey are put off straight away and we do not hear from them again.' (Clinical psychologist 13)		
	Therapeutic non-compliance	'When patients are not attending appointments, that can be frustrating, and you feel likeclinical time is wasted Or if you have asked a school to carry out a programme of work andyou find out later that they have not done it.' (Speech and language therapist 5)		
Working within a medical model (Nurse specialists, clinical psychologists and speech and language therapists)	Priorities for care	'Often in a surgical team, appearance and function take high priority with regard to treatment planning [A patient] can have good physical outcomes but if they are not psychosocially adjusted, has it all been worth it?' (Clinical psychologist 12)		
	Multidisciplinary team audit points	'The audit points that suit the rest of the multidisciplinary team are not necessarily the best measurement points for other disciplines like speech and language therapy and psychology We could probably do with reassessing what the key assessment points are for us.' (Speech and language therapist 9)		
	Simplification of complex issues	'Psychological issues are very complex whereas what the rest of the service want from us is a yes or no or a single score or something concrete which I doubt we will ever be able to do in a meaningful way.'  (Clinical psychologist 14)		
	Invisibility of the role	'People do not have much understanding of what we do We can be valued for picking up the pieces when people are upset, for example, which is not necessarily our biggest skill or contribution.' (Clinical psychologist 3)		

firefighting.' (Clinical psychologist 14)

clinical trials) within their disciplines. While nurses often supported other clinicians' research (such as surgical trials), they acknowledged that they rarely carried out research within their own discipline.

Finally, participants from all disciplines suggested that they could be engaging more in interdisciplinary research and doing more to support the integration of preventative work.

#### **Facilitators of optimal care delivery**

A number of facilitators of optimal care delivery were identified by participants (Table 2). Participants from all three disciplines believed that the sharing of best practice was a key facilitator in creating an optimal service. Participants believed that this could be achieved through the provision of CL/P care training for non-specialists (such as midwives) and joint working, by engaging local services and by adopting a genuinely collaborative approach to working. Participants from all disciplines outlined the possibility of using alternative research methods to provide evidence for their contribution to the service. These included the use of qualitative methods and case studies, as well as the implementation of goal-based outcomes.

Clinicians from all three disciplines discussed opportunities to partner with academics and emphasised the potential benefits of additional support staff—including dedicated

community 'link' speech and language therapists, assistant psychologists, students and research nurses—to community service delivery and to audit and research productivity. Similarly, participants from all disciplines discussed the usefulness of technology for cost-effective communication and record-keeping, efficient data collection and the delivery of interventions. Finally, nurses and clinical psychologists discussed the importance of normalising psychological support to reduce stigma and increase uptake, and the value of building an multidisciplinary team that genuinely values patient-centred care.

# **Discussion**

#### **Appropriate allocation of resources**

Participants from all three disciplines expressed concerns regarding a steady decline in resources over the previous 10 years. At a regional level, this had reportedly led to the understaffing of CL/P care units, downgrading of posts and delays in or failure to replace key staff members. Despite being categorised as a commissioned specialist service, participants reported being instructed to cover other clinical services, which reduced their capacity to support those affected by a CL/P at crucial times in the treatment pathway.

Authoritative reports on the optimal delivery of child and adolescent mental health services and speech and language therapy have recommended a minimum number of full-time equivalent staff relative to the population in need, including an appropriate balance

Table 2. Facilitators of optimal care delivery as identified by cleft lip and palate speciali	st
healthcare professionals (n=50)	

healthcare professionals (n=50)			
Theme (type of practitioner)	Facilitators	Supporting quotes	
Sharing best practice  Nurse specialists, clinical psychologists, and speech and language therapists)	Training opportunities for non-specialists	'It is doing more teaching with the midwives and maybe getting into the antenatal units to explain our service, show that [cleft] is not all	
		doom and gloom making sure they have up-to-date information.' (Nurse specialist 7)	
	Joint working with non-specialists	'Joint working [with non-specialist clinicians] can be really beneficial for all involved joint home visits to see families for example There is less likely to be conflicting information given to families, and it is dropping into the normal pathways that any other family would be on.' (Nurse specialist 14)	
	Engaging local services	'School involvement, nursery involvement working with the Cleft Lip and Palate Association's regional staff engagement of local services is key.' (Speech and language therapist 14)	
	Collaborative working approach	'We have Clinical Excellence Network meetings at least four times a year and we have a whole paediatric psychology department in the hospital that I can link in with We meet with the other cleft teams in our region Sometimes there are opportunities to go to conferences so I feel very well connected and get lots of input and knowledge from my colleagues.' (Clinical psychologist 10)	
Using alternative methods to evidence contribution (Nurse specialists, clinical psychologists, and speech and	Qualitative approaches	'I think qualitatively interviewing parents who experienced the service before the [nurse specialists] were introduced, and comparing that with parents' experiences now We need to be finding other ways of demonstrating the contribution we make because I think people forget what it was like not having [nurse specialists] around.' (Nurse specialist 9)	
language therapists)	Case studies	'We know we can change speech, what we need to do now is show how we do that, when is the best time [to intervene], how intensive it needs to be We have got such wonderful material among us all for some case study analyses which would help us describe exactly what we do.' (Speech and language therapist 1)	
	Goal-based outcomes	'We are trying to use the goal-based outcomes with the patient  Hopefully if we start to collate those they could ultimately be used for research.' (Clinical psychologist 19)	

