Resource Manual for Commissioning and Planning Services for SLCN

Professor Pam Enderby
Dr Caroline Pickstone
Dr Alex John
Kate Fryer
Anna Cantrell
Diana Papaioannou

© RCSLT 2009
Acknowledgements

The RCSLT and the Project Team would like to thank all those who assisted in drafting this guidance. We have received valuable advice from many reviewers from within the speech and language therapy profession who have given up their time generously. Experts on particular topic areas from related professions have also been consulted and assisted with detail. Service Commissioners and senior managers have commented on drafts showing patience and fortitude!

We would particularly like to thank the many who contributed to the focus groups which helped to shape this document.
The aim of this section is to set out the context for this resource. This work forms part of a range of tools which can support leaders with service planning and delivery, in line with both government and local priorities.

It is essential for service providers to demonstrate quality and productivity and to:
- show value for money
- be able to provide a strong financial argument for the need to invest in services for people with speech, language, communication and swallowing needs
- demonstrate improvements in outcomes for individuals, families and society

Value for money is not about being the cheapest option but about delivering the most return (impact, best outcomes) for a given investment over time.

The key drivers for change to services include:

1. The broad context, which can be divided according to the following factors:
   - Political and Legislative factors
   - Economic factors
   - Social factors
   - Technological factors

2. The near or local context, including:
   - Localised policies
   - Addressing local needs
   - Service provision
   - Workforce
   - The evidence base

THE BROAD CONTEXT (MACRO ENVIRONMENTAL ANALYSIS): FACTORS FROM THE WIDER WORLD

The Macro-environmental analysis commonly takes the form of a PEST analysis:

- Political and legislative factors
- Economic factors
- Social factors
- Technological factors

*Political and legislative drivers*

Devolution has resulted in changes to the powers of the different institutions across the UK.

The government in power at Westminster maintains responsibility for policy and legislation in relation to key areas including: tax, benefits, foreign affairs, international development,
trade and defence for the four countries of the UK. Government in Westminster is also responsible for health, social care and education in England, but these areas are devolved for Northern Ireland, Scotland and Wales.

As a result of devolution, each country of the UK may have different parties in power, with the possibility of increasing powers in the future. The impact of this is the diversification of policy and direction of travel.

Legislative drivers

The main areas of UK-wide legislation that are relevant include the following themes:
- Human Rights
- Disability Discrimination
- Equality

Though there is different local interpretation, these far-reaching legal instruments define the rights and responsibilities of people and those commissioning and providing services for them.

Public protection has also been strengthened through the introduction of registration of professionals, for example, through the Health Professions Council.

There is separate legislation relating to health, education and social services in each of the devolved administrations in England, Northern Ireland, Scotland and Wales.

Economic

The current challenging economic backdrop will have a significant impact on the financing of public services, with local planners and commissioners prioritising services which are value for money, evidence based and releasing cash through innovation.

Social

In order to plan and deliver services, it is essential to identify the demographic factors relevant to speech and language therapy (SLT) and the challenges that these bring.

- The population is aging: people are living longer.
- The birth rate is falling: most families are having fewer children
- The infant mortality rate is also falling, with more children surviving premature birth or health problems or injury in infancy.
- The urban population is growing.
- The proportion of the population in employment is falling.
- The proportion of the population with English as an additional language is increasing, particularly in urban areas.
THE NEAR OR LOCAL CONTEXT

Localised policies

Central to the new reforms is the emphasis on local decision-making within a national framework. Across the four countries of the UK there are requirements to provide services to accord with local need and influence. In England there is a particular focus on increasing the range of potential providers (plurality of provision) with commissioners having a role to stimulate the market.

For each country, arrangements have been established to assess whether commissioners are achieving better health outcomes for the local population. Part of this process will be an assessment of how well commissioners are performing against specified competencies/indicators/targets. For example, in Northern Ireland these targets are based upon high-level outcomes linked to local strategies.

With the devolution of power to local levels, there is a focus on developing more robust accountability. There is an emphasis on joint working to support integrated commissioning, service planning and provision across health, social care and education.

There are different approaches to this development with different structures and commissioning and performance management arrangements being established across the UK. The dominant theme in strengthening accountability is "putting service users at the centre" with respect to:

- Access and self-referral
- User voice at strategic to operational to individual case management
- Population/local engagement
- Information and advice for users, parents/carers
- Patient Rights
- Self-management of conditions

Some localities will be commissioning or planning speech and language therapy services as a single service whilst others will be commissioning integrated services, cutting across traditional boundaries, with health services integrated with education or social services. In many areas, this has already happened for children's services.

It is recognised that, often, no single agency can deliver best outcomes for their service users by working in isolation. Joint commissioning is advocated wherever the meeting the needs of individuals requires contributions from a number of agencies.

Similarly, some service planners or commissioners will be organising services around disease groups, such as services for persons who have survived a stroke. In either case, it will be important for speech and language therapy managers to liaise with other services to ensure that SLT provision is incorporated in their service plans.

Special arrangements are in place for commissioning services for unusual, low incidence or costly interventions. Speech and language therapy managers should identify the specialist commissioning procedures that may be required for individuals requiring
particular interventions such as costly augmentative communication aids, protracted or intensive interventions.

Addressing local needs

In general terms, the UK is experiencing a number of long-term demographic changes (some of which are identified above).

There is significant local variation within these general trends. It is important to understand what these changes and variations imply in relation to the provision of local SLT services. Other local factors to be taken into consideration include: employment, cost of living, housing, transport and, particularly, levels of deprivation.

There are information resources available online from which planners, commissioners and providers can find out more about local and regional demographic factors. Some of these can be found signposted on the RCSLT website www.rcslt.org.

Local public health teams will also be able to sign-post local services to relevant data and information for their area.

There will also be learning from data collected by services. The RCSLT has developed an online tool called Q-SET, the Quality Self-Evaluation Tool to help you collate local SLT service derived information http://www.rcslt.org/resources/qset. Q-SET should be used alongside national and local data to support service planning and evaluation of service delivery.

Through completing Q-SET, provider services can:
- use the resource every 9-12 months to review progress in meeting action plans and to demonstrate service enhancement
- compare their service with other similar service types e.g. urban, rural, acute, community, adult, paediatric, education, 3rd sector
- demonstrate that their service meets the needs of the service users
- identify areas of strength and generate action plans relating to areas of development.
- submit the results as part of the evidence for a clinical audit
- retain ownership of the monitoring and development of services ensuring that strong professional standards are maintained in the context of multi-agency teams

Service providers completing Q-SET will support commissioners to:
- reduce the ‘postcode lottery’ of service availability and quality
- have high quality information that is relevant and accessible
- have an overview of developments, trends and initiatives within the service
- have accurate and timely statistics to support performance management and monitoring
- collect data to contribute to the debates on benchmarking. Where benchmarks do not yet exist Q-SET will enable Commissioners to contribute to this in the future
- collect examples of good practice to inform other pieces of work and the development of services as a whole.
Locally derived information will help SLT services to illustrate:

- the numbers of patients/clients seen
- sources of referral
- amount of resource used in providing a service to the client e.g. number of sessions and skill mix
- nature and severity of the disorder, disability, psychosocial impact at the onset of intervention
- nature and severity of the disorder, disability, psychosocial impact at the completion of intervention.
- level of satisfaction with the service.

**Service provision**

Speech and language therapists have a role in delivering specialist and targeted support to clients, carers and their families. Speech and language therapists can also reduce long-term demands on services by addressing immediate needs that arise from circumstance rather than underlying impairment. Providing training for the wider workforce is integral to the speech and language therapists core role, as outcomes for people with speech, language and communication needs SLCN are improved when the whole workforce is able to contribute appropriately to care pathways.

SLTs also work with the wider workforce contributing to the public health agenda, promoting health and well-being in respect of communication and swallowing. There is little awareness outside the profession of the role of speech and language therapists in preventing the development of speech and language impairments and the further impact and consequences of different speech, language and communication disorders upon health, education, social integration and employment.

