# Report to NHS England on Behalf of

# The Clinical Reference Group for Cleft Lip and Palate

## April 2016

# Variation in Speech and Language Therapy Provision

# For Children born with a Cleft Lip and Palate

# England and Wales (Anonymised).

Speech Therapy:
Changing lives one word at a time

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Parent CFSC 2016

# EXECUTIVE SUMMARY

1. Speech and Language Therapy (SLT) is an essential component in the multidisciplinary assessment and treatment of children born with cleft palate.
2. There is considerable local and regional variation in how SLT for children born with a cleft palate is funded and provided in England and Wales resulting in unacceptable inequity in care. This is likely to impact on outcomes for children and is at odds with NHS England's stated ambition *'to bring equity and excellence to the provision of specialised care and treatment'.*
3. In Regional Cleft Units specialist speech and language therapists (SLTs) assess and make recommendations for therapy if needed. The National Service Specification for cleft (NSS)[1] requires local services to provide the therapy closer to the child's home.
4. Local SLT is frequently not being provided to the recommended level as a result of local service / commissioning decisions and budget constraints.
5. There is strong evidence to suggest that SLT services are being commissioned and provided based on cost rather than evidence based practice or national recommendations, resulting in rationing of provision where demand exceeds capacity.
6. Unlike other specialisms in cleft care, the NSS currently contains no core standards for SLT provision.
7. There has been a systematic dilution of SLT services and down-grading of specialist SLT posts since 2010 resulting in a reduced level of skills and expertise, which impacts on therapy provision and speech outcomes.
8. These issues are not reflected in the Cleft Quality Dashboard because it takes 6 years for changes in provision to be evident in speech outcomes.

This report recommends that the commissioning of SLT in cleft care should be based upon process standards defined using the available evidence:

**Regional cleft units will have a specialist team of SLTs with appropriate skill mix (Band 6-8), a consultant level Lead SLT (Band 8b/c) and a ratio of 1 wte specialist SLT to 20 cleft births per year. There will be additional SLT funding for regional teams who are commissioned to provide local therapy.**

**Local SLT services will have an identified link SLT for children born with a cleft palate who works closely with the regional specialist SLT team.**

**Therapy will be based on evidence and best practice jointly agreed between the local SLT team and the regional specialist SLT team.**

We seek the support of NHS England Specialised Commissioners, regional Commissioners and local clinical commissioning groups (CCGs) in managing the inequities in SLT provision, some of which can be addressed within the provider units with commissioner support, and others which require communication with local services.

## BACKGROUND

Around 870 babies (1/700) are born annually in England, Wales and Northern Ireland with cleft lip and/or palate[2]. Cleft care is a complex, long term multidisciplinary pathway from birth to adulthood involving surgery, audiology, ENT, orthodontics, nursing, dental health, clinical psychology and SLT*.* Primary outcomes for affected individuals include speech, facial growth and psychological well-being. Children born with cleft palate are at high risk of developing speech difficulties requiring SLT [3] which may have long term consequences for literacy and psychosocial development that can persist into adulthood[4,5,6,7,8].

In 1998, the investigation of cleft services in the UK commissioned by the Department of Health[9] found "poor standards of care and poor clinical outcomes" including disappointing speech outcomes compared to other European centres[10]. This led to a reorganisation and centralisation of cleft care to improve standards. A 'hub and spoke' model was recommended for SLT with coordination of care between the regional specialist SLTs and local provider services. RCSLT further recommended 1 wte specialist SLT for 20 cleft births and ring-fenced funding for local SLT provision[11].

The National Service Specification (NSS) for cleft (D07/5/A, 2013) describes the current service requirements in cleft care. It states that services such as SLT may be *"delivered by local specialist clinicians working as prescribed by hub clinicians."* For most specialities it identifies minimum process standards for the service to be provided but not for SLT, limiting its ability to guide service provision for this specialty. Concern has been raised recently about the gaps between specialised and local commissioning of SLT provision*.*

Speech outcomes in cleft care are defined within the NSS and will be influenced by many factors including surgery and therapy. A recent report on speech outcomes at age 5 years[12] and the The Cleft Registry and Audit NEtwork (CRANE) report (2015)[2] demonstrate significant variability in speech outcomes across regional services, with some failing to achieve nationally agreed standards. SLT provision is likely to be an influencing factor.

