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An Exploratory Study of Speech and Language Therapy Intervention for Children born with Cleft Palate ± Lip

Abstract:	Children born with a cleft palate ± lip are at risk of developing speech and language difficulties, which may require intervention from a speech and language therapist (SLT). To date, there is no strong evidence to support one approach to intervention over another, neither is it clear which approaches or methods of provision are commonly used. Objectives: To describe the range of speech and language therapy interventions being used with children born with cleft palate in the UK up to 5 years of age. To explore the different ways interventions are being delivered. Design: A prospective study to conduct 9 semi-structured focus groups. Iterative content analysis was completed. Setting: Regional Cleft Lip and Palate Centers in the UK. Participants: 62 Speech and Language Therapy professionals from specialist cleft teams and community services. Results: Four main codes were identified: 'intervention approaches', 'service delivery models', 'decision making and rationale' and 'patient centered care'. Participants frequently discussed how they adopt an eclectic style when delivering intervention, the importance of an individualized approach for each child and service delivery constraints, such as a lack of resources. Conclusion: Insight into the multitude of intervention approaches used by SLTs, aspects which influence their decision making and the variability of service delivery models was gained. Uncertainty regarding which intervention approaches and methods for delivery are most effective provides rationale for future research, to improve the effectiveness of speech and language intervention for children with cleft palate ± lip.

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Introduction

Children born with a cleft palate, with or without a cleft lip (CP±L), are at risk of developing speech, language and communication difficulties (Vallino-Napoli, 2011). Although a cleft palate is usually repaired during the first year of life, atypical speech patterns may prevail, with the potential for impact on intelligibility and consequences for a child's future social and educational progress (Richman et al., 2012).

Across the United Kingdom (UK), speech outcomes are audited at the age of five for children with CP±L. This is for the purpose of measuring the impact of interventions which have been provided at an individual and service level (Britton et al., 2014). Analysis of this audit data has shown that 38.8% of the population do not achieve normal speech by age five (The Cleft Registry and Audit NEtwork (CRANE), 2018). What constitutes 'normal speech' is subjective and may vary from one person to another but work by Sell et al. (2015) provides more objective data and shows that for some children, their speech is severely affected. They reported that 17.2% of children born with CP±L are classified as 'only just intelligible to strangers' or 'impossible to understand' at five years of age. These figures are reflected in data which records need for speech and language therapy in this population. Evidence from the literature indicates that more than 50% of children born with CP±L require intervention from a Speech and Language Therapist (SLT) during childhood (Hardin-Jones and Jones, 2005; Peterson-Falzone, Hardin-Jones and Karnell, 2009), suggesting that problems with speech are often persistent and have significant impact for the child concerned.

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Interventions delivered by SLTs may target a range of difficulties including speech sound substitutions, comprehension and expression of language and social communication skills. Improvement in speech, language and communication skills is expected to impact positively on other aspects, such as the child's literacy skills, confidence, participation and well-being (Bercow, 2018; Chapman, 2011; McCormack et al., 2009).

Speech and Language Therapy for Children with CP±L in the UK

Children born with CP±L may have multiple speech, language and communication needs, some of which could be unrelated to their cleft (Vallino-Napoli, 2011). The interventions delivered by the SLT primarily focus on outcomes related to the child's speech and language skills, for example articulating specific sounds, the expression of ideas and information or the processing and understanding spoken words.

Children with CP±L who live in the UK and require speech and language therapy intervention typically receive this from the government funded National Health Service (NHS) though in recent years the availability and uptake of privatized, independent speech and language therapy has become increasingly popular (Bercow, 2008). Within the NHS both regional specialist services and community-based services co-exist and often work in unity, although disparity regarding provision is widely recognized (Bercow, 2018; Bercow, 2008). A report by the Lead SLT Group and Chair of the Cleft Clinical Reference Group (Anonymous, 2016) found inequity in care due to local and regional variations in how speech and language therapy interventions for children with CP±L are funded and delivered, following a survey of specialist SLTs across the UK. This group concluded that speech and language therapy provision aligns with costs rather than evidence-based practice or national recommendations. They raised concerns regarding reductions in

skills and expertise of cleft specialist SLTs due to down-grading of posts, which the report considered would negatively impact upon the quality of intervention and speech outcomes.

Evidence for Speech and Language Therapy Interventions for Children with CP±L

A systematic review of speech and language therapy interventions for children with CP±L found little evidence to support any specific approach (Bessell et al., 2013). Included in their analysis was a consideration of the different types of speech impairment children might need intervention for. They summarized that cleft speech difficulties can include both articulation and phonological disorders. An articulation disorder is defined as an inability to produce specific speech sounds, whereas a phonological disorder is characterized by pattern-based speech substitutions as a result of cognitive-linguistic difficulties (McLeod and Baker, 2017). They suggested that future intervention studies should investigate and compare approaches including speech related motor techniques (aiming to elicit a sound by practising the physical movement of the articulators) and linguistic techniques (targeting the child's understanding and production of their rule-based sound system). The Bessell et al. (2013) review highlighted the need for further methodologically rigorous studies to inform the intervention evidence base for children with CP±L.

In addition to speech difficulties, children born with CP±L often have delayed language development (Lancaster et al., 2020; Pamplona et al., 2015). In their recent meta-analysis Lancaster et al. (2020) concluded that deficits in both expressive and receptive language functioning are apparent in young children with non-syndromic CP±L. However, language interventions for this population have been under researched compared to speech interventions (Pamplona et al., 2015). Pamplona et al. (2015) suggested this might be because speech disorders related to

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velopharyngeal incompetence are most prominent when treating these children,

hence research has been driven by this clinical priority. Nevertheless a systematic

review of early language intervention for children with CP±L has been carried out

(Meinusch & Romonath, 2011). While the authors concluded that findings were

limited due to flaws in the design of the previous research, they acknowledged that

inclusion of the mothers in the therapeutic setting appeared to positively influence the

language abilities of children with CP±L, supporting the use of behavior training

programs for care-givers.

Speech and Language Therapy Intervention in the Non-cleft Population

Studies investigating intervention approaches used in speech and language therapy

in populations of children with non-cleft related speech and language needs have

highlighted some of the challenges that arise in carrying out such work (Roulstone et

al., 2012). These include variation in how interventions are described and labelled, a

mismatch between the evidence base and clinical practice and an awareness that

interventions are complex and typically consist of multiple elements.

It was hypothesized that this variability may impact upon the delivery of intervention,

as SLTs may alter specific named approaches from the way they were originally

conceived and delivered in trials or exploratory investigations. This may not be a

conscious action but nevertheless, the lack of consensus between SLTs in how

interventions are labelled and described may pose challenges when comparing

approaches. Similar patterns were observed in studies of intervention for children

with speech sound disorder (Baker et al., 2018) and with primary speech and

language impairment (Roulstone et al., 2015).