The challenges of meeting the speech, language and communication needs (SLCN) of a given population are best understood through a social (participative) model. Key elements of a total service specification will start with:

- identifying the needs of the service user, parent or carer for support and information
- identifying/assessing and diagnosing specific SLCN and providing appropriate intervention.
- considering needs of service users within the environments they encounter
- training the wider workforce that interfaces with them to maximise opportunities for positive outcomes.

The balanced system (diagram 1) below illustrates the wider context for how SLTs contribute to this range of activities. The needs of service users should be considered in service specifications. The role of SLTs in supporting the active participation of service users in service planning, adapting the environment and enskilling the workforce is as relevant as the SLT role in identification and intervention.
Workforce

Careful planning of services, including joint commissioning, will help to shape the workforce and inform the skill mix required to deliver high quality services, improve outcomes and support value for money. Because the commissioning and planning of services relies on the evidence base for a given type of SLCN or model of practice, it is essential that clinical and managerial expertise from speech and language therapists is available to support innovation and quality of service design.

Speech and Language Therapists, as part of the wider workforce, may be employed by a range of organisations, including the third sector, social care and education or be working as private practitioners.

Equal Access to services is of importance to local decision makers. Local demographic profiling will inform workforce requirements. For example, bilingual staff and support workers are required in most areas to meet the needs of diverse communities. The appropriate skill mix should enable services to be family-centred and be culturally and linguistically appropriate and responsive. It may be necessary to consider increasing home delivered services or providing services in unusual locations.

The RCSLT also acknowledges the important role that Assistants and Support Workers have in the delivery of effective speech and language therapy services. Assistants and Support Workers are integral members of both speech and language therapy and multi-disciplinary teams, engaged in a wide range of clinical settings with diverse client groups, duties and responsibilities. [http://www.rcslt.org/aboutslts/rcslt_statement_v3.pdf](http://www.rcslt.org/aboutslts/rcslt_statement_v3.pdf)
In order to support more effective use of skill mix, SLT services also need to provide education and training of the wider workforce and not be focussed solely on direct patient / client care. For all services, this is critical to secure the appropriate balance of cost-effective universal, targeted and specialist services.

**PRACTICAL CONSIDERATIONS**

Many people involved in strategic planning, commissioning or reviewing services will not be familiar with speech and language therapy, its objectives, the needs of clients requiring speech and language therapy, the principles driving the profession, or the evidence base and the following points may support people.

- Where possible, draw on the evidence base.
- Communicate clearly and succinctly.
- Avoid using acronyms and provide a glossary of terms.
- Do not assume knowledge of local arrangements or the requirement to interface with other agencies.
- Set your service in the context of local priorities.

The RCSLT’s Communicating Quality 3 (CQ3) provides clear guidance on care pathways, clinical standards and issues related to quality assurance. This information should be used in submissions to support commissioning quality services.

The following guiding principles have been adopted and apply to all client groups. Services are to:
- be family centred and culturally and linguistically appropriate and responsive
- be comprehensive, coordinated and team based
- work with and communicate effectively with other services meeting the needs of the client
- be evidence based
- ensure equal access
- involve the family and carers
- include training and education of co-workers
- ensure practitioners continuing professional development and appropriate support.

Evidence of the impact of the service will be important to commissioners and providers. Providers will need to demonstrate the impact of their service, particularly when services are being reviewed. Determining the objectives of the service will support the process of outcome measurement. SLT services will need to provide information on outcomes achieved and levels of client satisfaction. Some of this information can be gathered through use of the RCSLT's Q-SET tool, as detailed above.

Managers of speech and language therapy services will need to equip themselves to engage effectively and positively with those who are commissioning or monitoring services. They will need to:
- identify who is commissioning or responsible for overseeing different services. For example, health commissioners may be working with commissioners for education/head teachers. It is important to identify who is taking the lead for each aspect of the service delivery in the locality.
- establish good working relationships and effective communication with those commissioners and planners for their area of responsibility.
- be aware of local priorities and commissioning plans and strategies.
- have a good understanding of the commissioning/planning/monitoring framework for the locality
- be equipped with local data, knowledge and evidence to the tendering process
- be clear of the unique contribution of the service to improving health, employment, education and social outcomes
- be able to clarify and demonstrate local working partnerships and collaborations
- provide data describing the service provided, (numbers and types of patients, numbers of attendances, health and social outcomes etc).

The RCSLT has developed a range of resources to support its members with Continuing Professional Development. CPD is a regulatory requirement for all SLTs and this requires all HPC Registrants to demonstrate how the CPD they have undertaken has sought to enhance service delivery and to be of benefit to service users. The RCSLT has endorsed this requirement through its own CPD standards. [http://www.rcslt.org/cpd/resources](http://www.rcslt.org/cpd/resources)
THE EVIDENCE BASE

The commissioning and planning of services must be informed by the evidence base of effective practices.

This Resource Manual SLCN is based on a synthesis of existing published research. The threshold for inclusion in the syntheses has favoured the most scientifically robust research methodologies which have often reflected medical (impairment) rather than social (participative) models of care.

In the section summaries, emerging practices that have not been included in the evidence synthesis, are referred to and should be considered alongside the syntheses. This tension between empirical evidence resulting from robust research, which by definition is retrospective, and the needs to encourage innovation and service re-design to support improvements in outcomes for people with speech, language, communication and swallowing difficulties is natural and unavoidable. Emerging practice will not have the same evidence base and therefore less empirically stringent measures of evidence need to be taken into account for these areas including professional consensus and measures of service user, parent or carer experience. However, because of the value of some emerging innovative practice, they have been included in this resource.

An overview of the methodologies employed in identifying practices that are included in this resource accompanies this document.

Using these resources

Speech and language therapy managers can assist commissioners by understanding their agenda and the objectives that they are to be assessed on.

The Royal College of Speech and Language Therapists is providing these resources to assist speech and language therapists in gathering the core data required to support service tendering agreements, service planning, monitoring arrangements and/or where services require specification.

Each part of these resources is focused on a specific area.

The resources provide:

- *The Contextual Synthesis*. This includes definitions, information on the incidence and prevalence of the disorder, key contribution of speech and language therapists, consideration of the implications and broader consequences of the disorder.
- *The Synthesis of Key Literature*. This summarises the evidence of the impact of speech and language therapy.

Each section within these resources gives succinct information to inform the factual content for any service planning activity. These include:

- Key points
- Topic –What is [the condition]?  
- How many people have [the condition]?
What causes [the condition]?
- How does this condition affect individuals?
- What are the aims/objectives of speech and Language therapy interventions for [this condition]?
- What is the management for people with [this condition]?
- What is the evidence for Speech and language therapy interventions in [this condition]?
- Studies
- Assessment methods
- Speech and language therapy interventions
- Summary
- References

This information will need to be put into context, using local information.

Other guidance and resource materials

It is recognised that service managers may wish to amplify or clarify, an aspect of their service by providing reference to other national or local research of relevance.

The RCSLT has a range of resources which can be used to further support and inform the commissioning, planning and provision of services for people with speech, language, communication and swallowing needs. These can be found on the RCSLT website: www.rcslt.org

The RCSLT is grateful to the experts from within the SLT community who contributed to the evidence published in this document.
METHODOLOGY FOR SYNTHESIS OF LITERATURE

Introduction

The focus of the interventional synthesis within these briefings is to provide a synopsis on the effectiveness of speech and language therapy interventions for each specific condition.

The interventional syntheses are produced by reviewers within the Information Resources Section (within the Health Economic and Decision Science Section) at the School of Health and Related Research (ScHARR). Information specialists/reviewers for this bulletin were Diana Papaioannou and Anna Cantrell.

Methodology

The interventional syntheses are not intended to be a full systematic review within each topic area. However, they draw upon systematic review techniques to ensure that the syntheses are developed according to systematic, explicit and transparent methods. The intention of the syntheses is to consolidate twenty articles which represent some of the best research for each topic area.

