



The Communication Trust
Every child understood



A collection of case studies highlighting effective practice in speech, language and communication

A report for commissioners, speech and language therapy teams, health services, schools and local authorities

The Communication Trust is a Consortium of over 35 voluntary sector organisations. We bring together our expertise to ensure that the speech, language and communication needs of all children and young people are met through signposting specialist training support and guidance to people working with children.

Thank you to members of the Consortium who provided case studies for this report. With particular thanks to Communication Matters, for allowing access to their networks within the augmentative and alternative communication (AAC) community. For more information about their work please go to www.communicationmatters.org.uk

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LITTLE
GEEZER
Just like my dad!

Introduction

The purpose of this document is to *'help local commissioners plan and deliver targeted and specialist services for children with speech, language and communication needs (SLCN) that meet the demands of their local area, based on evidence of what works'* (Better Communication Action Plan 2008 paragraph 1.4)

It seeks to do this by providing anonymised case studies based on the experiences of children with SLCN. It reflects the impact of poorly commissioned services on individual children and highlights the positive impact of effective practice.

The content of this document is derived from just over 80 case studies provided by 17 voluntary organisations and, in some cases, speech and language therapy services. A sample of the case studies is reproduced in this document.

Children with speech, language and communication difficulties have a wide range of needs and cannot be considered as a homogenous group.

Studies and data vary on how many children have SLCN. However, we know around 5-7% of the total population have SLCN arising from having a specific language impairment¹.

Children and young people also have SLCN arising from other impairments, such as those with autism, hearing impairments and learning difficulties, which takes this number up to around 10% of the total population².

In addition, we know that in some parts of the country, particularly in areas of social disadvantage as many as 50% of children have SLCN³.

This document has been developed by The Communication Trust.

1 Tomblin, J. B. et al (1997) *Prevalence of Specific Language Impairment in Kindergarten children* *Journal of Speech, Language and Hearing Research* 40

2 Law et al (2000) *Provision for children's speech and language needs in England and Wales: facilitating communication between education and health services* *DfES research report 239*

3 Basic Skills Agency (2002), *Summary Report into Young Children's Skills on Entry to Education*

Executive summary

An analysis of all cases studies has identified 11 critical key factors/ characteristics of an effective commissioning strategy

Key factor 1: Early Assessment (Case Studies 1 and 2)

Early assessment should be available to those children about whom there is concern regarding one or more aspects of their speech, language and communication development. The assessments need to take account of the views and concerns expressed by parents and children.

Key factor 2: Early Intervention (Case studies 3 and 4)

Early assessment should be followed by prompt, appropriate and effective interventions that are developed in partnership with the parents/carers and child.

Key factor 3: Service Co-Ordination And Strategic Planning (Case studies 5 and 6)

Services should be effectively co-ordinated:

- Around an individual child and his/her family
- Within educational settings
- Within areas
- At regional levels
- National levels (cf. core offer)

Key factor 4: Strategic Funding Plan (Case studies 7 and 8)

There should be a strategic funding plan at area level and it should be available to professionals and parents.

Key factor 5: Clear Outcomes And Regular/Ongoing Reviews (Case Studies 5 and 9)

There should be a clear focus on outcomes with regular reviews of needs and interventions to reflect the changing needs of the child and to ensure that they are making adequate/satisfactory progress.

Key factor 6: Transitions (Case studies 10 and 11)

Children and young people should not experience any interruption of, loss or reduction in speech, language and communication services at any transition point in their lives such as starting or moving school if current assessments demonstrate such input needs to continue.

Key factor 7: Provision Of Information (Case Studies 12 and 13)

The family of the children with SLCN should be provided with all the information on that

need as well as information on the services and resources that are available locally and regionally, if required.

Key factor 8: Access To Specialist Support (Case studies 14 and 15)

Local speech, language and communication services should ensure they cover the range of specialist knowledge that could be required or, if that is not viable, that they have agreements in place to access any specialist knowledge they do not have.

Key factor 9: Inclusive Educational Establishments (Case studies 16 and 17)

All educational establishments should be 'communication supportive' with the workforce having the appropriate knowledge and skills to ensure the progress of children and young people with SLCN.

Key factor 10: Access To Technology (Case studies 18 and 19)

Knowledge, or the ability to access knowledge of technological solutions to communication should be available to all children who need this level of support.

Key factor 11: Social Support Networks

Many parents of children with SLCN value the opportunity to be part of a parental support group.

Many children and young people with SLCN, particularly those in mainstream schools, value the opportunity to meet together.

The following sections describe each of these key factors in more detail using case studies to illustrate why they are important for children with SLCN.



Key Factor 1: Early assessment

Early assessment should be available to those children about whom there is concern regarding one or more aspects of their speech, language and communication development. The assessments need to take account of the views and concerns expressed by parents and children.

To ensure children can make education, social and emotional progress while at school they need to start with their language as close to age appropriate levels as possible. If SLCN are not identified prior to starting school or are ignored there can be a huge personal cost to the child in terms of:

- Learning as they cannot understand what is being said in lessons
- Poor self esteem as they cannot express themselves and make friends

Late identification results in significant stress to the family and any support is likely to be more expensive and take longer to make an impact.

A significant number of the 80 case studies indicated that identification leading to action in the early, pre-school years is still not happening. The most common reasons given for this are:

- Parent/carer concerns not being responded to by professionals
- Parent/carers are not aware that they can refer their child to a Speech and Language Therapy Service
- Early years workforce not recognising SLCN
- Shortcomings within the system – long waiting lists and overstretched services

Case Study 1 demonstrates the failure to identify need and respond to the concerns of a mother. Case Study 2 describes how a child, identified as being profoundly deaf shortly after birth, started school with age appropriate language.

Case study 1: Anna

'She'll develop at her own rate' / is anyone listening?

Anna's mother says: 'Anna was a difficult baby always crying and difficult to settle. She was my first baby and I didn't always know if I was doing everything right. By 18 months I felt there was something wrong but I didn't know what. She had a few words – that seemed OK. But, she didn't seem to play well, tended to break her toys and never spent any time on any one thing. I thought I might be doing something

wrong. I plucked up courage to ask the health visitor. She fobbed me off saying that she couldn't see anything wrong.'

When Anna started at a pre-school playgroup, her mother noticed that Anna's interaction with other children was poor, but pre-school staff insisted everything was fine and that Anna would 'develop at her own rate.' Anna's mother was not really convinced, she felt that the staff had very low expectations of Anna.