Another challenge facing investigators is the presence of a lag between the publication of research and its implementation in practice (Hegarty et al., 2018; Olswang and Prelock, 2015). Hegarty et al (2018) in their survey of practitioners on commonly used intervention approaches for children with phonological disorder found evidence of a 'research-practice gap'. Specifically, they found that frequently used interventions were not those which were identified as the most effective according to the evidence in the literature. Hegarty et al.'s (2018) findings highlighted the challenge clinicians face when implementing research findings into practice. Olswang and Prelock (2015) discussed these challenges and introduced implementation science principles, which advocate the application of research findings to practice. These principles promote the researchers' awareness of real-world settings, community engagement and consideration of behavior change theories. Conducting research which is driven by clinicians' priorities, a bottom-up approach, may positively influence the implementation of findings into everyday practice.

The complexity of speech and language therapy interventions has been highlighted as a challenge in both research and clinical practice. Further analysis of specific intervention approaches has proposed that some techniques encompass multiple elements (Baker et al., 2018). Baker et al. (2018) advocated establishing which elements drive positive treatment effects and considered the complexities of individual intervention approaches. The authors highlighted the importance of collecting detailed information related to how intervention approaches are delivered when conducting research.

Delivery of Interventions

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While determining the critical components of an intervention approach is important, variation in how individual SLTs deliver interventions must also be considered, given the potential for additional impact on outcomes. Roulstone et al. (2015) in the 'Child Talk' Study, a large-scale qualitative study of children with primary speech and language impairment, investigated how interventions are delivered in terms of the organization of services and individual SLTs' decision-making in the management of the children's needs. Child Talk found that SLTs individualize therapy, often using the phrase 'it depends' to illustrate how intervention management is influenced by various factors (Roulstone et al., 2015; Morgan et al., 2019). Some of these factors have been discussed in Furlong et al.'s (2018, pp.1135) paper; namely, "child factors (e.g., age, severity of communication disorder), family factors (e.g., cultural differences, engagement and attendance) and contextual factors (e.g., staffing pressures, access to published programs)". 'Environmental factors' were also discussed in Cronin et al.'s study (2020) which reported on interviews with Specialist SLTs who work with toddlers with CP±L.

Comparisons of service delivery options have been addressed in the studies described above (Roulstone et al., 2015; Morgan et al., 2019; Furlong et al., 2018). Sugden et al.'s (2018) study of intervention intensity for the population of children with non-cleft related speech sound disorder considered service delivery options. They concluded that detailed reporting of intervention intensity is required in future research to determine the optimal levels for effective treatment. Factors such as the frequency, dosage, location, duration and person delivering the intervention are all recognized to be crucial when investigating how intervention is delivered (Sugden et al., 2018; Hegarty et al, 2018; Roulstone et al., 2012; 2015).

Consideration of the content of interventions and the manner of delivery are equally relevant in the management of children with CP+/-L. To date, it has been mainly gathered through the audit process described above. What has proved more challenging however is how to gather robust data on the type of interventions, dosage and manner of delivery that could be used alongside outcome data to measure the impact of speech and language therapy intervention.

The aim of the present study was to understand expert opinions from clinicians, a key component of the Evidence-Based Practice triangle (Sackett et al., 1996), in order to complement the existing evidence base.

Method

Ethics

Ethical approval for this study was provided by Central Bristol NHS Ethics Committee (IRAS Number: 135015).

Design and Setting

An iterative qualitative method (Srivastava and Hopwood, 2009; Berkowitz, 1997) was used to obtain information about the types of interventions and patterns of service delivery offered by speech and language therapy services for children born with CP±L and to capture variations in service provision. The role of iteration, not as a repetitive mechanical task but as a deeply reflexive process, is key to sparking insight and developing meaning. Reflexive iteration is at the heart of visiting and revisiting the data and connecting them with emerging insights, progressively leading to refined focus of data collection and understanding.

Nine focus groups with speech and language therapy professionals were carried out in England and Wales. This approach, described by Robson (2002b), was selected following discussion with the cleft speech and language therapy teams as the best way to gather detailed information on the range and type of interventions being offered currently. Focus groups were scheduled at their regional cleft center site.

Participants

Sixty-two professionals participated in the focus groups: 43 cleft center specialist SLTs, 16 SLTs from community speech and language therapy services (eight with a specialism in cleft), three Speech and Language Therapy Assistants and one student SLT (Table 1). No participants dropped out of the current study. All cleft teams involved in recruiting to the Cleft Collective were invited to participate in the focus groups but not all were able to do so within the time available for data collection. During the focus groups only researchers and participants were present.

[INSERT TABLE 1 – Participants]

Procedure

Convenience sampling (Robson, 2002a) was used whereby invitations to participate in focus groups were emailed to the Lead SLTs at the regional Cleft Lip and Palate Services across the UK. A presentation about the study with eligible SLTs of a Cleft Speech Clinical Excellence Network meeting also drove recruitment. A team of five female researchers were involved in data collection, with research and clinical experience in the fields of speech and language therapy and psychology. Three of the researchers had PhDs and one worked part-time clinically as a Cleft Specialist SLT. All of the authors were involved in leading one or more focus groups.

Two researchers attended each focus group; one researcher acted as facilitator, whilst the other supported facilitation and recorded field notes. The research was undertaken from an ethnographic stance (Reed-Danahay, 2009; Ten Have, 2004), with the aim to obtain scientific descriptions of SLTs' service cultures and practice when working with the parents of and children with CP±L. Professional working relationships were established between some researchers and participants prior to the focus groups, as a result of previous involvement in research projects and clinical liaison. The researchers' clinical and research roles were shared with participants prior to the commencement of the focus groups.

Each focus group lasted two hours. Detailed notes were taken during each group, as were audio-recordings using Olympus DS-2400 dictaphones. Technical difficulties meant audio recordings were not captured during three of the groups and as a consequence, quotes are not available from those sites. The focus groups took place over a fifteen-month period to allow a realistic timescale for clinicians to be freed from clinical commitments for attendance.

Researchers developed a topic guide, to encourage dialogue related to intervention provision (Appendix 1). Participants were asked: 'which are the important aspects of service delivery in speech and language therapy intervention for children with CP±L?'. Once identified, the researcher probed further: 'which are the options available for these service delivery choices?'. Intervention provision variations were considered from both the specialist and community services. Following a semi-structured format, questions were open ended, allowing participants to draw on their experiences.