There is a body of evidence to support SLT for children with speech sound disorders, as demonstrated by a comprehensive narrative review of 134 studies[13]. Research on SLT in cleft care also shows beneficial effects of therapy [14].

This study and report were commissioned by NHS England Clinical Reference Group for Cleft Lip and Palate (D07) and the national Cleft Lip and Palate Association (CLAPA) as a result of growing concern over the inequity in SLT provision for children born with a cleft and potential impact on their life outcomes.

## METHOD

A survey was circulated to 158 local and 11 regional specialist SLT services in England and Wales in December 2015. The survey aimed to investigate:

- Regional and local SLT provision for children born with a cleft (England and Wales)
- Local service characteristics and dosage of SLT offered
- Waiting times for therapy
- What supports and constrains SLT service delivery to children with palate related speech difficulties
- The interface between local and specialist SLT services
- The funding pathways and grading for SLT in cleft care

## RESULTS

100% of regional surveys and 47% (75/158) of local surveys were returned. A thematic analysis was conducted on responses to the open questions. Any service changes since January 2016 are not included in this report. Whilst a response from 75/158 local SLT services is a relatively good response rate, it may be more representative of services that are actively engaged with the regional units.

### Regional Specialist SLT

There is a significant variation across regional cleft units in the number and grading of posts, the regional SLT funding (Table 1) and number of cleft births per specialist SLT (Figure 1).

The number of cleft births per wte SLT was calculated based on the mean number of births per year from 2005-2014 inclusive[2]. The level of funding in each regional unit was calculated based on the salary midpoint for each SLT and SLT Assistant (Band 3-8c) using NHS pay scales (2015-16). The amount of money spent on cleft SLT per child each year was also calculated.

Table 1 and Figure 1 show that units vary considerably both in terms of the numbers of children managed per wte specialist SLT (range 11-53) and SLT funding. Units J and K have in excess of 30 births per wte. This is significantly higher than RCSLT recommendations (11) of 20 new cases per wte specialist SLT. SLT funding ranges from £900 to £3300 per birth with a mean of £1964. The profile of skill-mix within specialist teams also varies across units. The units with the lowest SLT funding ratio are Unit K (£882/ 53 births per wte) and Unit I (£1211/28 births per wte).

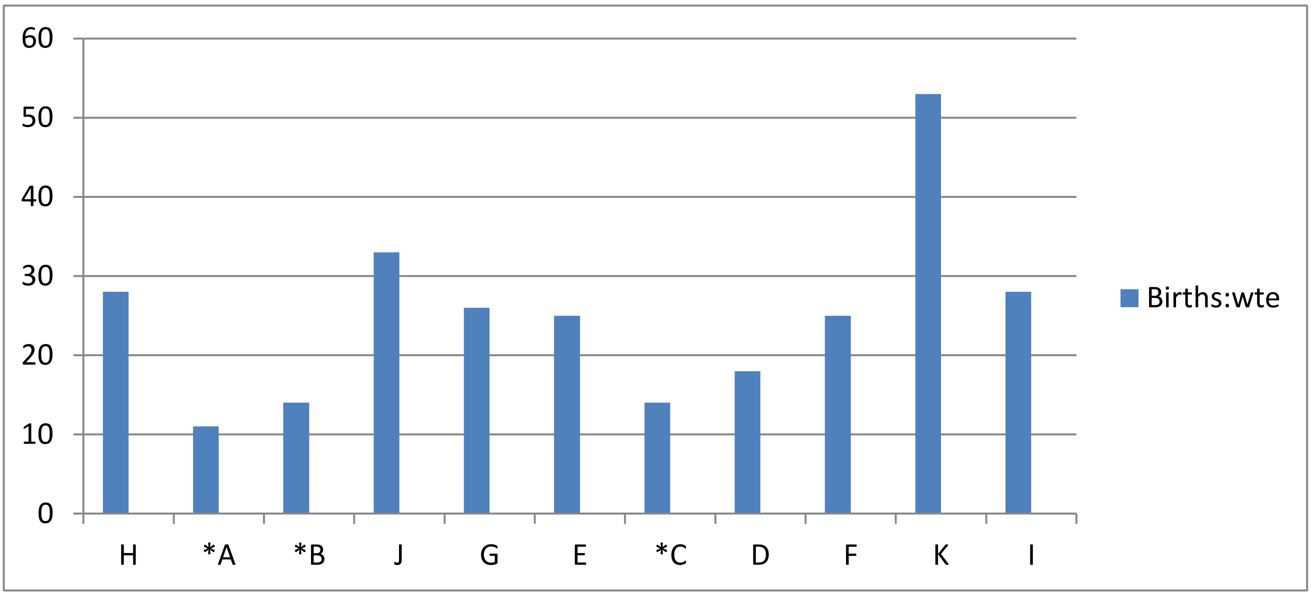
The three units with the most funding for SLT (Units A, B and C) have posts specifically commissioned to provide therapy locally. Units with lower funding levels (Units H, I and K) rely heavily on locally commissioned SLT services to support the small regional teams. The smaller the regional SLT resource, the more the children are reliant on the local SLT provision in their area.