Literature searching

Systematic literature searches were undertaken to identify a range of evidence for each interventional synthesis. The interventional syntheses do not attempt to consolidate all research within a particular topic area; rather they aim to present a careful selection of the most current research within that field. Therefore, the approach adopted for the literature search aims to be comprehensive reflecting this systematic and explicit approach.

Firstly, search terms were selected within the project team drawing on the expertise of four speech language professionals. This involved listing all possible synonyms describing the condition or population (for e.g. children/infant, stuttering/stammering) and combining those with terms to describe speech and language therapy. Terms were used in both free text and thesaurus searching. The following databases were used:

- ASSIA
- CINAHL
- The Cochrane Library (which includes the Cochrane Database of Systematic Reviews, Cochrane Central Register of Controlled trials, Database of Abstracts of Reviews of Effects, Health Technology Assessment Database and NHS Economic Evaluations Database).
- Linguistics and Language Behaviour Abstracts
- MEDLINE
- PsycInfo

All references retrieved from the literature searches were entered onto a Reference Manager Version 11 database using appropriate keywords.
Selecting and obtaining relevant articles

Articles for inclusion were selected to illustrate the range of good quality evidence within each topic area. An initial screening of articles was undertaken by the Information specialists/reviewers who adopted the following principles:

- Articles must be empirical research evaluating the effectiveness of a particular speech and language therapy intervention
- Only articles published in English language are included.
- In general, only the most current (1998-present) literature is included. However, exceptions were made to this if a particular article was felt to be important to include.
- Where possible higher level evidence was included (systematic reviews, randomised controlled trials). However, this research did not always exist in every topic area.
- Efforts were also made to seek out literature that provided a range of perspectives on interventions for each topic area, i.e. both quantitative and qualitative research.

Following initial screening, the remaining articles were examined by two members of the team; each having considerable speech and language therapy knowledge and experience. Approximately, twenty articles were selected by the two reviewers with disagreements being resolved by a third reviewer.

Assessing the quality of relevant articles

Formal quality assessment of the articles was not undertaken. Instead, quality assessment involved using checklists as a guide to give an indication of the overall quality of studies and highlight the main good and bad aspects of each study. For each interventional synthesis, the included study designs are listed and the problems with each study design noted. General observations on study quality are made and common errors within the studies, where appropriate, are specifically noted. The checklists used are one for quantitative and one for qualitative studies from the Alberta Heritage Foundation for Medical Research.1 Additionally, when an identifiable study design was used, the appropriate Critical Appraisal Skills Programme (CASP) checklist was selected.2

Syntheses of the twenty articles

Each article was read in turn by one of the Information Specialists/reviewers. The key points were summarised including the objective of the study, the participants’ characteristics, the methodology, the intervention, results and limitations. From this, articles were grouped into themes according to the factor being investigated (for e.g., length of intervention, personnel carrying out intervention, family involvement in treatment, nature of disorder). Results were summarised and drawn together within each particular theme and a summary paragraph provided at the end.

These syntheses first went out for review by selected individuals, identified by the research team, with particular expertise in the delivery or management of services to the

---


© RCSLT 2009
specific client group. Comments were included in the second draft, which was then dispatched to those selected by the Royal College Speech and Language Therapists who were invited to attend a focus group day. These therapists gave detailed consideration to their specialist area and contributed to the more general discussion of one further area. Issues to be captured in the key points were also identified within the focus groups. These comments contributed to the third draft of the syntheses, which again went out to reviewers. In some cases, further work was required in order to modify the wording and reflect discussion.

**Checklist for service managers involved in commissioning services**

- Have you presented incidence and prevalence figures and local demographic trends for the conditions in your area?
- Have you provided information on local access and use of services in the context of the number expected and highlighted your approaches to inequalities?
- Have you consulted systematically with users to inform development of this commissioning proposal?
- Does your proposal fit/link with local cross agency priorities?
- Have you outlined the range of services provided including training?
- Have you made clear how this fits with future planning for your service over the next 3-5 years?
- Have you stated the assumptions which underpin your thinking in the plan and for future developments?
- Have you offered predictions about the likely impact of investment in the proposal?
- Have you made clear where the risks are and what contingency plans you have put in place?

**Professor Pam Enderby**
**Dr Caroline Pickstone**
**Dr Alex John**
**Kate Fryer**
**Anna Cantrell**
**Diana Papaioannou**
RCSLT RESOURCE
MANUAL FOR
COMMISSIONING AND
PLANNING SERVICES FOR
SLCN

Cleft Lip/Palate and
Velopharyngeal Impairment
1. Key points-Cleft Palate and Velopharyngeal Impairment

1. Speech and language therapists play a unique role in the identification and assessment of children with cleft palate and VPI. The ability to diagnose the specific speech disorder as well as retained communication abilities are unique skills of speech and language therapists.

2. Children with cleft palate, and/or VPI are at risk of articulatory problems, nasal emission, hypernasal resonance and hearing problems which impact on intelligibility.

3. Improved communication has an impact on literacy, social skills, peer relationships, self-confidence and behaviour.

4. Difficulties with communication are a predominant feature in reducing access to education, employment and social integration.

5. Specialist investigation of speech disorders associated with cleft palate and VPI require specialist equipment and skills available within regional cleft centres. Speech and language therapists contribute to the decisions relating to appropriate management, surgery and prostheses or specific speech therapy treatment with the objective of normal speech.

6. Specialist speech and language therapists can support and guide other speech and language therapists, who can deliver therapy locally.

7. Programmes stimulating articulation, resonance, vocabulary and language development should be tailored for the child and shared with parents, nursery nurses, teachers and others.

8. Children with speech and language impairments need regular review and their management should be integrated into their educational programme.

9. Advisory and educational programmes for parents, teachers and carers should be part of speech and language therapy services.

10. Intensive therapy is associated with better outcomes for children with predominantly expressive speech and language disorders.

11. The provision of speech and language therapy, supported by speech and language therapy assistants/teaching assistants has been found to be cost-effective.

12. Parent based therapy and group therapy involving parents have been demonstrated to be more effective (but more costly) than conventional therapy.

13. There is evidence that early and more intensive speech and language therapy interventions are more effective.

14. Where problems are identified in speech and language development, a highly focussed and organised approach, incorporating collaborations across services and disciplines, is required.
in order to achieve good speech outcomes. Some children require attention to their speech and related communication difficulties through adolescence and even in adulthood.

2. What is Cleft Lip & Palate?

Cleft Lip and/or Palate is the most common congenital abnormality of the craniofacial complex. The term cleft refers to a split or a separation. In pregnancy, the areas of the face develop separately and then fuse together. The lip usually closes around five to six weeks after conception and the palate at around ten weeks. If during early pregnancy this process is disturbed, the result is a lack of fusion resulting in cleft. The type and severity of the resulting cleft can vary, involving only the lip or palate or both lip and palate together (Watson, 2001).

Intelligible speech requires sufficient airflow to allow production of nasal and oral speech sounds. A number of structures and musculature are involved in achieving velopharyngeal closure. There is rapid opening and closure of the velopharyngeal isthmus, involving the velum (soft palate at the back of the mouth), the lateral pharyngeal walls (side walls of the throat) and the posterior pharyngeal wall (the back wall of the throat). Velopharyngeal insufficiency (VPI) is the inadequate closure of the velopharyngeal isthmus resulting from a structural problem (Mercer & Pigott 2001, Conley et al 1997). The two main speech symptoms of velopharyngeal insufficiency are hypernasality (excess nasal resonance heard as a nasal tone on vowels) and nasal air emission (air escaping down the nose on consonants).