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Researchers initiated discussions about how intervention provision varies according to age, between birth and five years. The participants defined age categories and subsequently discussed how intervention provision varies for each age category in turn.

Throughout the session the researchers probed for additional detail and clarification e.g. 'could you describe it?' 'what do you mean by…?'. If required, the researchers suggested examples of intervention options raised in previous focus groups to stimulate discussions. The researchers checked their understanding of responses from participants by repeating comments back to participants using alternative vocabulary.

Once no new data were provided, the focus groups incorporated knowledge elicitation activities (Shadbolt and Smart, 2015) to enable participants to reflect in detail on their clinical practice and to make explicit the knowledge that they access in certain clinical contexts. Clinicians have specialist expertise and knowledge, which becomes second nature to them in daily practice and their rationale for decision making can be difficult to articulate to non-specialist listeners. During knowledge elicitation activities responses to stimulus questions were probed to ensure that clear and unambiguous data were collected. Where specific terms or labels were used to describe interventions, participants were asked to explain and elaborate on what they meant by the term to ensure that there was consistency in how interventions were described in the dataset. Examples of these activities are shown in Appendix 2.

Analysis

Qualitative analysis using iterative content analysis, as described by Elo & Kyngäs

(2008), enabled the researchers to form codes and sub-codes. Content analysis

uses a descriptive approach in both coding of the data and its interpretation of

quantitative counts of the codes (Downe-Wamboldt, 1992; Morgan, 1993,

Vaismoradi, Turunen & Bondas, 2013), supporting the use, interpretation and

integration of the data from the knowledge elicitation activities. This approach

provides an advantage over thematic analysis which is a purely qualitative, detailed,

and nuanced account of data (Braun & Clarke, 2006).

Transcripts from the audio recordings and field notes were read several times to

ensure the researcher (CW) was immersed in the depth and breadth of the content.

Transcripts were not returned to participants for corrections or comments. Codes

and sub-codes were discussed with all authors to check consensus of interpretation.

NVivo software version 10, (QSR International Pty Ltd, 2014) was used to support

the data analysis.

Results

Four codes were identified which covered what intervention is currently delivered and

how this is accomplished: 'intervention approaches', 'service delivery models',

'decision making and rationale' and 'patient centered care'. Each code was

populated with four sub-codes (Table 2).

[INSERT TABLE 2 – Codes and Sub-codes]

Each of the codes are described in sequence below, together with examples of data

which were used to identify the codes. Where relevant and to aid interpretation of

the findings references to the existing literature are included within the results

section.

Intervention Approaches

Therapeutic techniques

Participants discussed which therapeutic techniques they use with children with

CP±L between birth and five years. They categorized the type of intervention

provided into two broad categories: direct intervention and indirect intervention.

Direct intervention is delivered by the SLT whereas indirect intervention is often

consultative, guided by the SLT but delivered by another person, such as school staff

or a Speech and Language Therapy Assistant.

'We always do indirect therapy whatever we do' (FG 2)

Forty-nine direct intervention approaches were listed in total, with some specific

approaches reported to be in frequent use with this population. Participants reported

which approaches they would use with children in different age categories, which

they defined; the common age boundaries reported by seven out of nine focus

groups were, 0-18 months, 18 months-3 years and 3-5 years (Table 3). Participants

mentioned using technology, such as apps on iPads, to support their interventions.

[INSERT TABLE 3 – Intervention Approaches]

The practice of many SLTs was characterized by an eclectic approach, which

incorporates aspects of a few different intervention approaches rather than rigidly

following one approach as it has been originally described. These findings are

comparable to the non-cleft population (Baker et al., 2018; Hegarty et al., 2018) and evidence suggests most SLTs use an eclectic approach to intervention.

'That eclectic approach, we all do it' (FG 4)

'We don't tend to use a set, specific programme' (FG 6)

Participants recognized that activities they conduct, or ask communication partners to complete, often target multiple areas of development simultaneously. This approach was felt to allow for greater flexibility for the SLT to draw upon their experiences and promptly respond to the child's performance. SLTs commented that this enabled an individualized approach, targeting specific areas of need.

This eclectic approach recognizes that children with CP±L can experience various speech and language difficulties and participants are motivated to deliver patient-centered care.

Variability

Participants were aware of similarities and differences in the range of interventions provided by their service, making comparisons between community speech and language therapy services and regional cleft centers.

'That's not dissimilar to other teams' (FG 7)

Variability between individual SLTs regarding the selection of intervention approaches and their delivery was reported. Despite some participants raising concerns about whether they were carrying out interventions accurately, they also commented that variation is acceptable as it reflects the broad, variable nature of speech and language therapy interventions.

'Every therapist will be different from another therapist and then every child will have a different need and require different tools on the whole' (FG 4)

Previous research has highlighted that variability in which interventions are provided is usual for this population. For example, Bessell et al., (2013) reported both articulation and phonology therapeutic interventions in their systematic review.

Terminology

As participants discussed how interventions varied, they were mindful of their use of terminology and how SLTs may describe the same techniques or processes, but use different labels. These terminology variations were observed between and within focus groups, suggesting that SLTs within teams may vary in their use of terminology as well as those across teams.

'I'm just concerned that one person's indirect is another person's direct' (FG 2)

The Evidence Base

When discussing intervention approaches participants did not routinely mention the evidence base. Some comments suggested SLTs feel that replicating methods from intervention research papers does not always work in their clinical practice.

'Nobody follows one approach, no, ever ever, not unless you are doing a research project' (FG 5)

Participants often felt the recommended methods were too rigid to be implemented in their service. SLTs highlighted a lack of evidence related to intervention provision for children with CP±L.

'Where is the evidence base that says putting them on review for 3 - 6 months allows them to consolidate (FG 1)'

The use of non evidenced based approaches identified by Bessell et al. (2013) were observed in this study. For example, it was reported that Multisensory Input-Modelling (±Output) (Harding and Bryan, 2002) is delivered frequently between birth and three years of age, despite a limited evidence base for its effectiveness. Participants in the current study reported the effectiveness of this intervention, from clinical-level evidence, such as the child using more oral consonant sounds following intervention. It should be noted that the improvements observed by participants is anecdotal evidence and could be the result of enhanced language development and natural maturation.

Service Delivery Models

Frequency

Frequency denotes how often speech and language therapy intervention is provided. Kaipa and Peterson (2016) used the term 'dose frequency' similarly, to describe the number of times intervention sessions are delivered per unit of time, for example twice a week or twice a month. Participants mostly interpreted frequency in relation to direct intervention rather than indirect intervention. Variation was reported between services (Figure 1), for reasons such as the child's needs and availability of resources.