Anna then started at school. The teacher was not happy with Anna's behaviour and upset her mother by suggesting poor parenting. Anna's mother began to notice that her daughter mixed up words and misunderstood some things, but she did not know what to do. When she spoke to the school staff about her concerns she was told that Anna was '*developing at her own rate*'.

The school called in the Behaviour Support Team who noted that Anna did not always understand what was said to her, but they did not suggest a language assessment. They also stated that Anna did not have a behavioural problem. Nevertheless, the school could barely cope with her behaviour and insisted that she spent lunchtimes at home with her mother.

Anna began to stammer and her mother's friend, who happened to be a health visitor, suggested a self referral to the Speech and Language Therapy Service. At the age of 5 Anna was assessed and was diagnosed with a specific language impairment.

At the suggestion of the therapist, Anna's mother contacted Afasic and benefitted greatly from the information and publications she received but was disappointed that there was not a local support group.

Anna's SLCN were so severe that she was given a statement of special educational needs and received teaching assistant time in school. The teaching assistant had experience in specific language impairment and this was really helpful.

Outcomes

- Anna has improved confidence and self-esteem
- Her mainstream school has become more understanding
- Although Anna has made progress, she is now 9 years old and still has significant SLCN. Her mother is concerned about the transfer to secondary school

Costs incurred

- Teaching assistant at school: 17.5 hours per week for last 4 years
- Training courses run by the Speech and Language Therapy Service for the school staff and parents
- Speech and language therapy

Comments from Anna's mother:

'Among the costs I would add the cost to my health and sanity when I was desperately seeking answers and was constantly being fobbed off.'

'There is so much ignorance about specific language impairment. I had not heard of this condition and was horrified to discover that my friend (a health visitor), my own health visitor, and the staff at Anna's pre-school and mainstream school did not know about specific language impairment either. All general children's professionals should know about specific learning impairment. The local Speech and Language Therapy Service sent leaflets to the pre-school, but they need to visit. Knowing a face and name would make it easier for people to seek advice if unsure.'

'Health visitor screening should be improved. Anna's poor response to speech meant that a hearing problem was suspected and tested for more than once, but when no problem was found, no further investigations for speech and language difficulties were carried out.'

Case study 2: Emma

How early identification can work

Emma was identified as having a profound hearing loss through the Newborn Hearing Screening Programme¹. Although this was a traumatic time for the family, they say that they *'could not have had a better or a faster response'* from health and audiology services.

The education team *'were great'* according to Emma's mother providing regular visits from teachers of the deaf and the opportunity to visit their Early Years Centre. Emma's mother says, *'It was really good at the Centre as Emma could meet up with other deaf children, while I could meet other parents. Meeting deaf adults gave us hope. The Centre provided us with training on communication and early signs'*. Her parents also learned about support from the voluntary sector and made contact

¹ The Newborn Hearing Screening Programme has been available in the UK since 2006 and this should ensure that the majority of deaf children start school with age appropriate language skills if supported, but there is significant variation in availability of services across the country.

with the National Deaf Children's Society. In the early years Emma became a good communicator using signing which stopped her from becoming frustrated.

Emma received a cochlear implant at 18 months. Her family received support from the implant team, who worked closely with the local services to provide support and guidance as Emma started to learn and to listen. After implantation, Emma continued to sign, but as her listening improved, she slowly began to understand and use more speech. The change from sign to speech was child led and not forced upon the family.

The family accessed all the local statutory services and services provided by the voluntary sector such as a communication group at The Ear Foundation.

Outcome

- Emma is now 5. Her speech and language skills are within normal limits and she is attending mainstream school
- She has no support other than the sound system from which essentially benefits all the children. She is in the top group for everything
- Emma has both deaf and hearing friends. She is happy, well-liked and gets involved in everything

Costs

- Early support from local health, education and audiology services
- Support from the Implant team
- Emma attended fortnightly signing and communication groups at the ear Foundation at a small charge to her family

Comments

After the initial early diagnosis, the multidisciplinary team worked exceptionally well together linking with voluntary organisations.

Key questions

- Is the early years' workforce skilled enough to identify and/or respond to parental concerns regarding the SLCN of a particular child?
- Are there clear, publicised referral routes that professionals and parents can follow if they are concerned about the SLCN of a particular child?

Key Factor 2: Early intervention

Early assessment should be followed by prompt, appropriate and effective interventions that are developed in partnership with the parents/carers and child.

Following identification of SLCN it is important to provide prompt, appropriate and effective (evidence-based) interventions. This can prove very cost effective as a significant number of case interventions are usually more successful if they occur when the child is young and/or before the difficulty becomes entrenched.

Prompt intervention can reduce levels of stress and anxiety within the child and his/her family and reduce support required in the long term.

Parents are the prime educators of their children so it is important to design speech, language and communication programmes with them and ensure that they receive training and support. Case Study 3 below describes how there was early identification, but it was not followed by effective intervention. Case Study 4 describes an effective response to early parental concerns.

Case study 3: Orla

Early assessment, but little action...

Orla was born prematurely and diagnosed at around 4 months with a hearing loss, but results were inconclusive as to the exact level of the hearing loss. Therefore her first few months of life were very traumatic for her family who felt quite alone with their problems. Orla's subsequent diagnosis was a profound loss and she received a cochlear implant at about 3 years old.

Orla received very little local support apart from a visit once a week from a teacher of the deaf. There was no input from a speech and language therapist. Communication problems led to difficulties in the home. Orla became increasingly frustrated and relationships within the family were strained. When a few signs were successfully introduced her parents taught themselves more from books and the internet. Her mother says that they were delighted when a cochlear implant was suggested, but were then very disappointed afterwards when her language progress overall was very slow – *'we weren't prepared for that as she seemed very bright in all other areas. We just needed someone to give us some support.'*

'Our next disappointment was the nursery school was not prepared for Orla's arrival

and so I had to provide them with a lot of information and ideas for communicating with her. I even had to suggest where they might find a teaching assistant with sign language skills.' Orla's mother felt she had to act as a mediator between the nursery school and the local authority about the level of support required. Support was funded by the Early Years Inclusion Service but on a termly basis making it difficult for the nursery school to plan ahead. On starting school at 4.5 years Orla's understanding of the spoken word and her own use of language were equivalent to a child of two years.

By now her parents felt Orla required a specialist school. The request was turned down but her parents appeal to the Special Educational Needs and Disability Tribunal was successful. Orla's mother said *'it is not something we wanted to do. Appealing for the placement was at a massive emotional cost to the family due to the very high stress levels it caused.'*

Outcome

- After one year in her new specialist school, Orla has made significant, measurable progress (well over one year) in her oral language and a gain of one year and 10 months in her understanding of language.