Table 1: Type of Cleft or VPI condition

<table>
<thead>
<tr>
<th>Condition</th>
<th>Description of Cleft</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cleft Lip</td>
<td>Cleft lip can range from a simple notch in the upper lip to a complete gap in the lip running into the floor of the nostril, leading to nasal distortion. The upper gum is usually involved. There are varying degrees of involvement from a slight to full cleft occurring on just one side (unilateral cleft lip) to both sides of the lip (bilateral cleft lip).</td>
</tr>
<tr>
<td>Cleft Palate</td>
<td>Cleft palate may involve only the soft palate at the back of the mouth or may run forwards through the bone of the hard palate resulting in a complete cleft of the hard and soft palate (Watson, Sell &amp; Grunwell 2001, NHS Direct Web Pages 2008). Submucous Cleft Palate (SMCP) refers to a cleft covered by the mucous membrane lining the roof of the mouth; usually there is a bifid uvula, notch in the bone of the hard palate, and a groove in the centre of soft palate. Occult submucous clefts have an abnormal nasal side to the palate and muscle tissue may be missing affecting function.</td>
</tr>
<tr>
<td>Velopharyngeal insufficiency</td>
<td>VPI may be associated with a submucous cleft palate, a short velum and cleft palate conditions affecting the back of the mouth and syndromes which affect the structure of the mouth and pharynx (Mercer &amp; Pigott 2001, Conley et al 1997).</td>
</tr>
</tbody>
</table>
3. How many people have Cleft Lip & Palate?

Table 2: Incidence and Prevalence

<table>
<thead>
<tr>
<th>Incidence</th>
<th>Prevalence</th>
<th>Gender</th>
</tr>
</thead>
<tbody>
<tr>
<td>Northern Ireland 1981 to 2000 was 1.47 per 1000 live births (Gregg et al 2008)</td>
<td>1:682 (Gregg et al 2008) 15-20% unilateral complete cleft of lip and palate (CSAG, 1998)</td>
<td>More males than females are affected by cleft lip with or without cleft palate (Gregg et al, 2008)</td>
</tr>
<tr>
<td>1 per 700 births Around 70% of babies with cleft lips also have cleft palates (CSAG).</td>
<td>250,000 with clefting – facial and palatal. (Watson et al, 2001)</td>
<td>Males are twice as likely as females to have a cleft lip while females are twice as likely to have a cleft palate. (Watson et al, 2001)</td>
</tr>
<tr>
<td>Orofacial Cleft 1.46 per 1000 live births 0.69 per 1000 Cleft Palate 0.77 per 1000 Cleft Lip/Palate Clefts of the secondary palate present in 45% of the sample (CleftSIS 2003)</td>
<td>Native Americans: 3.74/1000 Japanese: 0.82/1000 -3.36/1000 Chinese: 1.45/1000 - 4.04/1000 Caucasians: 1.43/1000 -1.86/1000 Latin Americans: 1.04/1000 Africans: 0.18/1000 -1.67/1000 (Tinanoff, 2007) Native American, (3.7/1000), followed by Japanese (2.7/1000), Maoris and Chinese (2/1000), Caucasians (1.7/1000) and black descent (0.4/1000) (Vandera,1987).</td>
<td></td>
</tr>
<tr>
<td>Cleft Lip &amp; palate 1 in 750 cleft palate 1 in 2,500 Caucasian births (Tinanoff 2007)</td>
<td>30-50% of cleft palate conditions have VPI following palate repair.</td>
<td></td>
</tr>
<tr>
<td>Submucous cleft palate 0.02 percent (Gosain et al 1996)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>VPI 5% to 30% (Sullivan et al 2009)</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Sullivan et al (2009) studied the outcomes of repair and function over 29 year period. The results indicated that the risk of fistula or VPI was related to the age at surgical palatoplasty, the type of cleft and the level of experience in the surgeon. Surgery for VPI achieved a competent velopharyngeal sphincter in 85.1% of individuals, but it would appear they only operated on patients with moderate or severe hypernasality which explains this relatively low percentage. In those operations timed before 11 months of age, there was a lower incidence of VPI (> 12.5%) requiring a secondary operation. Sullivan et al reported that between 7 months and 46.4 months, for each
additional month in age at surgery there was 6% increase in the chance of VPI requiring a secondary operation. Timing of surgery was important in achieving a good functional outcome.

**4. What causes Cleft Lip & Palate?**

The causes of the congenital abnormality are not entirely understood. Cleft/Lip palate can occur in isolation (60-70% non-syndromic) or present as a complex disorder in associated syndromes (30-40% syndromic) (London Dysmorphology Database). It is associated with over 400 known syndromes. VPI may result from structural or functional deficits, such as, sub-mucus cleft or neurological disorders and compensatory learning or a mixture of structural, functional and learning strategies (Trost-Cardamone, 1989). Aetiology is multi-factorial and a number of factors may be related with a co-existence of factors for example, environmental and genetic factors (Lees 2001, Communicating Quality 3).

<table>
<thead>
<tr>
<th>Table 3: Causes of Cleft Lip/Palate &amp; VPI</th>
</tr>
</thead>
<tbody>
<tr>
<td>Genetics</td>
</tr>
<tr>
<td>Race</td>
</tr>
<tr>
<td>Environmental factors</td>
</tr>
<tr>
<td>Infections</td>
</tr>
<tr>
<td>Vitamin deficiency</td>
</tr>
</tbody>
</table>

**5. How does Cleft Lip & Palate affect Individuals?**

A range of difficulties affects individuals with the cleft condition and velopharyngeal dysfunction. The advent of antenatal diagnosis of the cleft lip condition has aided management and advice is routinely given to help reduce parental anxiety and prepare for birth, particularly with reference to feeding and the need for surgery.

Table 4: Impact of the Cleft condition VPI may result in the following
Impaired speech development and consequential developmental language delay is associated with the cleft condition and velopharyngeal dysfunction

Conductive hearing loss resulting from middle ear problems contributes to additional speech difficulties and language delay

Voice problems may occur in association with either hearing problems or velopharyngeal dysfunction

Impaired facial growth can precipitate articulatory difficulties

Dental irregularities such as gaps, asymmetry and malalignment impose articulatory constraints

Psychosocial difficulties associated with the adverse reactions by others.

Can cause selective mutism or reduced communicative confidence

Difficulties in infant feeding and somatic growth is associated with the cleft condition and in velopharyngeal dysfunction

Children born with cleft lip and/or palate vary enormously in their speech development. The severity of the cleft presentation does not always correlate with the level of difficulty a child will have in developing speech. Multifactorial influences impact on speech development and this will include the structure and function of the speech mechanism, influenced by the cleft condition, the presence of VPI and associated hearing problems. The early and skilful repair of a cleft palate (under 1 year) is recognised as fundamental to a good speech outcome and, indeed, other outcomes too.

The majority of the children with cleft palate do develop normal speech (Peterson-Falzone 1996) although some will need specialist speech and language therapy and a small proportion will also need further surgery. Speech problems related to the cleft condition can often be predicted as babble develops and hence it is possible to offer indirect therapy as speech develops (Russell and Albery 1999; Russell and Harding 2001).