'They have therapy for as long as they need it because they might be alternating between us and the community' (FG 3 – regional cleft team)

An explanation for the variability was that some participants from regional cleft

centers felt they were able to offer intervention more frequently than community

speech and language therapy services. Participants spoke positively about specialist

speech disorder teams in the community services, who were sometimes able to offer

more frequent intervention if required. Variation was also reported as a result of

factors related to the child's family and environment.

'As they become more engaged and more able you might increase the frequency' (FG 2)

[INSERT FIGURE 1 - Service Delivery Models]

Duration

Duration refers to the length of time an intervention session lasts, defined by Kaipa et

al. (2016, p.508) as "the total time period during which the intervention is provided".

Depending on the intervention targets the session length varied, however the

average duration for an individual therapy session was agreed to be between 30-45

minutes (Figure 1). Participants described adapting the duration of sessions

depending on the individual child and commented that they worked flexibly.

'Even with the really compliant children, when you try and go over the half hour, you notice

that the accuracy of their productions just tail off' (FG 3)

'When you are working with them and getting used to the session you might do longer and

longer with them' (FG 5)

Location

The location in which intervention was provided is widely variable (Figure 1). It was reported that numerous aspects influence this, such as service protocols and the presenting needs of the child and family.

'There are some really interesting things that you miss if you don't get the opportunity to do a home visit' (FG 1)

'Everything is done in centre, we don't do outreach at all' (FG 7)

Person to Deliver Intervention

Participants listed a variety of people who would deliver intervention to children with CP±L (Figure 1), although they did not define whether each person was perceived to be a direct or indirect contact. The SLTs reported that the person with a duty of care for a child decides who will deliver the intervention, based on service protocols, intervention targets and factors such as the geographical location, support networks and whether the child attends an educational setting.

The importance of involving communication partners, such as parents/carers and school or nursery staff in intervention delivery was discussed, raising questions regarding whose responsibility it was to consistently deliver intervention for a child with CP±L.

'You get the parents and be like oh can you have a go now and that's what I want you to do at home, give them things for homework' (FG 2)

Decision Making and Rationale

Resource Constraints and Barriers

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A shortage of resources, finances, staffing, equipment and overstretched services were issues that were repeatedly raised in all focus groups. These shortfalls were reported to impact negatively on intervention provision.

'We'll be doing more than community therapists because they have just got longer wait times' (FG 3)

Participants gave examples of ways that financial cutbacks have impacted on their choice of intervention approaches and affected decisions about the frequency or person to deliver the intervention.

'I don't have the equipment anymore to be able to tape, video and make it into a DVD' (FG 1)

Best practice regarding intervention provision was reported to be based on clinical judgment, prioritizing the child's needs. Participants described service constraints being a barrier to decision making and to children receiving appropriate and effective interventions with some services providing intervention based on cost rather than clinical judgments, confirming findings from Bercow: Ten Years On (2018).

'It would be capped, you can only see this child once, some areas there is no therapy, that's what happens' (FG 4)

Regional and Geographical Considerations

The phrase 'postcode lottery' is well known in UK healthcare; participants described how children with CP±L may be disadvantaged in terms of the frequency of intervention as a result of where they live.

'Depending on where the children live, there isn't always a cleft specialist there' (FG 1)

These inequalities in intervention provision exist nationally and remain unchanged since the report by the Lead SLT Group and Chair of the Cleft Clinical Reference Group (Anonymous, 2016).

Living further from a regional cleft center was reported to reduce access to intervention in some areas, with SLTs commenting they would be less likely to offer frequent direct intervention if they had to travel a substantial distance to deliver intervention for a child.

'If some children can't come to me, I can't offer weekly therapy because it would be just too much of my time spent travelling' (FG 1)

This issue was not reported by all participants and it seems that some geographical areas of England and Wales and specialist services are better resourced. Moreover, it appears that geographical location is not always a barrier to intervention provision if the child's parent/carer is able and willing to travel to access intervention. It was recognized that the time spent travelling to intervention sessions may impact on the child's school attendance and attainment.

Family Circumstances

Many participants considered the wider needs of the child's family as vital when delivering intervention.

'I do try and accommodate the parents as much as possible with regards to day and time' (FG 3)'

A shared understanding with communication partners of the child's targets and rationales for interventions were deemed crucial to intervention success. Family

dynamics and associated responsibilities, for example childcare for siblings was described as necessary to consider when planning intervention.

Siblings, looking after their children, school drop off, that kind of stuff is often a barrier to coming, chaotic families with lots going on' (FG 1)

Role of Cleft Specialist as Coordinator

Intervention for children with CP±L is provided by regional cleft centers, community speech and language therapy services and independent SLTs. Participants explained that when making decisions regarding intervention for this population it is crucial to liaise and collaborate with other services to ensure that care is cohesive.

'Our priority is to get them having effective therapy and we get whoever we can, wherever they are to deliver that' (FG 3)

SLTs from regional cleft centers voiced that their role involved supporting generalist SLTs, when setting targets and selecting intervention approaches.

'Helping set targets and monitor so you are supporting' (FG 2)

Likewise, community SLTs and Speech and Language Therapy Assistants commented that they receive supervisory support from the cleft specialist SLTs.

Patient Centered Care

Child's Presentation

Intervention delivery options and selection of approaches are informed by the child's progress and their developmental level. Participants highlighted the importance of

conducting a thorough assessment prior to the commencement of intervention, in order to ensure appropriate targets are set.

'Would depend on what they were working on and how they coping with it' (FG 1)

If a child presents with a specific medical or genetic diagnosis, impacting on their cognitive skills and functioning, it was reported to impact upon the intervention they received. Participants discussed that in certain geographical locations, intervention is only offered to those with a recognized Education, Health and Care Plan (Sales and Vincent, 2018), i.e., a legal document provided by UK local government agencies which specifies the provision and intervention required to support the child's development. Participants talked about taking a holistic approach when considering intervention provision, considering the whole child and how factors such as attention and listening skills or the child's cognitive ability may impact upon progress in therapy sessions.

'The priority when you first meet that cleft child, the cleft like characteristics or is it the attention levels, the language levels and which comes first and when are all kind of key' (FG 1)

Despite concerns being raised regarding a lack of resources and feeling constrained by specific care pathways, the importance of an individualized approach for each child was frequently stated as a critical factor. Participants spoke about putting the child at the heart of their decision-making regarding intervention.

'It's all about the individual basically' (FG 2)

Similarly, Baker et al (2018) reported that SLTs purposefully provide a wide variety of service delivery options, adapting interventions to suit each individual's needs.