team appreciation of

psychological issues

of gradings from consultant level to newly qualified (British Psychological Society, 2015; I CAN and Royal College of Speech and Language Therapists, 2018). Yet, erosion of both services has been reported across the UK, including a systematic dilution of specialist and community-based services and large variations in reported spending between geographical areas (Lead SLT Group for the Craniofacial Society of Great Britain and Ireland, 2016; British Psychological Society, 2015; I CAN and Royal College of Speech and Language Therapists, 2018; Longfield, 2019). Clinical directors have identified a lack of clarity about how commissioning and funding of services is handled, stating that funding decisions are often made without a full understanding of patients' needs and that inconsistencies in funding models between specialist teams can impede equitable service delivery (Searle

all working to the same goal.' (Clinical psychologist 10)

psychology... that they are very psychologically-minded... and we are

et al, 2015). Parents of children with a CL/P have also expressed concern and dissatisfaction at the availability of community support, citing long waiting times, a lack of continuity of staff and conflicting advice depending on the therapists' level of expertise (Lead SLT Group for the Craniofacial Society of Great Britain and Ireland, 2016). Without an appropriately resourced workforce, inclusive of applied scientists and specialist therapists, vulnerable patients are unlikely to be offered appropriate interventions (British Psychological Society, 2015; I CAN and Royal College of Speech and Language Therapists, 2018; Longfield, 2019).

These findings suggest that discrepancies in resource allocation are impacting specialist teams' ability to meet the UK's National Service Specification (Searle et al, 2015; Lead SLT Group for the Craniofacial Society of Great Britain and Ireland, 2016), which could ultimately jeopardise patients' and families' long-term outcomes. The need for specialist teams and commissioners to work more closely is crucial, as is ongoing implementation of feedback from key stakeholder groups. The substantial benefits of dedicated link community speech and language therapists in improving the quantity and quality of local service provision have also been demonstrated (Lead SLT Group for the Craniofacial Society of Great Britain and Ireland, 2016), suggesting that funding for these posts should be protected.

Participants also reported feeling that they faced an ongoing battle to justify the costs of home visits to their respective regional hospital managers, despite a report by the British Psychological Society (2015) stating that home visits are an evidence-based way of reaching vulnerable and/or marginalised groups and should be prioritised. Another proposed way of engaging families included the use of technology. For example, nurses reported that digital health records and mobile phones enabled easier communication, which saved mileage and nursing hours. Others felt that devices such as iPads could increase efficiency in the clinical setting, thereby saving the hospital money over time. Participants also felt that technology had the potential to be used in therapy, providing the opportunity to deliver interventions remotely in order to save on travel costs and to better meet the needs of families for whom English is an additional language. Research supports this, showing that digital tools are user-friendly, have the potential to foster and maintain clinical change, and may successfully augment traditional treatments (Speyer et al, 2018). Using support from assistant psychologists, students and research nurses may also be a cost-effective way of improving audit and research productivity without compromising clinical time. Ultimately, the integration of health economics to demonstrate longitudinal cost savings may be necessary.

#### **Evidencing the contributions of specialist health professionals**

Despite the evidence base to support broad therapeutic approaches (such as cognitive behavioural therapy), guidance for delivering these interventions to address condition-specific issues is scarce (Bessell et al, 2013; Norman et al, 2015). This created uncertainty for some participants and impacted their confidence, particularly if they were relatively new to the field. Participants also described how a lack of 'higher-level' empirical evidence (such as clinical trials) made it more difficult to demonstrate the value of their role, particularly when working within the surgically-focused context of a medical model. However, there are challenges associated with collecting empirical evidence when patients present with complex needs. To offer integrative and flexible care based on the needs of the individual, alternative methods of collecting evidence should be considered (British Psychological Society, 2015). These approaches could also provide information about how to appropriately target interventions at an early stage in order to prevent initial difficulties becoming more complex and entrenched over time.

Participants identified three alternative methods that could help to better document their contribution to the service:

- Qualitative approaches
- Case studies
- Goal-based outcomes.