Table 5: International Classification of Function and Disability and impact

<table>
<thead>
<tr>
<th>ICF dimension</th>
<th>Impact</th>
</tr>
</thead>
</table>
| Impairment    | - Inaccurate production of consonants known as – cleft type characteristics (Harding & Grunwell 1996) distinctive tone of voice: nasal voice quality, abnormal nasal airflow affecting consonant production, - nasal emission/ turbulence and/or visibly distracting facial/nasal grimace.  
- Limitation in the structure and function of the musculature of the mouth, palate and pharynx.  
- Delay in sound development.  
- Reduced hearing  
- Voice disorder (hoarseness or breathiness) associated with hearing or velopharyngeal dysfunction  
- Need for multiple operations to palate, ears, lip and/or nose |
| Activity      | - Frequently results in restricted speech intelligibility or distinctiveness of speech.  
- Reduced confidence in ability to communicate with others  
- Reduced ability to eat and drink/ swallow safely or gain adequate nutrition in infancy. |
| Participation | - Interaction with others affected by reduced ability to communicate. |
ICF dimension | Impact
--- | ---
- Self-esteem affected by negative reaction of others to appearance differences and speech abnormalities.
- Frequent hospital and clinic appointments during pre-school and school years for speech and hearing
- Need for parents to engage and support therapy programme with their child at any age
- Need for carers in child care and education to understand and meet the needs particular to the cleft condition e.g. hearing loss, speech difficulties, reduced confidence

---

6. What are the aims/objectives of SLT interventions for Cleft Lip/Palate & VPI?

Specialist speech and language therapists (SSLT) work as part of a team to provide a coordinated multidisciplinary care package. Specialist speech and language therapists aim to provide specialist assessments and treat/advise and support as indicated from childhood to adulthood with work encompassing prevention, specialist assessment and differential diagnosis, intervention, research and audit. Specialist Cleft Centres have been established with the expertise to act as regional advisory services which link with local speech and language therapy services regarding therapy and team management. The role of the specialist centre is to provide assessment, investigation, advice and intervention.

Table 6: Specialist Cleft Speech and Language Therapists aims of intervention

- To provide specialist assessment and differential diagnosis of babble, speech and cleft-related communication difficulties in children from birth.
- To provide assessment, investigation, advice and specialist cleft speech and language therapy intervention as appropriate on cleft palate and VPI.
- To liaise and actively contribute to the multidisciplinary team on care and management which may include specialist nurse, audiologist, surgeon, psychologist, orthodontist, maxillofacial surgeon.
- To identify and address any psychological impact which might affect well-being.
- To identify and manage early communication difficulties to prevent the development of abnormal speech patterns.
- To monitor babble and pre-speech development and the early stages of speech and language development to promote normal communication by school entry
- To counsel and advise parents and carers, local SLTs, health visitors and education agencies about speech and language development at each stage in development and as required.
- To evaluate speech and communication following primary palate repair, and secondary surgery such as fistula closure, osteotomy, contributing to team decisions and management, speech therapy and speech prostheses.
- To identify patients with velopharyngeal insufficiency in consultation with multidisciplinary team.
- To perform additional specialist assessments in particular the evaluation of the impact of structural abnormalities on speech e.g. velopharyngeal dysfunction, fistulae.
- To use evidence gained from speech/language characteristics to inform syndrome diagnosis and manage accordingly within the team.
- To advise on timing of intervention (CSAG1995) and provide advice to surgeons, on individual management and the surgical protocol.
To inform statements of special educational needs when appropriate.

To work in collaboration with the multidisciplinary team especially the Paediatrician and Clinical Nurse Specialist. To work with the nurse specialist and SLT dysphagia specialist as appropriate to advise on feeding difficulties and management of feeding swallowing difficulties as a result of dysphagia.

Table 7: Specialist Cleft Speech and Language Therapists Specialist Assessments

<table>
<thead>
<tr>
<th>Nasometry</th>
<th>An acoustic measure of oral/nasal airflow during speech</th>
</tr>
</thead>
<tbody>
<tr>
<td>Nasendoscopy</td>
<td>To assess the structure and function of the velopharyngeal mechanism during speech.</td>
</tr>
<tr>
<td>Videofluoroscopy</td>
<td>To assess radiologically, the structure and function of the velopharyngeal mechanism during speech to contribute to videofluoroscopic assessment of the structure and function of the velopharyngeal mechanism during speech</td>
</tr>
<tr>
<td>Audio-video recording</td>
<td>To ensure there are regular documented speech recordings in order to be able to monitor the outcomes of surgery and therapy and to undertake research studies. Use the digital recordings to assess speech and audit speech outcomes.</td>
</tr>
</tbody>
</table>

Table 8: International Classification of Function and Disability and Specialist Cleft Speech and Language Therapists intervention

<table>
<thead>
<tr>
<th>Impairment</th>
</tr>
</thead>
<tbody>
<tr>
<td>Advise on how best to encourage the movements and sounds needed for speech and discuss which sounds to discourage.</td>
</tr>
<tr>
<td>Advice and guidance on feeding and swallowing impairment</td>
</tr>
<tr>
<td>Advise and provide therapy to encourage the development of voice, resonance, airflow, sound production and the elimination of grimace.</td>
</tr>
<tr>
<td>Provide assessment/investigations to inform regarding the structure and function relating to speech and voice production.</td>
</tr>
<tr>
<td>Advise on maximising listening skills and stimulating language development</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Activity</th>
</tr>
</thead>
<tbody>
<tr>
<td>Provide advice and therapy to encourage the development of intelligible speech.</td>
</tr>
<tr>
<td>Advise on effective communication.</td>
</tr>
<tr>
<td>Advise on augmentive and assistive communication</td>
</tr>
<tr>
<td>Liaise with Dysphagia Speech &amp; Language Therapist and Specialist nurse where feeding/swallowing issues arise.</td>
</tr>
<tr>
<td>Advise on additional communication needs e.g. bilingual.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Participation</th>
</tr>
</thead>
<tbody>
<tr>
<td>Advise on strategies for coping with social situations</td>
</tr>
<tr>
<td>Support individuals and families</td>
</tr>
<tr>
<td>Build self-esteem</td>
</tr>
</tbody>
</table>

7. What is the management for Cleft Lip & Palate in the UK?

The SLT contributes to the management of cleft palate through their work with parents/carers, a team of cleft specialists and liaising as appropriate, with health and educational professionals. A cleft lip is usually repaired at around the age of three months. A cleft palate is usually repaired between 6 and 12 months. The team provides input throughout growth into adulthood focussing on care through in-depth speech and language therapy consultations and collaboration with community clinicians. These appointments are most frequent in the pre-school years during speech development, although therapy needs can persist throughout school years. Audit of speech outcome is made at 5, 10, 15 and 20 years of age (CSAG, 1998) to monitor speech in relation to growth. Teenagers who require surgery to advance the upper jaw are assessed for risk to velopharyngeal function pre-and post-operatively. An example of a timetable for specialist SLT consultations is outlined in table 9.

Table 9: Specialist Speech & Language Therapy input to the multidisciplinary care pathway

<table>
<thead>
<tr>
<th>Suggested age guides for intervention/ assessment/ investigations*</th>
<th>Activity</th>
</tr>
</thead>
<tbody>
<tr>
<td>Birth to palate surgery</td>
<td>Information about palate function for speech, and focussed advice to family and carers as required. Feeding: liaison with specialist nurses and involvement of dysphagia specialist speech and language therapist as required.</td>
</tr>
<tr>
<td>8-12 months Post palate repair</td>
<td>Preventative advice/early intervention. Monitoring and advice to parents and carers about babbling and early speech development.</td>
</tr>
<tr>
<td>18 months-2years</td>
<td>Unidisciplinary assessment and intervention if indicated for all children who have had a palate repair. Children with cleft lip are not routinely assessed by SLTs unless there are concerns. Liaison with audiologist regarding hearing issues</td>
</tr>
<tr>
<td>2 years</td>
<td>Multidisciplinary team review takes place with emphasis on hearing and speech development. Intervention provided either by specialist or community clinician to minimise the phonological consequences of the cleft palate. Video therapy may be offered</td>
</tr>
<tr>
<td>3 years</td>
<td>3 year speech assessment followed by specialist-led intervention as necessary. Referral to specialist multi-disciplinary clinic for palate investigation - if speech indicative of VPI/D Liaison with audiologist over suspected hearing loss</td>
</tr>
<tr>
<td>5, 10, 15, 20+ years</td>
<td>Multidisciplinary audit appointments; speech recordings for speech and language therapy audit/review of speech outcomes of all children who have had the lip and/or palate repair operation. Specialist-led intervention arranged and supported at any stage. Electropalatography may be offered for entrenched articulation difficulties.</td>
</tr>
<tr>
<td>16 -20 years</td>
<td>Pre and post osteotomy assessments advise about the risks and manage the effects of osteotomy on resonance and VP function.</td>
</tr>
</tbody>
</table>

(Communicating Quality 3 2006)
Management of suspected VPI starts with assessment of speech for abnormal features such as, resonance, nasal emission, nasal turbulence, nasal or facial grimace, dysphonia and patterns of consonant production. The assessment includes; perceptual speech assessment and instrumental investigation of structure and velopharyngeal function with videofluoroscopy, and may involve nasendoscopy, and/or nasometry. The results are considered by the plastic surgeon and the specialist speech and language therapist, a management plan agreed with the family which may include surgery, or prosthetics, with or without speech therapy. In some specialist centres, a specialist speech and language therapist will undertake the nasendoscopy procedure and will carry out videofluoroscopy with a consultant radiologist. Post-treatment assessment and follow-up usually occurs at 3 months and a year (Sell & Ma, 1996). Copies of the assessments and recordings are kept as a record of outcome and for audit.