Participants in this study illustrated how they work holistically and suggested that children with CP±L can present with complexities due to the multidisciplinary nature of their care. Aspects such as the child's hearing status and presence of complex medical needs were reported to be important to consider when planning intervention. Despite decisions surrounding intervention provision being managed by the SLT, participants voiced their aspirations to work collaboratively with the child and family, discovering their opinions and wishes for intervention too.

Timing of Input

An awareness of the child's cleft care treatment pathway affects how intervention is delivered, ensuring that the timing and type of intervention is appropriate. SLTs reported timing of surgeries, multidisciplinary care and the child's psychological adjustment as factors they include in their decision-making.

'What's happening with them in terms of their cleft care as a whole, other interventions, surgeries...how they are coping with the diagnosis and any other health issues' (FG 1)

When assessing whether a child would benefit from speech and language therapy intervention, participants identified that it was important to address the child's readiness. Intrinsic factors such as the child's motivation were considered alongside other priorities, such as education and extracurricular activities.

'Depending on the child's motivation, the parent's commitment, progress in therapy...it's all those areas we take on board' (FG 3)

Supporting Factors

Participants suggested that speech and language therapy intervention provision is more effective when support and carry over work is completed by other agencies and family members. Participants described their role in ensuring support networks were established for the child when receiving intervention and the challenges that present when a support network breaks down.

Flexibility in service delivery models was reported to be beneficial for intervention provision. SLTs from specialist services or regional cleft centers described an ability to work with greater flexibility and more resources (time, staffing, equipment) when compared to community services, however this was not the case for all.

'*That's the luxury of our service is that we can be very bespoke...not one size fits all' (FG 2)*

'*We see them when they are coming in for another appointment to reduce the burden' (FG 4)*

But where available the SLTs noted that this flexibility supports patient centered care and intervention provision based on clinical judgment rather than rigidity due to service constraints. These findings are consistent with those of Furlong et al. (2018), who reported that the location of sessions, family engagement and attendance were all important in ensuring patient centered care.

Age and Expectations

Although some speech and language therapy services have care pathways for children at specified ages, SLTs mentioned how they create packages of intervention taking into account the child's developmental stage and cognitive abilities, not just their chronological age.

'*It's not actually about the age it's about their developmental stage' (FG 1)*

They reported this as necessary to ensure that children access appropriate intervention for their needs. For most children without significant developmental delay however, participants were able to classify intervention approaches broadly into age categories (Table 3).

Discussion

This study aimed to investigate what intervention is currently provided by SLTs for children born with CP±L until the age of five and how it is delivered. Nine focus groups were carried out and subsequent iterative content analysis identified four main codes with corresponding sub-codes.

This study revealed that a wide range of intervention approaches are used by SLTs with this population and that variability exists in service delivery models. The variability described may be explained by the lack of evidence for speech and language interventions, leading to uncertainty for SLTs. Focus group participants were able to share examples of factors which they believed impacted positively on intervention provision, whilst acknowledging issues and constraints faced. It was clear from the content analysis that, while discrete codes and sub-codes could be identified, these were not independent of each other but rather were closely interconnected, as discussed below.

Intervention Approaches and Service Delivery Models

Inconsistencies regarding the use of terminology have been reported in previous studies (Baker et al., 2018; Roulstone, 2012). Inconsistent terminology, in particular the use of one label for more than one type of intervention or multiple labels for a single intervention, can be problematic in research and clinical practice. Without a

full appreciation of the degree of variation in terminology, there is the potential for confusion and a misplaced belief that practice is evidence based.

Participants reported using direct and indirect intervention with children with CP±L. Indirect intervention may often be offered due to resource shortages, limited availability for direct intervention provision and to support consolidation of skills after direct intervention sessions. Indirect intervention was valued equally to direct intervention by most participants in the current study. Sugden et al.'s (2018) study found the most common person to deliver individual intervention, in the speech sound disorder population, is an SLT. However, in present work participants named a range of people who deliver intervention, including the SLT. School staff and caregivers were reported to deliver indirect intervention for children born with CP±L, under the supervision of an SLT. Indirect interventions were sometimes provided in addition to direct intervention from the SLT. Sugden et al.'s study (2018) focused on both direct and indirect intervention provision in Australia, which may explain the variance in findings when compared to the current study.

Participants described a multitude of service delivery options and reported that as clinicians they often work flexibly. This is advantageous when delivering intervention in a climate with stretched resources, striving to meet the needs of the individual, whilst balancing service-level restrictions.

In the present study, the authors followed the advice of Baker et al. (2018) who advocated for the use of explorative methodologies when investigating speech and language therapy interventions. Participants listed intervention approaches delivered at specified ages and it is noted that there is a high level of overlap between the age categories, for example, diagnostic therapy and articulation therapy were in common

use with all children up to five years of age. The notion that intervention is delivered in an eclectic style has been identified in previous literature (Baker et al., 2018; Hegarty et al., 2018) and participants described how they rarely use one approach in isolation, favoring the use of multiple approaches concurrently to achieve a specific goal.

Meinusch & Romonath's (2011) systematic review of early language interventions for children with CP±L concluded that the involvement of caregivers in the therapeutic setting enhanced the child's language abilities. Participants in this study provided examples of liaison with caregivers, providing them with advice and therapeutic activities to support the child's development in the home environment. In addition to positive intervention treatment effects from other studies (Ha, 2015; Dobbelsteyn et al., 2014) this demonstrates successful implementation of research findings into clinical practice.

Previous research has investigated intervention factors such as the frequency, dosage, location, duration and the person to deliver intervention, which are recognized to be important when studying how intervention is delivered (Hegarty et al, 2018; Roulstone et al., 2015; Roulstone et al., 2012). Participants described a multitude of intervention factors, which reflect resource availability and consideration of the individual needs of the child and their family.

Decision Making and Rationale

The current study found that intervention provision was variable between individual SLTs and across services. Roulstone et al. (2015) reported similar findings in 'Child Talk' and both studies highlight that participants use the phrase 'it depends' when discussing intervention. This illustrates how multifactorial intervention management

is and the factors SLTs consider when delivering intervention. The work by Furlong

et al. (2018) supports this by categorizing factors as 'child factors', 'family factors'

and 'contextual factors'. The present study identified a number of additional factors

which need to be considered for children with CP+/-L including timing of surgery,

comorbidities such as hearing loss and syndromic status and location of the

intervention provision.

Patient Centered Care

Factors that were felt to influence decision-making regarding intervention were;

service level constraints, the needs of the child and family and previous clinical

experience, comparable to Furlong et al.'s (2018) findings. The current study

reported geographical challenges as a factor, for participants working in the regional

cleft centers, a finding that was not identified in Furlong et al.'s (2018) study. Cronin

et al. (2020) reported 'physical geography/population density' was an important

consideration for speech-language pathology practice when working with children

with CP±L.