Qualitative approaches can include many sources of information and can shed light on families' experiences and the factors that contribute to successful interventions, yet they remain underused in healthcare (Nelson, 2009). As a research strategy, case studies have traditionally been viewed as lacking rigour compared to more traditional methods

(Rowley, 2002). However, they can offer valuable insights into the 'how' and 'why' of a phenomenon, which may not be achieved using other approaches (Rowley, 2002). Single-case experimental design studies are also gaining traction in healthcare research, in which detailed analysis of a change in the dependent variable over time is conducted. Such studies have been shown to integrate well into routine clinical practice (Perdices and Tate, 2009). Meanwhile, goal-based outcomes tools are designed to capture changes in the unique goals that a patient or family member wants to alter through intervention. Such tools are driven by the patient and can be used with any intervention and therapeutic modality (Law and Jacob, 2013). Goal-based outcomes can also be combined with the clinician's rating of outcomes to give an overall assessment of the progress of an intervention (British Psychological Society, 2015). Unlike costly clinical trials, these types of evidence could be integrated into routine care with relative ease and could demonstrate the need for additional resources over time.

Several participants described feeling anxious about undertaking research. A previous study of CL/P services found that interventions are often trialled by teams, yet these studies rarely appear in the literature because of an inadequate research design and/or a lack of research time (Stock et al, 2020b). One potential solution to these challenges is to partner with academics. Such partnerships could combine the extensive knowledge of both parties and maximise the implementation potential of research findings (Haynes and Haines, 1998). Given the relative size of specialist fields, international partnerships could also increase research activity on a global scale. Participants in the present study felt that they could be engaging in more interdisciplinary research, as well as partnering with colleagues from broader perspectives, such as sociology, social policy, nursing and other health services (Nelson et al, 2012). Clinicians who are keen to pursue academic development could also explore opportunities to undertake clinical academic training.

#### **Collaborative working**

One of the key barriers to implementing an optimal service identified by participants was working within a restrictive medical model, whereby surgery often took precedence in treatment planning. Psychological research has consistently demonstrated that 'objective' treatment outcomes are superseded by the patient's own perceptions of the impact of their condition on everyday life, emphasising the importance of multidisciplinary holistic care (Clarke et al, 2013). According to participants in the present study, the integration of non-surgical specialties into the service is an important first step, but all disciplines need to be heard and feel valued for this collaboration to be meaningful. Recognising the unique contribution of all specialists and working collaboratively, rather than simply side by side, can help to ensure an optimally functioning team (Fox and Stone, 2013). Educating all specialties on the importance of patient-centred care and how to provide it may help to facilitate this change (Stock et al, 2020a).

In previous research, parents of children with a CL/P have reported a lack of knowledge among non-specialists, such as diagnostic sonographers, midwives and health visitors (Costa et al, 2019; Stock et al, 2019). In order to address these challenges, the nurses and clinical psychologists who participated in the present study suggested creating more teaching opportunities for non-specialists and carrying out joint family visits to ensure that non-specialists had access to accurate, up-to-date information, and that all clinicians involved were providing consistent advice. This may also increase the frequency with which those affected by complex conditions are directed to reliable sources of online information. Finally, participants identified engagement with other local services, including nurseries, schools and representatives of charitable organisations, to be a key facilitator of best practice.

#### Limitations

Several methodological issues in this study should be considered. First, although all nurses, clinical psychologists and speech and language therapists working in specialist UK CL/P services were invited to participate, not all were able to commit within the study's timescale, meaning that not all views are represented. To address this, members of all three clinical excellence networks also participated in focus groups to discuss the findings. Second, this study focused specifically on three key (non-surgical) disciplines. Future research could

explore the perspectives of other core disciplines, such as surgeons, orthodontists and other dental specialties, as well as other specialist services. Finally, further understanding of the extent to which these findings apply to clinicians based in other countries would be beneficial, as would highlighting key differences across global healthcare provision.

## **Conclusions**

Although multidisciplinary care for those born with a CL/P is a commissioned service in the UK, wide variations in regional and local resources have been reported. Consideration of services based on need should be promoted, as well as assessment of the utility and cost-effectiveness of various forms of technology and support staff. To further demonstrate the essential contributions of specialist health professionals and to improve the evidence base for intervention, clinicians should be encouraged to consider alternative methods of data collection and to seek out partnerships with academics and other interdisciplinary colleagues. It is crucial to work collaboratively, both within multidisciplinary teams and with community-based colleagues, to share best practice and to delivery truly patient-centred care.

#### Author details

<sup>1</sup>Centre for Appearance Research, University of the West of England, Bristol, UK

<sup>2</sup>Welsh Centre for Cleft Lip and Palate, Bristol, UK

<sup>3</sup>Spires Cleft Centre, Salisbury and Oxford, Bristol, UK

 $^4$ Centre for Outcomes and Experience Research in Children's Health, Illness and Disability, Great Ormond Street NHS Foundation Trust, Bristol, UK

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The authors declare that there are no conflicts of interest.

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# **Key points**

- Variations and inequities in specialist healthcare in the UK have been identified.
- Barriers to optimal care include working within a restrictive medical model, declining resources and an insufficient evidence base.
- Specialist clinicians should be encouraged to partner with academics, share best practice with non-specialists, and work more closely with commissioners to ensure fair allocation of resources and to optimise outcomes for patients and their families.

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