Speech and Language Therapists in ‘Hub and Spoke’ networks work together in delivering the care package. Therapists in local community services, may undertake specialist training provided by those in the specialist service. Specialist SLTs in cleft and VPI provide specialist training, workshops and patient specific support. Each cleft centre develops a working relationship with the relevant community Primary Care Trusts (PCT) but different service delivery models in each PCT but necessitate flexibility and adaptability to ensure equal access to specialist SLT for all children with cleft palate and VPI.

Each specialist speech and language therapy service contributes to multiple multidisciplinary and multiple unidisciplinary SLT teams across their network. Optimal patient care requires a good level of communication for intra-disciplinary liaison. It is highly challenging and time consuming for all those involved to communicate effectively in all directions. Also, this model does not fit many PCT protocols and can present barriers to providing effective shared care.

Augmented and Assistive Communication

Augmented and Alternative Communication (AAC) refers to any system of communication that is used to supplement or replace speech, to help people with oral communication impairments to communicate. For people with cleft palate or VPI who need AAC, this could range from ‘low tech’ aids such as signing, drawing, writing, or communication books, to ‘high tech’ aids such as computerised voice output communication aids. AAC may help those with a learning difficulty or syndromic condition in association with cleft or VPI to communicate. The objectives of introducing AAC to an adult with an acquired communication problem is to maximise their communicative function in the areas of life that are seen as a priority by the patient, and continually review the changing needs of the patient. It is necessary to:
- identify participation and communication needs
- assess capabilities in order to determine appropriate options
- assess external constraints
- find strategies for evaluating the success of interventions.

(Beukelman & Mirenda, 1998)

To ensure appropriate access to the range of resources available, individuals who may benefit from communication aids need to have access to an AAC specialist or team, who are skilled in assessment, planning, intervention and review in this area.
Cultural diversity

Many individuals and families who have English as a second language, or are from a culture which has particular beliefs and customs, will require specialist and sensitive consideration by the speech and language therapist. These individuals may have more difficulty in accessing services and participating in life, if these special needs and preferences are not understood and taken into account. An interpreter may be required to assist the SLT assessment, to ensure it is both accurate and reliable and to facilitate understanding of therapy and implementation of treatment strategies. The articulation and sound structure in the individual’s first language may require different approaches in therapy. There is a time and cost implication when working with interpreters/co-workers, for example, in taking a case history, completing a full assessment in all languages spoken by the individual (if appropriate) and their family. Timings of services need to be culturally sensitive, for example, not offering appointment times which coincide with religious observations (Communicating Quality 3, 2006).

8. What is the evidence for SLT interventions for Cleft Lip & Palate?

Details of studies

All studies were published in English, with the earliest being published in 1995. Six studies were conducted in Mexico, four in the USA, one in the UK and one in Belgium.

The number of children who took part in the studies ranged from 10 to 647 children. The studies covered a range of interventions and associated factors including early intervention, involvement of parents in therapy, type of speech therapy approach, intensity of therapy, electropalatography and multi-disciplinary care.

Study quality

Generally, the overall study quality was average. Study populations were on the whole very small and this is a major drawback of the evidence. In terms of study design, the majority of studies were clinical trials. The results from these studies need to be interpreted with caution due to the limitations of clinical trials i.e. lack of randomisation introducing bias. Of the four randomised controlled trials included, only one study described how randomisation was undertaken. The observational studies involved cross-sectional data collection; meaning that cause and effect cannot be determined. Two studies, on electropalatography (EPG), were case studies. One case study involved six participants whilst the other EPG case study was a single-participant case study. This limits the generalisability of these studies, but nevertheless the findings are powerful. It is worth noting that the findings from the non-UK papers need to be interpreted cautiously due to generalisability of findings to the UK population, not least differences in health care delivery.

All of these studies consider speech and language interventions or practices for children and adults born with cleft palate and/or cleft lip.

Parental Involvement in Speech Therapy

Parental involvement in speech therapy was investigated specifically by three studies.
Whilst investigating the benefits of an early intervention programme, Scherer et al (2008) examined whether parents can be trained to deliver a programme. Mothers of 10 children with unilateral CLP received between two and four 45 minute training sessions. They were taught how to model target words and how to respond if their child produced a word correctly or not. After three months, the mothers’ and children’s use of language were assessed in play sessions. The results demonstrated that mothers were able to learn the methods in a relatively short space of time and maintain use of the strategies over three months. Furthermore, these children showed significant gains in speech and language.

Pamplona et al (2000, 2001), in two separate studies, investigated whether including mothers as an active participant in speech therapy sessions would improve the communicative style of the mothers and the language development in their children with cleft palate. Over a period of one year, two groups of children received 3 hours of play sessions per week in addition to 3 hours of speech language therapy per week. In one of these groups, mothers were actively included in the speech language therapy sessions, resulting in significant improvement in both children’s and mothers’ linguistic performance. 89% of mothers who had been present in the speech and language therapy sessions modified their mode and style of interaction compared with only 19% of mothers who were not present at the therapy sessions. In addition, children whose mothers were present at the therapy sessions showed significant improvement in language performance in comparison to children whose mothers were not present.

These three studies have important implications for service delivery. Successful parent-led intervention and parental involvement in treatment could lead to a reduction in the number of therapy sessions required and have implications on cost.

**Early Intervention**

Three studies investigated early provision of speech language therapy for children with cleft palate and/or lip.

Blakeley et al (1995) investigated a multi-disciplinary programme of care for 41 cleft palate children, in which a strong emphasis was made on early diagnosis and timely therapy. The children involved were 12 months at the start and aged 5 years at the end of the study. Regular evaluations of speech and hearing were undertaken every 3-4 months and prompt therapy received as required. This study achieved excellent outcomes in terms of speech with 93% of the children demonstrating normal articulation by age 5 years. However, the absence of a no-treatment comparison group makes it difficult to quantify the added value of this organised multi-disciplinary care. One would expect a proportion of children to attain normal articulation, without any specific interventions; this cannot be determined in this study. It is interesting to note that the children were closely monitored and the appropriate intervention administered promptly. The frequency of review visits (every 3-4 months) has implications in terms of burden of care for the participants and their carers. In the UK teams have designed their care pathways with this in mind. Furthermore, there was an additional intervention in this protocol involving the fitting of orthodontic appliances for speech. This protocol is not practiced in the UK and therefore this study has little applicability to a UK setting.