## Table 1: REGIONAL SLT FUNDING

| Regional Administrative Unit | Mean Cleft Births per yr (2005-14) | No. wte SLT | No. births per wte SLT | SLT Funding per cleft birth (£) |
|---|---|---|---|---|
| *A | 70 | 6.4 | *11 | *£3316 |
| *B | 67 | 4.8 | *14 | *£2634 |
| *C | 45 | 3.31 | *14 | *£2916 |
| D | 101 | 5.6 | 18 | £2419 |
| E | 65 | 2.58 | 25 | £1678 |
| F | 104 | 4.2 | 25 | £1608 |
| G | 155 | 5.9 | 26 | £1777 |
| H | 78 | 2.8 | 28 | £1564 |
| I | 114 | 4.0 | 28 | £1211 |
| J | 153 | 4.6 | 33 | £1601 |
| K | 95 | 1.8 | 53 | £882 |
| **MEAN** | - | - | **25** | **£1964** |
| **RANGE** | - | - | **11-53** | **£1K-£3.3K** |

- *Starred services have allocated funding provided through specialised commissioning to deliver some SLT at a local service level*

## Figure 1: Number of Cleft Births per Regional Specialist SLT (wte)



While this survey focuses on children born with a cleft palate, it must be noted that all regional units support an additional complex caseload of children and adults with non- cleft velopharyngeal dysfunction. Non-cleft referrals are thought to double the active caseload for any specialist cleft team and local services.

## SLT Provision

The survey showed variation in the provision of local SLT both within and across regions. Regional services support a varying number of local SLT services and those services vary in their allocated sessions for cleft (Table 2). For example, Unit H supports 78 births per year and 6 local services. All 6 have allocated cleft sessions amounting to 2.1wte but subject to local funding decisions. By contrast, Unit G supports 155 babies per year and 26 local services. Just 5 of these services have local link SLTs with allocated sessions of 1.2wte.

**Table 2: Provision of designated SLT by local services**

| Regional Unit | No. Local SLT Services supported by the unit | No. Local SLT services with allocated cleft sessions | No. wte locally funded SLTs |
|---|---|---|---|
| *C | 5 | 0/5 | *0 |
| *A | 9 | 2/9 | *0.1 |
| *B | 10 | 3/10 | *0.3 |
| E | 10 | 7/10 | 1.0 |
| D | 12 | 6/12 | 1.1 |
| I | 21 | 7/21 | 1.1 |
| J | 15 | 3/15 | 1.2 |
| G | 26 | 5/26 | 1.2 |
| F | 33 | 16/33 | 1.2 |
| K | 11 | 3/11 | 1.9 |
| H | 6 | 6/6 | 2.1 |
| **TOTAL** | **158** | **58/158 (37%)** | |
| **Starred services have allocated funding provided through specialised commissioning to deliver some SLT at a local service level* | | | |

Unit A, with a high level of specialised funding, supports 9 local services but there are minimal locally funded SLT sessions and a high volume of local therapy has been provided by the regional service. By contrast, Unit K, with a low level of specialised finding, has a high level of locally funded specialist SLT sessions focussed in 3 local SLT services. This helps support the regional unit but is subject to local funding decisions.