Costs

- School fees are on-going – currently £23,500 plus home school transport

Further comments from Orla's mother

'I still find it strange that I don't worry about knowing exact levels of speech ability or hearing levels any more. That's what having confidence in the people who are now working with Orla has done for me. I was always led to believe that the professionals working with her would support us but it rarely worked out that way in the early days, but it's been that way from the start at her specialist school. They've lifted a massive weight from me and I've only just got used to it. Having a child who cannot wait to go to school each day and who whinges that the holidays are too long is proof that the fight with the local authority was worth it.'

Case study 4: Becky

How it can work...

Becky is an adopted child with a history of neglect and lack of stimulation in her early years. Quite early on her adoptive parents had concerns about her speech and language. She was referred to the Speech and Language Therapy Service when she was two years old.

Her parents were delighted to get an initial speech and language assessment within a few weeks. This assessment showed that Becky had a delay of 12 months in her speech and language skills. Her mother says that *'Becky was only using a few single words and always seemed very shy and reluctant to communicate with anyone. This worried us, especially as Becky herself was having more tantrums. We were worried how she would ever cope at nursery school if she couldn't communicate.'*

The community paediatrician carried out a Ruth Griffiths Assessment (development scale for children aged two and under) which also indicated a delay of a year in speech skills.

Becky was immediately referred to an early language group run by therapists as part of an Early Intervention Programme. This group targeted her understanding and production of early vocabulary and provided parental advice. Her mother says that *'Becky certainly made a lot of progress in her language, but still didn't seem to have confidence in speaking to other people.'*

Her mother was pleased when Becky was reviewed two months after the group ended and it was found that her language skills had improved significantly (the South Tyneside Assessment of Syntactic Structures results indicated her language skills were now within normal limits).

However, there were still concerns around the clarity of her speech and her ability to communicate confidently. The South Tyneside Assessment of Phonology test showed Becky was having difficulties in using 's' and 'z' sounds and she was very reluctant to communicate for the fear of not being understood.

Her mother says that *'Becky would normally have been offered therapy in a group for these difficulties; however we were worried about her shyness and unwillingness to speak in a group and so we dared to ask if she could have individual therapy sessions and couldn't believe it when it happened.'*

Becky received an 8 week block of individual therapy and made excellent progress.



After the therapy, she was able to use the 's' and 'z' sounds consistently in her speech at the beginning, middle and ends of words. Her confidence to communicate was also greatly improved. Her mother said, *'It couldn't have worked better.'*

Outcome

- Becky can start at nursery school with clear intelligible speech that can be understood by adults and children and so her confidence has increased as a result.

Costs

- The initial cost of speech and language therapy in early years. This early intervention has prevented the need for longer term on-going support.

Key questions

- Are there local services in place to respond to parental and/or professional concerns about the language development of a particular child, aged two or under?
- Are parents involved in the development of these programmes and do they receive any required training?
- How well is your area meeting the standards of the Aiming High for Disabled Children's Core Offer with regard to assessment and support for children with SLCN?

Key Factor 3: Service co-ordination and strategic planning

Services should be effectively co-ordinated around an individual child and his/her family within educational settings; within areas; at regional level and at national levels (cf. core offer).

The following case studies illustrate:

- The need for service co-ordination to ensure that the best use is made of resources to provide the most effective support for the child, his/her family and the educational establishment.
- The need for a key worker to help parents co-ordinate the family's relationship with numerous professionals.
- The unsatisfactory variation in arrangements throughout England highlights the need for national policy to set out what should be a core entitlement. For example, speech and language therapists work within schools and directly with teachers and teaching assistants in some areas but not others. In some areas children over the age of 12 only receive input from a speech and language therapist if they are in a special school. In other areas children under the age of two cannot access the speech and language therapy service.
- The frustration experienced by parents over the lack of access to specialist assessments and support in a number of areas such as services for children with more complex needs, stammering, selective mutism, and the use of technology to help communication. The lack of commissioning specific expertise at a regional/sub regional level to resolve this issue.
- Haphazard and unco-ordinated services at area level with no evidence of a strategic response or plan. For example, speech and language services can be discontinued due to the therapist going on maternity leave or because a child changes schools. Families are distressed when there is lack of co-ordination around their child particularly when the service has been discontinued without sufficient explanation or reason and when they feel that the needs of their child are not understood.

The two case studies that follow illustrate lack of co-ordination around the child and successful co-ordination respectively. Case Study 5 demonstrates the lack of co-ordination over a seven year period.



Case study 5: Lena

Parents as key workers

Lena was referred to her local Speech and Language Therapy Service aged 3 years and 3 months but was discharged just before her fifth birthday even though her speech and language was described as 'still delayed.' Her parents were very unhappy and her mother says *'when I asked for a reason the therapist said that Lena had made 'satisfactory progress' and so all that was needed was some advice on further ways to help. We just had to go with that.'*

Lena struggled when she started school. Her parents became increasingly anxious and queried dyslexia which affects other family members. Initially the class teachers were reassuring. However in year 2 the school became concerned and asked her parents to refer her to the Speech and Language Therapy Service, explaining that it did not have the authority to make a referral. At the end of year 2, aged 7, the speech and language therapist confirmed the 'rate of progress was slow' but that 'therapy was not appropriate' and that encouragement at home and school would be sufficient. Lena's parents felt let down again.

Lena struggled in junior school despite the school trying different approaches to support her. Her mother felt she was forever visiting the school about the situation and Lena was becoming increasingly stressed and unhappy. The school described Lena as having general learning difficulties.

In year 4, the Learning Support Service supported Lena but she was falling further behind. In a year, she made only 6 months progress in reading and 8 months in spelling. The Learning Support Service's report said she was suitable for a statement.

The school requested a statement in year 5. The educational psychologist's report stated that Lena's verbal intelligence score was 75 but her non-verbal intelligence score was 112; her comprehension was poor; she could not re-tell stories or relate incidents well; and had a limited vocabulary. Despite this, he did not recommend a speech and language assessment.

Her parents could not believe it when the local authority did not issue a statement on the grounds that Lena's needs 'could be met by the school from their own resources'. By now, she was in year 6. In desperation, her parents lodged an appeal with the Special Educational Needs and Disability Tribunal, paid for an independent educational psychologist's assessment and sought advice from parents' advocacy

services. Lena's parents were advised to re-refer Lena to the Speech and Language Therapy Service and take her to the Children's Development Centre (CDC). The Tribunal ordered the local authority to make a statement of special educational needs.