In contrast, Hardin-Jones (2008) directly investigated speech outcomes by comparing four groups of toddlers. Forty toddlers, 30 with repaired cleft palate and ten without cleft palate (non-cleft group), took part in the study. At 17 months of age, 20 toddlers with repaired cleft palate had been referred for therapy (referred group) whilst the remaining ten were not referred for therapy (not referred group). Of the 20 referred (and so requiring therapy), ten toddlers did not receive therapy (no
therapy group). Speech therapy consisted of approximately one hour per week of one-to-one sessions delivered at the child’s home. At 27 months of age, there were significant differences between the non-cleft and not-referred toddlers and the therapy/no therapy toddlers. The non-cleft and not-referred groups produced a significantly larger number of stable consonants, and correctly produced a larger percentage of total consonants, oral stops, oral fricatives, glides, and labials than the no therapy group. The non-cleft and not-referred group also produced a larger percentage of total consonants and oral stops than the therapy group. In all but one measure, no significant differences were found between the therapy and no therapy groups. Children who received therapy produced a significantly greater percentage of glides than non therapy toddlers. This perhaps indicates early intervention was not successful in this instance.

Scherer et al’s (2008) parent-implemented intervention was delivered at an early age, when the children involved in the study were 14-36 months with the perceived benefit being of addressing communication difficulties before they have had time to become established. Language was significantly improved in the children receiving the intervention and this in part could be due to the early implementation of therapy.

The parameters measured in evaluation of the benefits of early intervention vary and some of the measures are likely to be as dependent on other factors such as fluctuating hearing during the study period, undiagnosed VPI, or unrelated speech and language problems. More UK based research is much needed in this area.

Types of speech therapy approach

One author in particular, Pamplona et al (1999) has investigated a number of different speech therapy (ST) approaches for cleft palate children.

Pamplona (1999) randomly assigned twenty-nine 3-7 year old CP patients with compensatory articulation disorder to two different ST approaches. One group received an articulatory speech intervention, whereby errors were treated on a phoneme-by-phoneme basis. The other group received a phonologic speech intervention whereby errors were corrected at the rule level. The goal was to produce correct speech sounds for communicative purposes rather than the correct production of sounds as a goal itself. Every 3 months, each child was assessed until compensatory articulation disorder was judged to be completely corrected. A significant difference was found between the groups: the mean total time of speech intervention for the articulating speech intervention group was 30.07 months compared with 14.5 months in the phonologic group.

Pamplona (2004) tested the phonologic approach against a naturalistic approach based in whole language philosophy. Whilst the phonologic approach to therapy involved goals set on phonologic rules, the naturalistic approach looked at therapy according to whole language principles, with play and story being the main context for the intervention. Both groups were measured in terms of time taken from onset of therapy until complete normalisation of articulations. No difference could be found in total time of speech therapy and phonologic therapy.

Pamplona (2004) further compared speech intervention for CP children with associated compensatory articulation disorder, but this time in terms of how therapy was delivered. Forty five 3-10 year old children with repaired cleft palate, who exhibited compensatory articulation disorder, attended a 3-week speech summer camp for 4/hours per day, 5 days per week for 3 weeks. A
comparison group received conventional speech therapy which consisted of 1 hour sessions, twice a week, for 12 months. At the end of their respective treatment periods, both groups demonstrated a significant decrease in their compensatory articulation disorder, with no treatment modality being better than the other. The majority had completely corrected or showed mild compensatory articulation disorder. However, in terms of total hours speech therapy received, there was a significant difference between the groups. The conventional approach involved 104 hours of therapy per patient whereas patients attending the speech summer camps received 60 hours of speech therapy. In terms of cost, there was again a notable difference - summer camp treatment cost $100 per patient whilst conventional therapy was $412 per patient.

Multidisciplinary care

Blakeley et al (1995) set a target of achieving normal articulation in a group of 41 children over a 4 year period. This target specified that 90% of the children would have normal articulation and normal oral nasal resonance at age five. The programme of care incorporated early diagnosis, early intervention, parental involvement and speech habilitation including temporary speech appliance. The focus was on prompt and appropriate multidisciplinary care throughout the child's first 5 years. Excellent results were achieved with 93% of children having normal articulation at the end of the study. The authors comment that as they themselves were involved in the care of these children, they were in a suitable position to influence programme co-ordination i.e. the authors could step in to ensure treatment was co-ordinated properly. However, there was no control group in this study, and one would expect a proportion of children to attain normal articulation, without any specific intervention, thus the additional added value of this integrated approach cannot be quantified. Furthermore there is the possibility of bias introduced by the authors being involved in the study outcomes.

Treatments supplementary to speech therapy

Two studies investigated the use of supplementary interventions/ therapies alongside speech language therapy; both demonstrating considerable effectiveness.

Kuehn (2001) looked at the use of continuous positive airway pressure (CPAP) in the treatment of hypernasality. CPAP is the application of progressive resistance to the velopharyngeal muscles of the patient as he/she speaks. Forty-three 3-25 year old patients, who were born with CP and had clinically diagnosed hypernasality, received CPAP therapy over an 8-week period for 6 days per week. Patients were instructed to recite a set of words or sounds as the CPAP therapy was administered. Although variable across patients, the results demonstrated an overall net reduction of speech hypernasality, but not complete absence. Since the study did not report any long-term follow-up it is not possible to comment on the maintenance of any gains or continued improvement. Ysunza (1997) evaluated the use of videonasopharyngoscopy as visual feedback during speech in cleft palate patients. There were two groups of patients; one receiving speech therapy only and the other as well as receiving 3 weekly 1-hour speech therapy sessions over a period of 12 weeks, 9 patients received two additional sessions per week using videonasopharyngoscopy as visual feedback. During these biofeedback sessions, the patients and speech pathologist together identified anatomical structures at rest and during speech. Attempts were then made to modify negative movement of the lateral pharyngeal walls during speech. After 12 weeks, all patients receiving biofeedback had modified negative movement of the lateral pharyngeal walls. In contrast, only one of the 9 patients who did not receive biofeedback sessions modified lateral pharyngeal wall movement during speech. However, this latter group of patients then received biofeedback.
sessions; which resulted in all participants completely correcting their modifying lateral pharyngeal wall movement. This study shows that visual biofeedback therapy has potential to improve velopharyngeal movement patterns using therapy involving

**Electropalatography**

Two studies investigated the use of electropalatography (EPG) as an aid to speech language therapy; both demonstrating considerable effectiveness. EPG allows the patient to receive visual feedback on the placement of the tongue. This is by electrode contact between an artificial plate and the subject’s tongue. It is important to note that the following evidence for EPG is based on two studies carried out on a very small number of participants; making it difficult to generalise results, but nevertheless with very good outcomes, over relatively short periods compared with traditional methods.

Michi (1993) reported on the outcomes for six subjects, aged four-six years old, who had received primary palatography at less than two years of age. The children had received no previous speech language therapy; four exhibited palatalized misarticulation and two showed lateral misarticulation. Each child was randomly assigned to one treatment; EPG visual feedback or no visual feedback. Therapy was delivered once a week for one hour per session. Visual feedback via EPG was achieved by teaching the child correct and incorrect lingual-palatal contact patterns in relation to the EPG visual display. The children were taught the correct articulatory placement and how sensations relayed to the visual display. Children receiving visual feedback were only shown a waveform display. The children were assessed according to their pronunciation of /s/ sounds and tongue placement was measured on a welcome home by EPG. Results were positive. Visual feedback via EPG was useful for treatment of tongue placement when measuring /s/ sounds in children who exhibited excessive posterior tongue elevation; but less so for children with slight posterior tongue elevation. Children with both excessive and slight posterior tongue elevation learnt appropriate frication more quickly if treated with visual feedback than those children who received auditory stimulation. The authors make a note of some disadvantages of this therapy; notably the high cost of routine use of EPG and the requirement of dental specialist involvement in fabrication of the artificial palatal plate.