In 63% (100/158) of services there are no designated SLT sessions for children born with a cleft palate. Some have a named local link SLT who coordinates care for but does not necessarily provide the therapy. The remaining 37% (58/158) of local SLT services do have designated cleft SLT sessions with the level of expertise varying from generalist (band 5) to consultant (band 8c).

It is noted that the number and grading of specialist SLT posts is being eroded. Since 2010, there has been a loss of 3.5wte at highly specialist regional level (band 8), while in some local SLT services, previously designated cleft sessions have been downgraded or absorbed into other posts.

## SLT Service Delivery

This survey identified inequity in the provision of therapy depending on where children live. In 73% of survey responses, caseload demands were cited as the main factor constraining service delivery.

There is variation in how therapy is delivered in terms of frequency, location, who delivers it and dosage. Local therapy is most commonly provided by generalist community therapists with limited specialist skills and knowledge about cleft. By contrast, those regional units with sessions commissioned to provide therapy locally (e.g. Unit A) can usually offer more specialised therapy.

As children move from preschool to school age, the model of therapy is more likely to be consultative with far less direct therapy delivered by a qualified SLT and more by teaching assistants.

**Dosage:** In 16% (12/75) of services, children are seen in 6-8 week on/off blocks with waits in between. Other services operate a protocol of half termly or termly visits. Dosage varies but monthly direct SLT sessions, with a maximum of 12 per year is common. Four services set a limit on the number of SLT sessions a child can have annually.

**Service protocols:** Some local services provide age limited packages of care. Two services offer no direct therapy before age four, two services offer no therapy after age five unless a child has additional needs, and 11/75 (15%) offer no direct therapy after 11 years of age. Three services offer consultative only services with no direct therapy offered.

**Waiting times:** Few services (7%, 5/75) are able to offer immediate therapy. The most frequent waiting time is 2-8 weeks (51%, 38/75) with 16% (12/75) reporting waits over 18 weeks and the longest waits over 12 months. There are also hidden waits between blocks of therapy. Timely therapy is essential in cleft care to avoid disordered early speech habits becoming entrenched. In addition, diagnostic therapy is often required to assess the need for revision surgery.

**Prioritisation:** One third (25/75) of local SLT services operate a formal prioritisation system for therapy provision. Some services are commissioned to see children in strict order of date of referral regardless of clinical need, while others operate more informal prioritisation at the discretion of the individual therapist.

Variability in local SLT service provision means children supported by the same regional cleft service may receive very different SLT care. For example, Unit B supports 10 local SLT services. One of these local services (B1) has no designated cleft sessions and operates a consultative model of service delivery. Children typically receive 1 direct SLT session of 30-60 mins per term. By contrast, another local service (B2) has a specialist local link therapist with 0.2

wte at band 7. Here, therapy is usually provided by the specialist link for 20-40 mins on a weekly basis with 10-12 direct contacts per term as required.

Variability in provision also exists at a regional level. Factors including demographics, geography and funding have led to the evolution of very different models of service delivery with three main models:

1. **Centralised model**: These units tend to run clinics at the regional centre and offer therapy advice and some training to local SLTs. They may have some limited scope for providing therapy at the centre. Units I and J function in this way.
2. **Dispersed model:** Units with limited SLT funding that are dependent on locally funded link SLTs to support the service. Here the regional SLT team rely upon regular joint working through local liaison clinics and shared protocols. Units H and K function in this way.
3. **Hub and Spoke model:** Units have made a business case specifically for regionally funded SLTs to deliver therapy locally. This has happened in Units A, B and C.

## DISCUSSION

This survey provides strong evidence that CCGs and SCGs are commissioning and providing SLT services based on cost and demand rather than evidence based practice.