A few weeks later, Lena was assessed at the CDC. The CDC highlighted Lena's severe language difficulties particularly in finding the right word to use and making sense of what was said to her. This impacted severely on her literacy skills and her ability to learn in all areas of the curriculum. **Lena was on the point of transfer to secondary school and she was still functionally illiterate, while her parents were emotionally drained.**

As a result of assessment, Lena's statement of special educational needs specified 13 hours of support per week, in her secondary school, provided jointly by the local authority and health trust in the form of speech and language therapy input. Her parents state: *'getting the diagnosis finally made it much easier for us to work with the school and to understand her problems, but we still had to work closely with the school to ensure she got all the support she was entitled to.'*

Outcomes

- It took two and a half years with the support in secondary school to make a noticeable improvement.
- At the end of Key Stage 4, Lena gained: 5 GCSEs, grades C – G, and 6 other qualifications

Costs

- In secondary school 13 hours a week (combination of teaching assistant/speech and language therapist's time)
- Parents had to pay for independent assessments
- Huge emotional costs to the family and their relationships

Parents' comments:

'We cannot believe the lack of resources to look at the whole picture. When we knew the extent of Lena's SLCN, we asked why she was discharged so often from speech therapy and we were told 'insufficient funding.' The system seems to be just about fire-fighting. You don't get anywhere if we as parents don't push children's progress, or lack of it, and it should be properly monitored. It shouldn't be down to the parents to do it.'

Case study 6: Josh

Co-ordination working well

All seemed to be going well for Josh. He said his first word at 18 months. At two years of age, all his development in terms of sitting, crawling, walking etc were within normal limits, while he had no significant medical history (a few ear infections). His hearing was within normal limits. However, around three and a half years, he had only a few single words and signs and so was referred to his local Speech and Language Therapy Service by the health visitor, who was concerned about his small number of spoken words, even though there were no other concerns around his development.

A month later, Josh had an initial speech and language assessment, which showed that his comprehension was within normal limits but his ability to express his thoughts was very much delayed. At this point, much to his parents' concern, the practitioners at Josh's pre-school reported that they had observed some inappropriate behaviour from Josh during playtime and put it down to his difficulties initiating and joining in with play as he could not get his message across.

Josh's mother was delighted that shortly after his assessment, he was offered a block of group therapy sessions to which she and his pre-school key worker were also invited. The sessions focused on early language skills and Josh's mother says that 'we learned a lot from watching the therapist play with Josh and it gave us both ideas to try with him to get him talking more.' The sessions also provided direct therapy for Josh and allowed the therapist to gather more information about Josh's communication needs for identifying future targets and interventions.

In the meantime, two members of the pre-school staff participated in ELKLAN training (specific courses of up to 10 two hour sessions to train staff in becoming more effective in developing children's speech, language and communication skills) which allowed them to improve the communicative environment of the Josh's pre-school, not only for Josh, but for all the children who attended.

A speech and language therapist visited the preschool to deliver Makaton signing training to all the staff and to Josh's parents. In fact the staff now use signing with all the children in the pre-school. A Common Assessment Framework (CAF) meeting was set up so that professionals were able to liaise on the future needs of Josh and his family.

As a result, Josh was assessed by:

- An educational psychologist who is currently reviewing Josh's progress on a regular basis

- By a specialist doctor and a consultant paediatrician for a general developmental assessment

Recently, a Transition Inclusion Support Meeting (TISM) has been arranged by the early years inclusion advisor to ensure appropriate support is in place when Josh starts at mainstream school.

Outcomes

- Josh's spoken vocabulary has increased, albeit at a slower rate than expected, but he is using signs, both Makaton signs and made-up signs, effectively. Importantly, this has reduced frustration for both Josh and his family.
- The training delivered to pre-school staff increased their confidence in both supporting Josh and other children with communication needs. In addition, it has increased the likelihood that other children with communication needs will be identified by the pre-school staff and referred on, as appropriate.

Costs

- Training given by speech, language and communication therapists:
 - ELKLAN course for pre-school staff (cost of course and any necessary staff replacement costs)
 - Makaton (pre-school) 2 hours
 - Makaton (school in future) 2 hours
- Liaison with other professionals e.g. CAF reviews (2 hours); future TISM (2 hours)
- Extra teaching assistant support in school (2 hours per week)

Key questions

- Is there a joint local authority/Primary Care Trust strategic plan or approach in place for meeting the needs of children with SLCN in your local area? (If not, the National Literacy Trust *Guidance Document for local areas in addressing a strategic approach to speech, language and communication in the early years* is a useful starting point).
- Is there a regional approach to commissioning services to ensure access to specialisms and ensure low incidence needs can be met?
- Are there arrangements in place for key workers for families that need them?



Key Factor 4: Strategic funding plan

There should be a strategic funding plan at area level and it should be available to professionals and parents.

To be effective the strategic plan needs to be underpinned by a strategic approach to funding. Often the inequalities in provision of services and resources are due to the existence of different funding sources (statutory, charitable and private). Consequently, much valuable time is spent by professionals and parents chasing sources of funding or arguing about priorities for funding.

A speech and language therapist writes:

'Communication aids are vital in giving children a way of expressing themselves. Because our speech and language therapy team has very little funding to buy communication aids that we can loan to children, we have to rely on borrowing them from companies. There is usually a wait of a few months and then we can only borrow devices for two weeks, which imposes huge time pressure in terms of having to support the child with the communication aid and make a decision as to whether it is suitable or not. When we do place a bid, we struggle to receive funding to buy the child a device and even if successful have to wait a few months, during which time the child is without the communication aid required.'

A clearly costed area strategic plan (with 'pooled' human resources and ideally 'pooled' budgets), which reflected a national 'core offer', would at least offer transparency and perhaps reduce the instances of a recurring parental feeling that they 'have to battle to access resources.' Again the national core offer seems vital in removing the unacceptable variation in provision between areas.

A parent provides a very sobering perspective on funding:

'The bottom line is not financial – it is the difference between the child being enabled to interact, communicate and express himself, and being unable to do this which is the most fundamental of human activities and rights.'

Case Study 7 describes how a child's need for communication was assessed but 20 months later he is still waiting for funding to buy the appropriate device. Case Study 9 describes how a mother turned to a voluntary organisation when she felt local services were not meeting the needs of her son.

Case study 7: Sam

Waiting for funding

Sam has severe verbal dyspraxia (i.e. difficulty in making and co-ordinating the precise movements required for the production of clear speech). He was referred to the local Speech and Language Therapy Service when he was two years old.

Sam's mother says: 'I felt he understood what was being said as well as my other children had done at his age, but he just didn't seem to want to speak and any words that he did use were very difficult to make out. I was worried about the assessment as I knew Sam would not really want to do anything.'