In the current study, participants from regional cleft centers described their role in the

multidisciplinary team and how they incorporate supporting the child and family

through their cleft treatment journey into their intervention provision. This was

viewed as an additional aspect of intervention provision when compared to local

speech and language therapy services and the non-cleft population. This

multidisciplinary role demonstrates how intervention is delivered in a holistic manner

and contributes to wider public health care, endorsed by Public Health England

(Hindle and Charlsworth, 2019).

Limitations

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The present study has some limitations which should be acknowledged. This study

aimed to investigate intervention provision across the UK, however participation from

Scottish and Irish sites was not possible within the time available and findings may

not therefore accurately reflect service provision in these geographical locations.

It is recognized that there was less participation representing community speech and

language therapy services in this study, therefore findings could be biased towards

specialist service intervention provision.

A further limitation of this study is that transcripts were not checked by participants

for misinterpretations following the focus groups. Additionally, the researchers' prior

clinical experience and existing relationships with participants may have influenced

the data, as participants may have experienced acquiescence bias, responding

positively in order to please the researchers (Winkler et al, 1982).

Clinical Implications

The aim of this study was to undertake exploratory work to understand interventions

currently provided in clinical practice and usual patterns of dosage and delivery for

children born with CP±L up to 5 years of age across the UK. The findings from this

work do not yet assist us in providing evidence to support interventions for children

with CP±L. New knowledge which can be used to inform clinical practice has

nevertheless already been generated by this work and has informed the

development of a survey of intervention received by participants in the Cleft

Collective Cohort Study (Wren et al., 2018). The Cleft Collective Cohort Study is a

large prospective clinical cohort study of children born with CP±/L, investigating

causes of cleft, the best treatments and the impact of cleft on those affected and their

families (http://www.bristol.ac.uk/cleft-collective/professionals/access/). Survey responses will be available for clinicians and academics to combine with other data collected by the study, for example speech outcome data, to address clinically meaningful questions regarding the impact of SLT intervention.

We now have a clear picture of the range of interventions being used by SLTs in England and Wales for this population. We know at what ages each is being used and we have an understanding of the factors which affect clinical decision making and choice of intervention. This repertoire of interventions will aid clinicians who are new to the field in their management and will provide a qualitative benchmark for services to compare themselves to.

This study's objective to understand expert opinions from clinicians, a key component of the Evidence-Based Practice triangle (Sackett et al., 1996), complements the existing evidence base. Discussion from participants in this study regarding the challenges they face implementing research findings into practice, aligns with previous findings from Hegarty et al. (2018). It is therefore important for future studies to adhere to implementation science principles (Olswang and Prelock, 2015), thus increasing the likelihood of research findings being incorporated into everyday practice. Inconsistencies related to terminology are important to consider in future research studies, to ensure a deep understanding of the nature and content of intervention approaches used in speech and language therapy practice.

Conclusion

The present study has identified a large number of speech and language therapy interventions which are being delivered to children born with CP±L across the

England and Wales. Exploration of service delivery models and the aspects which

influence SLTs' decision making, with regards to intervention provision have

illustrated both similarities and differences nationally. Many of the intervention

approaches discussed in this study were not in the Bessell et al. (2013) review, either

because they did not fulfil the eligibility criteria suggesting the evidence is low level,

or because they had not been reported in the literature at the time of the review.

Current evidence for the latter remains at low level however, limited mostly to single

case or small group studies.

This study recognizes the uncertainty as to which interventions are effective for this

population and which methods of delivery are the most appropriate. Determining

which interventions and patterns of delivery are most commonly used within this

population will help identify which are the most salient interventions to investigate in

efficacy studies and in turn have the potential for immediate impact on practice.

Declaration of Conflicting Interests

The authors declare that there is no conflict of interest with respect to the research,

authorship, and publication of this article.

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Figure Legend

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FIGURE 1 - Service Delivery Models

Appendix 1: Topic Guide for Focus Groups

- Consent to be obtained for participation
- Introduce the research project

- What are the important domains of interest in speech and language therapy (SLT) intervention for cleft?

- What are the options available for each domain (identified in previous point) in:
  - the central cleft service?
  - the local community SLT services within the region?
  - independent SLT services?

- How does this differ for various age ranges between 0-5 years of age?

- How might this information be represented in questions in a survey?

Probes:
- Encouraging participants to expand on a point they have raised.
- Asking for clarification from participants.
- Defining terms such as 'domains of interest' for the participants.
- Repeating back and summarising the information provided in order to stimulate further discussion.

Appendix 2: Knowledge Elicitation Activities

Activity 1 - Classification of Intervention Approaches:

The aim of this activity was to discover whether intervention approaches could be classified into specific categories.

Discussion from previous focus groups highlighted variation across participants, and sites and their individual opinions regarding this matter.

1. Focus group participants were divided into sub-groups of 2-3 people whilst sat at a table.

2. Participants were provided with 6 cards: 'Early Communication', 'Language', 'Articulation', 'Phonology', 'Social Communication' and 'Other'.

3. Participants were instructed to lay the cards horizontally on the table and use these as the category headings.

4. A further 46 cards with the name of an intervention approach on were provided to each group. The intervention approaches were reported from previous focus groups to be in use with children with CP±L until 5 years of age.

5. Participants were given approximately 15 minutes to place the intervention approach cards under the corresponding categories. If participants were unable to assign a card to a category they were prompted that they could leave it to one side or place it in between 2 or more categories.

6. The discussions between the participants whilst completing the activity were audio recorded and the researchers made notes regarding the participant's decision making and interesting points raised.

7. After the sub-groups had completed the activity the focus group facilitator asked the participants to describe how they found the task, any difficulties they experienced, and if they felt anything was missing.