Although there is a body of evidence to support therapy for children with speech sound disorders and cleft palate[13,14], this survey shows typical NHS intervention bears little relationship to the published evidence. In most research studies children receive 2-3 sessions of therapy per week delivered by an expert SLT[13.] By contrast, most children are being seen 3-12 times per year by a generalist SLT using blocks of therapy or a consultative model. Smaller doses of therapy are not evidence based and may not achieve similar outcomes[18]. There is also little published evidence to suggest 6 week blocks of therapy with gaps in between or consultative models of SLT are effective for children born with a cleft palate. It is difficult to provide a consultative model of care without the specialist skills and experience to do so.

A recent review of the literature regarding the best model of service delivery for speech and language impaired children[15] concluded that decisions on format, provider and setting are being determined by caseload, premises and willing parents and schools rather than evidence based practice.

This survey shows that the provision of therapy is based on caseload demands rather than evidence based practice, and the variability in how SLT is commissioned and funded is resulting in unacceptable inequities in SLT for children born with a cleft palate.

## Public and Patient Involvement

Patients and parents are increasingly aware of inequities in SLT service provision and have been highlighting this to the Clinical Reference Group for Cleft Lip and Palate for two years. This was one of the drivers behind this survey and report (see Appendix 1)

CLAPA conducted a survey in 2015 of parents / patient views on access to SLT in UK. Parent views reflected the findings in this survey. For example:

"We waited 6 months for an appointment and now we are finally getting seen. It's a different lady every time and there are sometimes 12 week gaps between sessions"

"We have had 5 different SLTs. There is no continuity and each SLT has a different way of teaching"

"My son was getting 6 sessions then going back on a waiting list which made SLT more difficult"

## Speech Outcomes

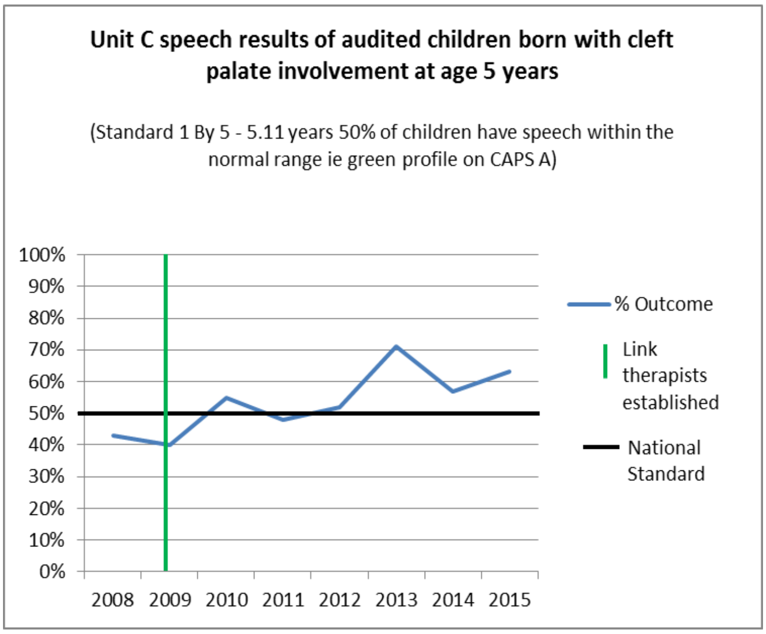
A recent report on speech outcomes in cleft care at age 5 years[12] and the CRANE report 2015 demonstrate significant variability in speech outcomes across regional services. It is not possible to identify a direct relationship between SLT provision and speech outcomes because cleft care is a complex intervention and speech outcomes will be influenced by a range of factors including type and timing of primary surgery, hearing management and parental involvement. However, the potential impact of SLT provision on outcomes is highlighted by two examples from this survey.

In 2009, Unit C (part of a larger cleft network) reorganised its SLT provision. Designated Link SLTs, who also worked as SLTs in the hub cleft unit, were funded by the regional cleft team through specialised commissioning and appointed to work in each of the 5 local Health Boards. The link SLTs have worked collaboratively with local SLTs and the hub team to improve both the quality and quantity of therapy children receive. Adopting this model of care has ensured that SLT provision is equitable and accessible across the area with greater control over local delivery. Unit C now has a capitated budget of £2916 per cleft birth. Figure 2 demonstrates improvement in speech outcomes since the introduction of (regionally-funded) Link therapists.