Sam was reluctant to participate at the assessment and in the therapy sessions that followed. His progress was slow although ongoing assessment showed that his understanding of language was appropriate for his age.

Sam's indistinct speech made him unwilling to interact with other people and this was a huge concern to his family. The augmentative and alternative communication (AAC) specialist speech and language therapist assessed Sam about two years after his initial assessment. She identified that Sam would most likely benefit from a communication aid. Initially a symbol board was tried. It was old and unreliable and consequently Sam was reluctant to use it. A higher tech customised talking computer with very specialist software was then loaned to Sam from the company Dynavox. Sam liked this communication aid and demonstrated that he was capable of using it to convey single word messages.

Unfortunately, the communication aid on loan did not quite suit Sam and so a different aid was tried. The local Speech and Language Therapy Service had only a small range of devices available so once again a loan was organised from a company, Liberator. There was a period of several months to wait before a loan device was available and when it finally arrived, Sam was ill and unable to participate in the two week trial. Sam then had to wait another two months before he could borrow the communication aid again. This device was perfect for Sam and he really enjoyed using it to communicate; however, there was no funding available to make the purchase.

Sam attends a mainstream school with a full time teaching assistant as he requires support to access most areas of the curriculum due to the severity of his communication difficulties, but no high tech communication aid.

Sam's mother says 'Sam was so happy when he tried the machine and could speak

to us and now he is having to wait until somebody finds some money to buy it – 20 months is a long time in his life.'

Outcome

- A bid for funding to buy the device was made to the Primary Care Trust and the Education Service 7 months ago, but sadly there is not currently any funding available for communication aids and so Sam is still waiting. It is now 20 months since his need for a communication aid was first assessed.

Costs

- The devices loaned from Dynavox and Liberator were free of charge
- The cost of the communication aid now required for Sam is £4593
- Training in the use of the new aid will be provided free of charge by the firm supplying it
- Full-time teaching assistant support in mainstream school
- Sam is receiving ongoing support from the Speech and Language Therapy Service, funded by the Primary Care Trust and has received specialist speech and language therapy input for each area of need - he has one therapist to help with his speech development and one speech and language therapist to help with his AAC needs

Case study 8: Kevin

A charity filling the funding gap

Kevin is now 4 years old and has a profound hearing loss. His mother was concerned about his hearing from an early stage but continually had to request further hearing tests as *'nobody was listening to me and I knew something was wrong with his hearing.'* Kevin was not screened at birth. Distraction tests (very basic tests to assess hearing) at 9 months were inconclusive, however, a much more sophisticated test (an auditory brainstem response test) used at 17 months showed that he was profoundly deaf.

Initially Kevin wore digital hearing aids but after 12 months he showed no benefit from them and so he received cochlear implants at 28 months. His mother reports:

'I thought once he got the implants his hearing would be alright, but it didn't seem to be much better and nobody seemed to be able to help me or Kevin. A teacher of the deaf came sometimes but she didn't really know how to help us as she was new and the speech and language therapist was on maternity leave. If it hadn't been for

my Mum I don't know what I would have done.'

Kevin's mother became quite desperate and it was at this point that she heard about the Auditory Verbal (AV) programme which is a parent-centred approach with the aim of enabling deaf children to talk through listening. She joined the programme as did Kevin's grandmother who played a significant role in the family.

When Kevin started the AV programme at two years and 9 months, it was found that he was able to hear across the frequencies needed to understand speech but had not learned how to make sense of the sound. He was using one single word and understanding two words when spoken sequentially.

Outcomes

- Regular AV Therapy sessions have increased the rate of his language development. He is beginning to close the language gap with hearing children
- AV Therapy has put the parent at the centre, teaching his mother and grandmother the skills they need to further Kevin's listening and spoken language development at home, as part of everyday life
- Kevin's mother, who had previously had a poor record of engagement with other agencies, makes a four hour round trip to AV^{UK} fortnightly to access the training sessions
- The AV therapist has liaised with Kevin's local team, including the sharing of language goals and assessment results. This is also helping to rebuild the relationship between Kevin's mother and the local team

Costs

- AV^{UK} is a charity and they have met the service and travel costs, due to the family's low income
- AV^{UK} has also borne the costs of liaison with Kevin's local Speech and Language Therapy Service (staff time; travel expenses for meetings with local team)

Key question

- Is there a clearly costed strategic plan in place in your area for delivering effective speech, language and communication services?

Key Factor 5: Clear outcomes and regular/ongoing reviews

There should be a clear focus on outcomes with regular reviews of needs and interventions to reflect the changing needs of the child and to ensure that they are making adequate/satisfactory progress.

Within the case studies there are some good examples of objective setting; evaluations of input and ongoing monitoring, but this is not universal.

There are examples where services have discontinued therapy simply because the programme had ended. In other cases; the child became too old for a specific group, but still had needs; however, no other intervention was suggested. Interventions are ceased or significant reductions in therapy are often made when children transfer from nursery provision to mainstream primary schools; from primary schools to secondary schools and from special school to mainstream schools. In all these different circumstances a focus on clear outcomes with regular reviews to ensure that progress was being made, would highlight the continuing needs of the individual child rather than the needs of the systems.

Case Study 5 (Lena) in Key Factor 3 is an example of where there was no ongoing monitoring after Lena's therapy was discontinued when she was five years old. Also there was no evidence of clear objectives having been set and shared with her parents.

Case Study 9, on the other hand, shows the use of regular monitoring and reviews, leading to other interventions as required.

Case study 9: Sandeep

Meeting changing needs through regular reviews

Sandeep's parents say:

'We only ever had one real worry about Sandeep and that was just before his second birthday. Sandeep had always had a lot of colds and chest infections, but this time it developed into pneumonia and a collapsed lung. That was bad. Apart from that he has always seemed quite happy, but quiet. We had noticed he was not saying very many words, but were not overly worried until we realised his younger brother had more words and was putting them together. We ignored it for a time and then went to our doctor for help.'

Sandeep had an initial speech and language assessment when he was two years and 8 months. The therapist also found him to be a very quiet, shy child, who was reluctant to separate from his mother during the assessment. No words or

vocalisations were heard in the clinic and he was not cooperative for formal assessment.

Input

Sandeep attended a block of one-to-one therapy sessions from two years 9 months to two years 11 months. His single word vocabulary increased and, much to his parents' delight, the occasional two word phrases were emerging. At a review meeting, Sandeep was still noted to be a very reluctant communicator, taking time to settle at each session in the clinic.