8. Comparison between the group's classification of approaches stimulated further discussion.

9. Photos were taken of the cards at the end of the activity for further analysis.
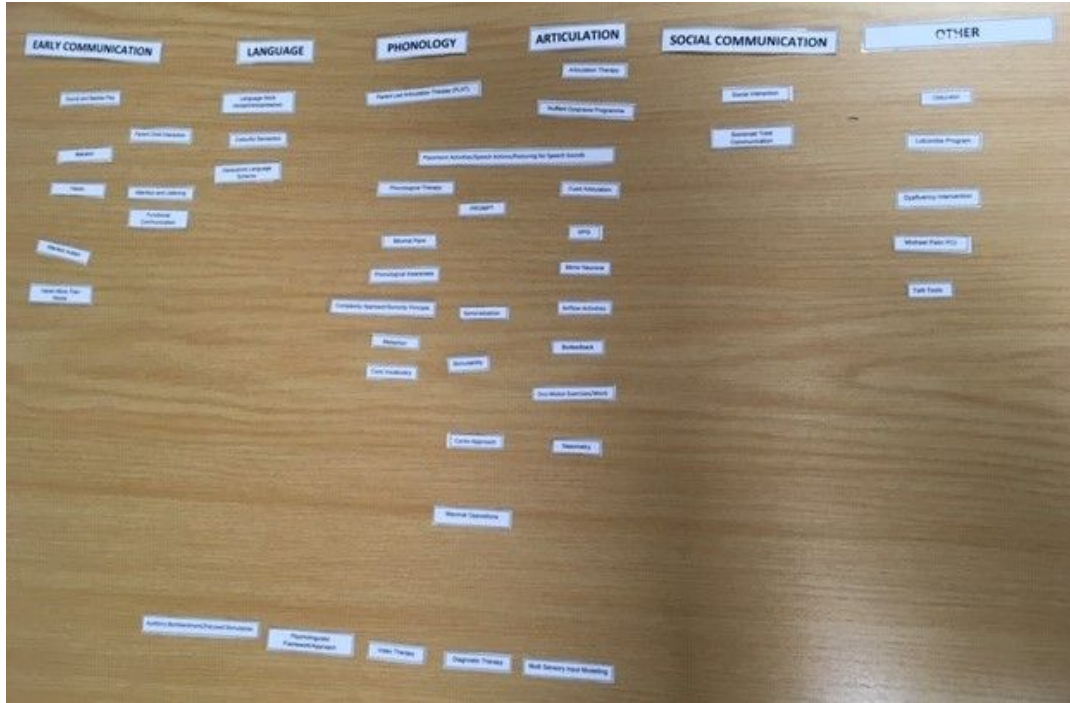
Primary Aim for Episode of Care:
...To...enable...child to...use some oral pressure consonants e.g. p, b, f.
....

Approach/Method	Specific Programmes Used	Training/Advice Given
1 MS IM	1 MS IM	1 Demonstration to parent / local SLT
2 Airflow activities	2	2 Discussion of explanation to parent / local SLT & school staff
3 Moving on to phonological therapy	3	3 Modelling & explanation to child.
other: Oral articulation prompts	other:	other: ....

Resources and Homework

Resources and Homework
1 MSIM online aware & verbally explained
2 Specific sound target advice & resources
3
other: ....

Who was the agent of change?
?? Client SLT
....

Who was the facilitator?
? Mum, local SLT, school staff
....

Age of child ...4½ to 5½ yrs

Activity 2 - Delivery of Intervention

To support the development of an intervention tool (online data collection tool) for use in the Cleft Collective Speech and Language Study the researchers wanted to explore the use of terminology related to the domains of intervention.

1. Individual participants were provided with an A4 sheet of paper with predetermined fields:

    - Primary Aim for Episode of Care
    - Age of Child
    - Agent of Change
    - Facilitator
    - Approach/Method
    - Resources and Homework
    - Specific Programmes used
    - Training/Advice given

2. They were asked to complete the fields whilst thinking about a child they have provided intervention for. They were given approximately 10 minutes.

3. After they had completed the sheet the focus group facilitator stimulated discussion about the ease of the task.

4. When participants highlighted terms that they found challenging to comprehend the focus group facilitator prompted by asking about their interpretation and encouraged other participants to compare their opinions. This was audio recorded for later analysis.

5. The sheets were collected by the focus group facilitator at the end of the activity and were used for analysis.

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<u>Appendix 3: Intervention Approaches Reference List</u>

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Participant's Characteristics

Focus Group	Location	Number of Participants and Roles
1	Cambridge	4 CSLTs, 4 CSLTs/LSLTs
2	Bristol	3 CSLTs, 4 CSLTs/LSLTs, 1 SLTA
3	Swansea	5 CSLTs, 1 LSLT, 1 SLTA
4	Salisbury	3 CSLTs
5	Manchester	5 CSLTs, 1 LSLT, 1 SSLT
6	Newcastle (joint focus group with SLTs from Leeds)	13 CSLTs, 1 SLTA
7	London	3 CSLTs, 1 LSLT
8	Birmingham	2 CSLTs, 4 LSLTs
9	Newcastle	5 CSLTs, 1 LSLT, 1 SLTA

CSLT(Cleft Specialist Speech and Language Therapist), LSLT (Local Speech and Language Therapist),
SLTA (Speech and Language Therapy Assisstant), SSLT (Student Speech and Language Therapist)
CSLT/LSLT (SLT with a split role, involving some specialist cleft skills and another role)

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Codes and Sub-Codes

Code	Sub-Code
Intervention approaches	Therapeutic techniques
	Variability
	Terminology
	The evidence base
Service delivery models	Frequency
	Duration
	Location
	Person to deliver intervention
Decision making and rationale	Resource constraints and barriers
	Regional and geographical considerations
	Family circumstances
	Role of cleft specialist as coordinator
Patient centred care	Child's presentation
	Timing of input
	Supporting factors
	Age and expectations

FG (Focus Group)
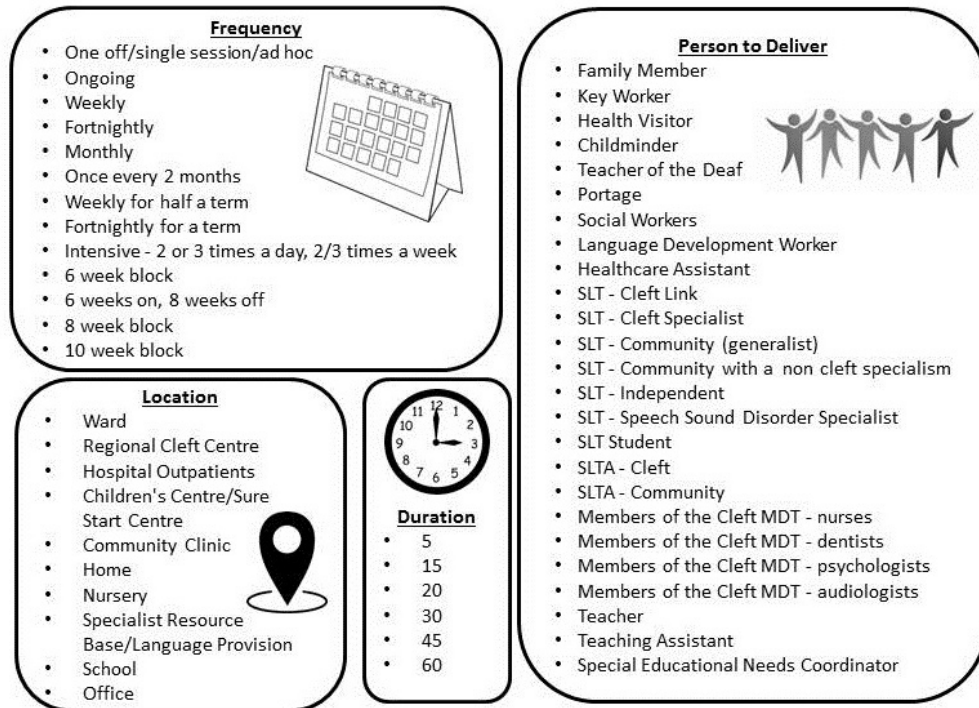
Intervention Approaches