By contrast, for birth cohorts 2004-08, Unit K has demonstrated audited speech outcomes at the bottom end of the national range (CRANE, 2015). A multi-disciplinary action plan is in place to improve speech outcomes in Unit K through type and timing of primary surgery, proactive surgical follow-up and hearing management. Efforts are being made to optimise use of the existing SLT resource through collaborative partnerships with local SLT services. However, Unit K has been identified in this report as the regional unit with the smallest capitated specialised SLT budget (£882 per cleft birth) and inequitable local SLT provision, which is subject to local funding. It is a significant risk that the low level of specialised funding for SLT provision in Unit K may be a limiting factor to the improvement in speech outcomes achievable.

These examples demonstrate the need to strive for equity in SLT provision, before we can expect equity in speech outcomes across the UK.

**Figure 2: Speech Outcomes in Unit C 2008-15**



## CONCLUSIONS

This report highlights a mismatch between the stated goal of NHS England *"to ensure that patients have equal access to services regardless of their location"* [17] and current inequity in SLT provision for children born with a cleft palate both within and across regional services. This is creating a high level of concern amongst patients and parents and potentially impacting on children's speech outcomes.

Despite RCSLT recommendations of 20 births per wte SLT and the requirements of the NSS, there is no correlation between the number of cleft births and the level of specialised and local SLT funding and provision. Funding at a specialised level ranges from £882 to £3316 per cleft birth and caseloads of 11 to 53 births per wte SLT.

There is also inequity at a local level in waiting times, prioritisation, dosage and frequency of SLT, with protocols being determined by cost and caseload demands rather than evidence based practice. Despite working collaboratively with local SLT services it is very difficult for specialised SLT teams to ensure equitable provision due to variation in local service protocols.

There has also been a significant dilution in NHS provision of SLT. This includes restructuring of services, down-grading of posts, removal of specialist care pathways, failure to recruit when staff leave and redundancies. SLT appears to be disproportionately targeted for down-grading of posts and reduction in provision. There is an urgent need to address the inequity in this area of specialised commissioning.

## RECOMMENDATIONS

The Cleft Lead SLT forum and Clinical Reference Group for Cleft Lip and Palate recommend that:

- The National Service Specification for Cleft Lip and Palate (D07/5/A) is amended (as shown in Appendix 2) to include process standards for SLT in order to guide both local and specialist commissioners and address service provision inequity.
- All regional cleft units will have a specialist team of SLTs with appropriate skill mix (Band 6-8), a consultant level Lead SLT (Band 8b/c) and a ratio of 1 wte specialist SLT to 20 cleft births per year.
- There will be additional SLT funding for regional teams who are commissioned to provide local therapy.
- SLTs working in the regional specialist team must have appropriate competencies, skills and training to fulfil the NSS and manage the risks associated with making recommendations about surgery based on speech.
- Local SLT services will have an identified link SLT for children born with a cleft palate (+/- Cleft Lip/Alveolus) and related disorders who will work closely with the regional specialist SLT team. The local link SLT for cleft may be employed locally or (with appropriate specialised commissioning) may be funded via the regional cleft unit.
- Therapy provided will be based on evidence and best practice and jointly agreed between the local SLT team and the regional specialist SLT team.
- National, evidence based guidelines on best practice in SLT with children born with a cleft palate should be developed.