Whitehall (1996) described the use of EPG in the treatment of an 18-year old Cantonese-speaking woman who had undergone late palate repair at the age of 13. At assessment, the patient exhibited moderate hypernasality, audible nasal emission, a moderate speech disorder, abnormal patterns for attempts at alveolar stops, fricatives and affricates and posterior placement and lack of grooving for fricatives and affricates. The patient previously received 13 speech therapy sessions, with poor treatment results. The treatment aim was to improve the placement of articulation for alveolar plosives, fricatives and affricates. The patient received 23 one-hour sessions over a period of four months where sounds were targeted at word and conversational level, using EPG to provide visual feedback. Significant improvement was seen quickly following treatment. EPG readings noted a more anterior placement for /s/ and /t/. Perceptual judgements of speech indicated /s/ and /t/ were acceptable in single words. In conversation, /s/ was deemed acceptable; /t/ was deemed 55% accurate (pre-therapy accuracy level 11%). The affricate /ts/ achieved 100% accuracy in single words and 90% accuracy in conversation. Nasal emission and nasal plosion were eliminated from these phonemes. Hypernasality was not reduced by this treatment as would be expected.
Speech outcomes over time

Two cross-sectional studies investigated the speech outcomes for groups of children born with cleft palate after having followed treatment protocols. It is worth noting in this section that cross-sectional studies record data at one point in time, therefore making it impossible to determine cause and effect.

Sell et al (2001) investigated the speech outcomes in patients with unilateral CLP in the context of an examination of the UK cleft services. Speech therapy histories for 268 5-year olds and 257 12-year olds were examined. Information on the amount of treatment children had received and their speech outcomes were obtained. Children in both age groups had received speech therapy of reasonable duration with half of all 5-year olds and 60% of 12-year olds receiving speech therapy that lasted for more than one year. However, on speech outcomes, nearly a fifth of 5-year olds were judged to have speech impossible to understand or only just intelligible to strangers. 19% of 12-year olds had speech different enough to provoke comment, impossible to understand or unintelligible to strangers. Therefore, even though children had received a reasonable amount of speech therapy, there was still judged to be a need for further speech therapy treatment. Furthermore 18% of both age groups still presented with hypernasality suggesting a structural anomaly.

Van Lierde et al (2003) looked at speech intelligibility and hypernasality amongst a group of 14 CP patients (age 16-23 years) who had undergone a two stage procedure with a soft palate repair at an average age of 14 months, and closure of the hard palate at 8.10 years. Each patient had followed identical treatment protocols which included surgical treatment and speech therapy (minimum of 2 years, 2-3 times per week). Although some errors persisted, eleven out of the 14 patients were judged to have overall normal speech intelligibility. Over half of the patients still demonstrated hypernasality, which suggests this was left untreated and would not be considered a totally acceptable outcome. Delayed hard palate repair with these timings is not commonly practiced in the UK.

Summary
Parental involvement is an important factor in the success of speech therapy for children with cleft palate. Inclusion of parents in the treatment may have important implications for service delivery in terms of speech outcomes and cost. In terms of types of approach to speech therapy, this appears to require consideration as different approaches or methods of providing therapy may shorten treatment time considerably. It is less clear whether early intervention can significantly improve therapy outcomes for both speech and wider communicative competence and confidence outcomes in the cleft population. Electropalatography (EPG) appears to be successful in treating articulation disorders; however the evidence for this treatment is based on small numbers of participants, but nevertheless is shown to be highly effective for those with sever intransigent persistent speech disorders.

References


regarding articulation, resonance and voice in Flemish adults with unilateral and bilateral cleft palate. [Review] [31 refs], *Folia Phoniatica et Logopedica*, vol. 55, no. 2, pp. 80-90.


<table>
<thead>
<tr>
<th>Study</th>
<th>Country</th>
<th>Study design</th>
<th>Subjects</th>
<th>Intervention</th>
</tr>
</thead>
<tbody>
<tr>
<td>Kuehn, D P (2001)</td>
<td>USA</td>
<td>Clinical trial</td>
<td>3-25 year olds born with cleft palate and clinically diagnosed hypernasality N=41</td>
<td>Continuous positive airway pressure therapy</td>
</tr>
<tr>
<td>Michi, K (1993)</td>
<td>Japan</td>
<td>Case study</td>
<td>Six 4-6 year olds who had received primary palatography at 2 years of age (no previous speech therapy)</td>
<td>Electropalatography</td>
</tr>
<tr>
<td>Pamplona, M C (1999)</td>
<td>Mexico</td>
<td>Randomised controlled trial</td>
<td>3-7 year olds with cleft palate N=29</td>
<td>Speech intervention: Phonetic approach vs. Phonologic approach</td>
</tr>
<tr>
<td>Pamplona, M C (2000)</td>
<td>Mexico</td>
<td>Randomised controlled trial</td>
<td>3-5 year old children with cleft palate N=41</td>
<td>Involvement of mother in speech therapy sessions</td>
</tr>
<tr>
<td>Pamplona, M C</td>
<td>Mexico</td>
<td>Randomised</td>
<td>3-4 year old</td>
<td>Involvement of mother in</td>
</tr>
<tr>
<td>Study</td>
<td>Country</td>
<td>Study design</td>
<td>Subjects</td>
<td>Intervention</td>
</tr>
<tr>
<td>-------</td>
<td>---------</td>
<td>--------------</td>
<td>----------</td>
<td>--------------</td>
</tr>
<tr>
<td>M C (2001)</td>
<td>controlled trial</td>
<td>children with cleft palate N=59</td>
<td>speech therapy sessions</td>
<td></td>
</tr>
<tr>
<td>Pamplona, M C (2004)</td>
<td>Mexico</td>
<td>Randomised controlled trial</td>
<td>3-7 year olds with cleft palate, with compensatory articulation disorder N=30</td>
<td>Speech intervention: Phonologic approach vs. naturalistic approach</td>
</tr>
<tr>
<td>Pamplona, M C (2005)</td>
<td>Mexico</td>
<td>Clinical trial</td>
<td>3-10 year old children with repaired cleft palate who exhibited compensatory articulation disorder N=45</td>
<td>Conventional speech therapy approach vs. spec summer camp</td>
</tr>
<tr>
<td>Scherer, N J (2008)</td>
<td>USA</td>
<td>Clinical trial</td>
<td>14-36 month old children with unilateral cleft palate and/or lip N=20</td>
<td>Parental delivery of an early intervention programme</td>
</tr>
<tr>
<td>Sell, D (2001)</td>
<td>UK</td>
<td>Observational study</td>
<td>525 children with history of unilateral cleft palate and/or lip (268 5 year olds, 257 12 year olds)</td>
<td>Duration of speech therapy and requirement for more speech therapy</td>
</tr>
<tr>
<td>Ysunza, A (1997)</td>
<td>Mexico</td>
<td>Clinical trial</td>
<td>11-12 year olds with cleft palate N=17</td>
<td>Videonasopharyngoscopy for visual feedback alongside speech therapy</td>
</tr>
</tbody>
</table>
9. References cited


4. Communicating Quality 3 2006 Royal College of Speech and Language Therapists.


7. Sell, D Grunwell, P. 2008 Great Ormond Street Speech & Language Therapy Department Schedule.


15. Medic 8 articles on cleft palate accessed 071108
   http://www.medic8.com/healthguide/articles/cleftlip.html

16. Mercer, N. & Pigott, R. 2001 Assessment and surgical management of velopharyngeal
dysfunction. In Watson, A., Sell, D. & Grunwell, P. (Eds.) 2001 Management of Cleft Lip and


18. North Thames Regional Cleft Centre 2008 Guidelines

19. Peterson-Falzone, S. 1996 The relationship between timing of cleft palate surgery and
speech outcome: What have we learned and where do we stand in the 1990s? Seminars in
Orthodontics, 2, 3, 185-191.


   227-257.

23. Sell, D. & Ma, L. 1996 A model of practice for the management of velopharyngeal

   in nonsyndromic patients with cleft palate: a 29-year assessment of one surgeon’s


26. Trost Cardamone, J. 1989 Coming to terms with VPI: a response to Loney & Bleom, Cleft
   Palate Journal, 26, 68-70.

27. Vandera, A. 1987 Incidence of cleft lip, cleft palate, cleft lip and cleft palate among races: a


29. Watson, A. 2001 Classification. In Watson, A., Sell, D. & Grunwell, P. (Eds.) Management of