0-18 months		18 months - 3 years		3 -5 years	
Approach	**Training/Advice/Strategies**	**Approach**	**Training/Advice/Strategies**	**Approach**	**Training/Advice/Strategies**
Airflow Activities	Babble Advice	Airflow Activities	Attention Autism Program	Airflow Activities	Attention Autism Program
Articulation Therapy*	Babble Bag	Articulation Therapy*	Babble Bag	Articulation Therapy*	Facilitator Training
Attention and Listening Activities	Babble Workshop	Attention and Listening Activities	Dysphagia Advice	Attention and Listening Activities	Feeding Advice
Auditory Bombardment/Focused Stimulation	Dysphagia Advice	Auditory Bombardment/Focused Stimulation	Early Communication and Play Advice	Auditory Bombardment/Focused Stimulation	Hearing Advice
Complexity Approach/Sonority Principle	Early Communication and Play Advice	Biofeedback	Facilitator Training	Biofeedback	Leaflets
Core Vocabulary	Facilitator Training	Complexity Approach/Sonority Principle	Feeding Advice	Colourful Semantics	Lidcombe Program
Cued Articulation	Feeding Advice	Core Vocabulary	Hearing Strategies	Complexity Approach/Sonority Principle	Michael Palin PCI
Derbyshire Language Scheme	Hearing Advice	Cued Articulation	It Takes Two (Hanen Program)	Core Vocabulary	More Than Words (Hanen Program)
Diagnostic Therapy*	It Takes Two (Hanen Program)	Derbyshire Language Scheme	Leaflets	Cued Articulation	Parent Led Articulation Training Session
Drilling	Leaflets	Diagnostic Therapy*	Lidcombe Program	Cycles Approach	Parent/Adult Child Interaction
Functional Communication	More Than Words (Hanen Program)	Drilling	Michael Palin PCI	Derbyshire Language Scheme	Parent and Children Together (PACT)
Generalisation	Parent/Adult Child Interaction	Dysfluency Intervention	More Than Words (Hanen Program)	Diagnostic Therapy*	Review Phonecall
Language Work (receptive or expressive)	Voice and Vocal Hygiene Advice	Functional Communication	Parent and Children Together (PACT)	Drilling	Voice and Vocal Hygiene Advice
Makaton	YouTube videos	Generalisation	Parent Led Articulation Training Session	Dysfluency Intervention	Worksheets
Maximal Oppositions		Langauge Work (receptive or expressive)	Parent/Adult Child Interaction	Electropalatography	YouTube videos
Metaphon		Makaton	Voice and Vocal Hygiene Advice	Functional Communication	
Mirror Neurone		Maximal Oppositions	YouTube videos	Generalisation	
Multi Sensory Input Modelling (+/- Output)*		Metaphon		Implicational Phonological Universals/Markedness	
Non-directive Play Therapy		Minimal Pairs		Langauge Work (receptive or expressive)	
Nuffield Dyspraxia Programme		Mirror Neurone		Makaton	
Oro Motor Exercises		Multi Sensory Input Modelling (+/- Output)*		Maximal Oppositions	
Phonological Therapy*		Multiple Oppositions		Metaphon	
Placement Activities/Posturing for Speech Sounds		Non-directive Play Therapy		Minimal Pairs	
Psycholinguistic Approach		Nuffield Dyspraxia Programme		Mirror Neurone	
Social Interaction		Oro Motor Exercises		Multi Sensory Input Modelling (+/- Output)*	
Somerset Total Communication		Phonological Awareness		Multiple Oppositions	
Sound and Babble Play*		Phonological Therapy*		Nasometry	
Stimulability		Placement Activities/Posturing for Speech Sounds		Nuffield Dyspraxia Programme	
VERVE Child Interaction		PROMPT		Obturator	
Video Therapy		Psycholinguistic Approach		Oro Motor Exercises	
		Rule Abstraction and Cognitive Flexibility Therapy		Parent Led Articulation Therapy	
		Social Interaction Work		Phonological Awareness	
		Somerset Total Communication		Phonological Therapy*	
		Sound and Babble Play*		Placement Activities/Posturing for Speech Sounds	
		Sound Discrimination Work		PROMPT	
		Stimulability		Psycholinguistic Approach	
		Talk Tools		Rule Abstraction and Cognitive Flexibility Therapy	
		VERVE Child Interaction		Shape Coding	
		Video Therapy		Social Interaction Work	
				Social Stories	
				Sound Discrimination Work	
				Stimulability	
				Talk Tools	
				Ultrasound	
				Video Therapy	

Direct Intervention
Indirect Intervention
See Appendix 3 for reference list
*Approaches reported to be most frequently used

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Frequency
- One off/single session/ad hoc
- Ongoing
- Weekly
- Fortnightly
- Monthly
- Once every 2 months
- Weekly for half a term
- Fortnightly for a term
- Intensive - 2 or 3 times a day, 2/3 times a week
- 6 week block
- 6 weeks on, 8 weeks off
- 8 week block
- 10 week block

Location
- Ward
- Regional Cleft Centre
- Hospital Outpatients
- Children's Centre/Sure Start Centre
- Community Clinic
- Home
- Nursery
- Specialist Resource Base/Language Provision
- School
- Office

Duration
- 5
- 15
- 20
- 30
- 45
- 60

Person to Deliver
- Family Member
- Key Worker
- Health Visitor
- Childminder
- Teacher of the Deaf
- Portage
- Social Workers
- Language Development Worker
- Healthcare Assistant
- SLT - Cleft Link
- SLT - Cleft Specialist
- SLT - Community (generalist)
- SLT - Community with a non cleft specialism
- SLT - Independent
- SLT - Speech Sound Disorder Specialist
- SLT Student
- SLTA - Cleft
- SLTA - Community
- Members of the Cleft MDT - nurses
- Members of the Cleft MDT - dentists
- Members of the Cleft MDT - psychologists
- Members of the Cleft MDT - audiologists
- Teacher
- Teaching Assistant
- Special Educational Needs Coordinator

Service Delivery Models

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