Sandeep then attended an Early Language Group aged from three years 4 months to three years 6 months to focus on developing his spoken language and understanding of language; and confidence. The review at the end of this intervention reported that Sandeep remained at the two word level, meaning that he never tried to put more than two words together at any one time. A standardised test showed that his understanding of language was at the first percentile, indicating that 99% of his age group would have scored better than him. After this review, a report was circulated to the other professionals highlighting concerns and areas for further development. His parents were now very worried about his lack of progress and the fact that his brother's language was now so much better than that of Sandeep.

It was decided that Sandeep should be prioritised for a further one-to-one block of therapy, but he continued to have very slow language development and a delay in both spoken language and in his understanding of language. He also had difficulties with the use of language in social situations – he just did not want to speak until he felt very sure about new people and new situations. His parents were concerned that people outside the family had difficulty in understanding what Sandeep was saying and it became more apparent that his emerging speech was characterised by speech production difficulties. Therefore, his therapy began to target speech sounds.

It took several sessions for Sandeep to allow any oral examination. When he ultimately relaxed sufficiently to permit an examination, a malformation in the back of his mouth was identified and so a referral was immediately made to the specialist speech and language therapist and Ear, Nose and Throat Team at the local hospital. It turned out that Sandeep had had a history of early feeding difficulties which his mother had not thought to mention previously as other professionals had previously dismissed this information.

Sandeep's family were very worried about going for the specialist assessment and so Sandeep's local therapist went along too. Sandeep's mother was pleased about this as she *'felt able to ask questions which I might not have done if I had been on my own.'*

The specialist team found that he had a chromosomal disorder, which could cause varying degrees of learning difficulties.

Sandeep continued to be followed up by the specialist team and also had input from the community Speech and Language Therapy Team. His therapist completed advice for inclusion in a statutory assessment of his special educational needs and recommended school based speech and language support. Sandeep had a three month block of therapy targeting more advanced language concepts and then he was transferred to school based therapy.

Outcomes

- Over a period of three years 7 months, Sandeep received a total of 5 blocks of community therapy
- He attends mainstream primary school, with teaching assistant support. His language remains delayed but in line with his cognitive skills
- His speech is now intelligible
- A formal language assessment - The Clinical Evaluations of Language (CELF) Pre-school was used when Sandeep was just under 6 years old. In a few sections Sandeep scored very highly; in others at the low end but several sections hovered around the low average to above average range. He was particularly weak in understanding the more abstract language concepts and the use of grammatical markers in words. These areas were targeted in his next block of therapy
- Current input from the school based Speech and Language Therapy Service is twice a term for monitoring, target setting, plus training and advice for parents and school staff

Costs

- 17 hours for a teaching assistant support in mainstream school
- Provision of ongoing therapy and language support for child over a period of 3 years and 7 months
- Support for the parents during this time
- Referral to other agencies for the malformation in the back of his mouth

Key questions

- Are clear objectives set for children requiring interventions for their SLCN?
- Is there ongoing monitoring and review of the progress of children on speech, language and communication programmes?



Key Factor 6: Transitions

Children and young people should not experience any interruption of, loss or reduction in speech, language and communication services at any transition point if current assessments demonstrate such input needs to continue.

The case studies highlight two major issues.

First, the reduction in therapy support because the child has reached a certain age, for example, some areas do not provide speech, language and communication support to secondary age children unless they attend a special school. In others support is reduced as the child transfers from the Early Years Team to mainstream primary education where community based Speech and Language Therapy Services take over responsibility. In one case study a child received speech and language input from the age of 18 months as she had had no speech, no babble and minimal sounds. A total communication approach (using not only oral language but also gestures, sign language gestures, facial expressions etc) was adopted and she received direct therapy on a monthly or fortnightly basis as required during her early years. When she transferred to mainstream school, she still had significant needs, but the local therapy team could only provide advice and some limited training for the teaching assistant on a half termly basis. The concern here is that such reductions are due to the 'systems' that are in place rather than being focused on the needs of the child.

The second issue at transition is the need to have appropriate transition processes in place to facilitate the move between two establishments or two teams as this will allow time for appropriate preparations to be made. For example, in an extreme case, a child who uses signing, gesture, symbol boards, Dynavox VOCA (voice output communication aid – an advanced talking computer) to communicate must be received by staff who know how to work with these systems. Unfortunately there are examples where staff members have not known about such communication aids and so the progress of the child has been put in jeopardy.

Case Study 10 cites the example of a young person transferring from children's services to adult services, which is usually an anxious time and can be an extremely traumatic time if appropriate preparations are not made in advance. Case Study 11 describes the simple steps that were taken to facilitate the smooth transition of a boy who stammered into his secondary school.

Case study 10: Susan

Lack of preparation for life beyond school

Susan has a profound learning disability and a hearing impairment that is not corrected as she will not wear her hearing aids. Susan used signing throughout school. When Susan moved to adult day services a few staff could sign, but when she moved into a residential home, no staff were able to sign. Despite a reassurance that staff would be trained this did not happen.

To the distress of her parents, Susan's behaviour deteriorated significantly, as she became more and more frustrated by her inability to communicate. Her parents could not understand why this had happened as it was clear Susan used signing to communicate. Her mother says, *'It was awful having to watch Susan being locked into a world of silence with aggression being the only way she could get noticed.'*

Susan was assessed by a speech and language therapist who not surprisingly concluded that she needed not only objects and photographs but also sign supported speech to facilitate her comprehension and expression throughout the day.

Her parents felt totally helpless when, it was then stated that there were no facilities at that time to support the staff team to learn a sign supported system. Susan's behaviour continued to deteriorate for several more months. The residential organisation then agreed to train one of their staff as a Signalong (a flexible sign supporting system for use in environments where English is the main language) coordinator and that all staff could attend the foundation training.

Thereafter, the manager of Susan's residential home committed funds to the purchase of an extensive Signalong vocabulary and, having seen the success of its implementation with Susan, has now made Signalong training a priority for new staff to attend.

Outcomes

- Incidents of aggression have significantly reduced as staff communicate more meaningfully using objects, photographs and Signalong
- Staff at Susan's day service have also received Signalong training and they are now reporting that incidents of aggression have noticeably decreased there too

Costs

- Training of a Signalong co-ordinator who could then instruct the other staff – 5 day course costing approximately £900 (with ongoing subscription fees, starting

in year 2 of £70 and requirement to attend a conference every other year at a cost of £80). Costs at current levels from website. (The co-ordinator would be able to provide chargeable courses to other establishments and groups and so this would help to defray initial outlay.)