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## APPENDIX 1: A PARENT'S EXPERIENCE OF LOCAL & REGIONAL SLT

I am a bit hazy on the sessions he had (has had intensive input over the years age 2-6) but he fully benefited from the regular weekly sessions that we attended at the cleft centre and some week long sessions. Even though I had to take B out of school, arrange work, not book any holidays until I knew he had a place on the holiday speech weeks and bring a new born and then toddler along to the weekly/daily sessions this all seemed necessary and appropriate and would not hesitate to travel and make this a priority to improve his speech. It did without a shadow of a doubt. I am in no doubt had we not have received this input from the specialist centre B would not have the clear, understandable speech he has today. When I was offered local sessions, this was appreciated with some apprehension but this would limit the time he would miss from school. Travel to the centre would make him tired and potentially affected his attention span during the sessions. He was missing half a day to travel to the Regional Centre and attend the session. The local option would mean a 10 minute travel and so reduce the time spent out of school. Local therapy was initially successful, we were introduced to a lovely speech therapist who worked with school and with the specialist SLT and progress was made. She also worked with the teaching assistant that had been allocated to B during the school day. The Teaching Assistant was very keen to support B but needed the extra input as she had never worked with a child with a cleft. The school had allocated the resources and support from the Unit K team was there. Unfortunately this speech therapist left the service and following this we had a number of different speech therapists who B never related to and so little progress was made. The teaching assistant no longer received any support so even though the school had provided the time for her to work with B she was limited with what she could do. The SENCO for the school contacted the local therapy services; they were having staffing issues and allocated different therapists. The last local therapist (4TH OR 5TH) we saw had to me little knowledge of how to improve the "S" sound B was struggling with. The sessions were cancelled at the last minute, was originally booked in for 6 weeks but the local speech therapist wanted to abandon further work after a couple of sessions as she felt there would be little improvement with the "S" sound from her experience (1 session was very late in the day after a full day at school and then there was a gap of a few weeks) and B would have to live with not been able to pronounce his "S" correctly. I was told many children have a lisp and I would have to accept this. We had not at this point had the full sessions initially set out and was told my expectations were too high for him!

The regional specialist assessed B felt there was still some work that could be done to try and improve the pronunciation of the "S" sound with daily intensive therapy offered on a week camp. We were prepared by the Specialist that we may reach a point where things we are good as they could be and I fully accepted this but did not feel the local service had given him all the opportunity to reach his potential, the specialist input from the Unit K Team did give him the opportunity and I now have a 10 year old boy who has clear and articulate speech. When I talk to others they cannot believe he has had issues with his speech.

I cannot thank the specialist team enough or fully explain in words what a difference they have made to my sons' life now and in the future.

## APPENDIX 2: RECOMMENDED CHANGES TO THE NATIONAL SERVICE SPECIFICATION FOR CLEFT LIP AND PALATE D07/5/A

**P9:** No change

**P11:** Change to "Lead Consultant Level SLT with a major commitment to cleft care"

**P16:** Facilities: Add "Access to suitable NHS accommodation to run SLT liaison clinics and provide therapy as required"

Equipment: Add "Appropriate equipment for recording, archiving and storing speech recordings with ongoing funding for replacement"

**P20:** Replace the current core standards for SLT with the following:

1. 100% of children born with a cleft palate (+/- Cleft Lip/Alveolus) will be offered assessment by a specialist SLT between 18-27 months ( see Appendix 4, P66, No. 1)
2. Speech records will be taken in line with national audit requirements…. (see Appendix 4, P66 No. 2)
3. Specialist SLTs at the regional unit must have appropriate experience, training and proven commitment to cleft care. The Consultant Lead SLT would be expected to have specialist skills to a level of Band 8b/c (as defined by Agenda for Change) and all SLTs in the team to be Band 6 (as developing specialist) or above
4. Specialist SLTs at the regional cleft unit will be responsible for a caseload of up to 20 cleft births per year for each whole time equivalent. The number of births per wte may vary depending on the skill mix and requirements of the service.

**P22:** Should read <u>Royal College of Speech **and Language** Therapists</u>

**P44:** Appendix 2 – Local Care Guidelines: Speech and Language Therapy: Replace the current paragraph with the following (or include this as a recommended standard on P20)

"Local SLT services will have an identified link SLT for children born with a cleft palate (+/- Cleft Lip/Alveolus) and related disorders who will work closely with the regional specialist SLT team. The local link SLT for cleft may be employed locally or (with appropriate specialised commissioning) may be funded via the regional cleft unit. Therapy provided will be based on evidence and best practice and jointly agreed between the local SLT team and the Specialist SLT team working at the regional unit. "

**P66:** **<u>APPENDIX 4</u>** – This is now out of date as we only routinely audit speech at age five years and not at 10 years or 15/18 years