Susan's mother comments:

'Our daughter has been taught at a school with total communication for deaf and special needs children, it came as quite a shock that her residential home didn't understand the importance of following this up.'

Case study 11: John

It can be so very simple... sometimes!

John has a stammer, a history of speech sound difficulties and mild language difficulties. He was looking forward to transferring to his new secondary school.

His previous speech and language difficulties had largely been resolved through speech and language therapy both in the clinic and at school, but he still required time to process language and to articulate his sentences carefully. He was fairly confident about the move to secondary school; however his mother was getting really worried, saying:

'John has done really well with his speech therapy but he always seems to stammer when he goes to new places or meets new people and his new teachers will maybe just get cross with him and this will make it all the worse.'

The therapist comments that *'parents are often more worried than their child at times of transition, and knowing that someone is advocating on behalf of their child can help allay their fears and, if parental fears are allayed, the child is also likely to feel more relaxed about a new situation.'*

Therefore, prior to transfer, the speech and language therapist gave John 4 credit card sized cards with written messages to explain that he sometimes stammers and asking the teacher to help in one of 4 ways. For example, one card said: *'I sometimes stammer so please give me time to speak'*. The therapist put her name, contact details and the NHS logo on the back of the cards.

The therapist also wrote to the special needs co-ordinator (SENCo) at the receiving secondary school in order to explain John's difficulties and to request that staff

give him time to speak. She also enclosed copies of the cards so that staff would recognise them as bona fide if John used them. The SENCo subsequently ensured that this letter was copied to all staff who would come into contact with John.

Outcomes

- John wrote the following to his speech and language therapist after starting at secondary school: *'I have the cards in my pocket and occasionally I have to use one. I feel very confident having them on me it makes me feel happy knowing they are there for me'*
- At a later review appointment, John reported that teachers did give him time to speak and that he finds this helpful. He always shows one of his message cards to supply teachers so they are aware.
- On a self rating scale, John rated 21/22 speaking situations as 'very easy' or 'easy' and this included school situations such as answering a question in class or reading aloud (which are often difficult for children who stammer). He was even quite keen to speak in a presentation his form will give to the whole year group.
- His mother was delighted and says, *'I cannot fault the school in how they have managed John's move to secondary school. I am totally convinced the (supportive) attitude of the staff was helped by the therapist's letter to the SENCo and the message cards that John carry – they seem to act like a kind of security blanket for him.'*

Costs

- Speech and language therapist time to write the letter and make the message cards.

Key questions

- Are there clear criteria in place for the reduction or cessation of speech and language support? Are these linked to the child achieving objectives and being able to make satisfactory progress without support?
- Are there processes in place for the critical transition points in a child's life?



Key Factor 7: Provision of information

The family of the child with SLCN should be provided with all the information on that need as well as information on the services and resources that are available locally and regionally, if required.

The collection of case studies indicates that:

- There is an element of chance in parents accessing the right service and/or the right person within that service
- There is a lack of information about the different resources and approaches that can be used and so it is difficult for parents to enter into meaningful discussions about the planned intervention for their child
- Few parents seem to access the very informative Early Support Booklet, Information for parents – Speech and Language Difficulties, by Every Child Matters
- Not all parents are given information about services and voluntary organisations that are available locally, and any specialist services and/or resources that are available at a county or regional level
- Not all parents have their child's needs explained to them and the options available for appropriate interventions

Case study 12 describes how parents had to take the initiative in developing the right sort of communication aids for their son. Case study 13 tells the story of a mother's quest for information and help for her son.

Case study 12: Ravi

It was all due to parental determination/finding our own way

Ravi is now 12 years old and has severe athetoid cerebral palsy (control of the muscles is disrupted by spontaneous and unwanted movements) affecting all his motor functions, including and especially control of his lips, tongue, face and jaw as well as his hands. He can weight bear and step but he is very unsteady and so does not undertake any unaided walking. He uses a power chair.

His fine motor skills are very poor and so he cannot feed himself or manipulate objects. Therefore, access to computers is very difficult for him and so he needs a range of specialist switches and keyboards.

Ravi has no speech, but he makes a lot of involuntary sound. He has no obvious cognitive impairment but he is quite immature due to his physical and linguistic limitations.

Ravi's parents say, 'We knew from early on in Ravi's life that we would have to spend a lot of time looking after him – he hardly slept for the first 6 months and didn't stop crying for 4 months - but we didn't realise that so many of the other things he needed would also be left up to us to sort out. Right at the beginning the social worker made it clear that his physical and speech needs weren't up to her and didn't tell us who to go to for help. Eventually we got sent to the Child Development Centre and the speech and language therapist there didn't seem to understand about children like Ravi who have no speech.'

When Ravi was about 15 months old, his parents heard about the Bobath Centre in London and asked for a referral as they were living in a rural area with no expertise in athetoid cerebral palsy. This was agreed and funded by the Primary Care Trust. The assessment that followed identified his communication frustrations and so Ravi was introduced to some symbols and choice making tactics, the start of augmentative and alternative communication (AAC). Ravi also had swallowing difficulties and so a special drink thickener was advised but this had to be overseen by a speech and language therapist. This initial visit was at the beginning of the summer holidays and Ravi's mother continues, *'and of course with our luck when we got home we found the therapist didn't work during the summer holidays and so once again we had nobody to help us. However, our doctor found us a community therapist who just happened to have knowledge of cerebral palsy.'*

When Ravi was two and a half years old, he received his first VOCA (voice output communication aid) and at the same time he began using symbols in a book (which is described as low tech), while his mother introduced him to signing as, by chance, she had a Stage 1 qualification in British Sign Language. Ravi's ability to sign is severely impeded by his physical disability but it is useful, in a very limited way, with people who know him well. In fact his ability to use any AAC device or book is similarly hindered as he cannot point well due to the uncontrolled movement in his arms and so he often uses an adult finger as a sort of counter-weighted pointer which speeds his access up a lot.

Ravi's access to aids remains problematic and getting solutions to this, according to his parents, does not seem to be anyone's particular responsibility. Good occupational therapy input is vital for Ravi's disability, but he had no paediatric occupational therapy until he was about 7 as there was no occupational therapist in the area. Ultimately, after requests from his parents, the local authority funded one in order to support

the school. When the Primary Care Trust later appointed a paediatric occupational therapist, she did not have the specialist knowledge to support Ravi.

Consequently, Ravi's first VOCA was not well used because of these access issues. His current one has a very specialised keyguard on it with holes spaced in a very exact position and with a very precise thickness of perspex. The prototype was made by his father and a better version was eventually made by a local medical physics technician, but there is usually a waiting time for his services of about 6 months – a long wait for such an essential aid.

Again it was Ravi's parents who adapted and experimented with a range of layouts/packages before customising a particular product in a way that best met his needs. This work took months and years and is still ongoing. Ravi's mother says *'Ravi's current speech and language therapist is good and could do this work, but she has no time to do so as she has a large caseload.'*

Similarly Ravi's low tech communication book, which has been much admired by others, was totally devised by his parents, in terms of layout and using a range of spoken word frequency lists and Widgit Literacy Symbols.

Outcomes

- Ravi does not have behavioural problems and he is able to communicate most of what he wants, although more abstract ideas can take a bit of working out
- He has done well at mainstream school and was above average in maths and science in the Key Stage SATs at the end of his time in primary school, achieving level 5 in both (average level is 4). He was slightly below average in literacy

Costs

- First VOCA cost approximately £4500; second one from CAP (Communications Aid Project from 2002-06, government funded) approximately £5000, wheelchair mount for communication aid - £300
- Speech and language therapy time
- Specialist Centre – approx £2500 per visit (2 week block) 7 visits
- The family's time and effort – £1000s (*'but of course in reality free'* – parent's comment)
- Support package at school: first year at secondary £26k, but it is anticipated the second year will be less due to fewer training needs

Parents' comments:

'Well we have actually learned a great deal about all sorts of things! But actually much of it should not have been down to us. So what we have, unfortunately,

learned is that if we do not do it or push for it, it will simply not happen, or not happen in any meaningful way!’

‘There is no doubt that he would not be in mainstream school at all or be doing nearly so well at school if firstly, we, as his parents, had not fought every step of the way, from tribunal at age two, to ensuring a comprehensive and adequately provisioned statement well in advance of him starting secondary school and secondly if he had not begun to have his communication needs met before age two and before behavioural and other frustration issues has a chance to develop.’

Case study 13: Tom

‘By chance...’

Tom is currently 5 years old. His mother states: *‘I became worried about Tom when he was still a baby. He did not sit up until 10 months, and never crawled. I asked the health visitor about this but she told me not to worry. By the age of 14 or 15 months, he wasn’t really talking and I knew another child around the same age who had lots of words. This didn’t seem right. Tom just said ‘mama’ and ‘dada’. He only had one other word - ‘door’- which he used for everything! By the time he reached 18 months, I was really worried and felt I had to do something, but I didn’t know what.’*

By chance, Tom’s grandmother heard about a study into late-talking babies at a university and so his mother contacted the researchers and they assessed Tom who was now 20 months old. Tom’s speech and language were too poor for the study and so his mother was advised to seek speech and language therapy.

Tom’s doctor made a referral to the Speech and Language Therapy Service, but there was a 6 month wait. He was now two years old and his mother had not been offered any advice on how to help him. Finally Tom saw a speech and language therapist and he was given a place at the weekly language playgroup at the Child Development Centre (CDC), which he attended for about 6 months in all, by which time he was three years old and too old for it. The speech and language therapist at CDC felt that he had both verbal and motor dyspraxia (an impairment in the organisation of movement) and that his co-ordination was poor for his age.

Around this time, his mother then heard about another research study at a university, which was looking at the links between speech and language impairment and dyslexia. Tom is now part of this study and is assessed regularly every 9 months or so. These assessments are indicating that Tom has a significant speech and language delay

After the language group at the CDC, Tom started nursery and had to return to community speech and language therapy. There was none available at first because there was no therapist in post. Eventually one was employed to work just one day a week and when his mother heard this she spent a considerable time on the phone to make sure that Tom was included in the therapist's schedule.

When Tom reached three and a half, his parents realised they needed to start looking at schools and they had also heard about a Language Unit. However, before they could visit the Language Unit, they were required to refer Tom to an educational psychologist. Tom's speech and language therapist contacted the local authority but his mother heard nothing 'for ages' and kept e-mailing to ask what was happening. She just wanted some information and action. Eventually, the educational psychologist came to see Tom and she did a number of assessments. He was just under 4 years of age at this stage, but scored in the 18-24 months range in several of the sub-sections, and 12-18 months in the speech and language sections. Subsequently, the educational psychologist issued her report in which she agreed that the Language Unit was a potentially suitable placement and that the parents could visit it. The parents then visited the Language Unit and were impressed.

In the meantime, the SENCO at the nursery heard about an Early Support course for parents and mentioned it to Tom's mother. After some discussion with the course leader, it was agreed that Tom's mother could attend, although the educational psychologist had some reservations about its suitability. In the event, Tom's mother found the course really helpful. She learned about how systems worked locally and she also heard about Afasic for the first time and has used the helpline several times to access information.

Outcome

- Tom has now started in the Language Unit. His most recent speech and language therapy report indicates that his sound production and receptive language are both improving, while his sentences are getting longer. There are no objective test results currently available.

Costs

- Various assessments and speech therapy in the community
- 6 months attendance at the language group at CDC. Held weekly for one and a half hours with 7 children, a speech and language therapist, a pre-school teacher and up to three voluntary assistants
- Nursery received funding for a support assistant
- Currently attends a Language Unit 4 days per week (approximately £8000 per year). No support when in mainstream school on the fifth day each week

Parents' comments:

'We cannot believe the length of time everything took and how little information we could get. It was getting on to the Early Years course, despite some of the professionals trying to stop us from going, that gave us the information we needed.'

'We had to do lots of chasing. If you don't ask, you don't get!!! Not all parents are able to do this.'

Key questions

- How well is your area meeting the standards of the Aiming High for Disabled Children's Core Offer with regard to information for parents?
- Do parents of children with SLCN routinely receive the Early Support Information Booklet on Speech and Language Difficulties by Every Child Matters or any other similar information booklet?
- Do parents receive information on the speech, language and communication services and resources that are available at local, regional and national levels including support from voluntary organisations?



Key Factor 8: Access to specialist support

Local speech, language and communication services should ensure they cover the range of specialist knowledge that could be required or, if that is not viable, that they have agreements in place to access any specialist knowledge they do not have.

There is an enormous range of speech, language and communication difficulties. Language delay, language disorder, speech problems, stammering, selective mutism, semantic pragmatic difficulties, oro-motor dyspraxia are some of the needs represented in the 80 case studies. In addition there are specific groups of children with particular needs such as cerebral palsy, hearing impairment, Down's syndrome, autism and complex and multiple special educational needs. All these needs and groups will require different levels of knowledge and different interventions.

It is unlikely that all the knowledge required to meet these different needs will be located in one person or even in one team if it is very small.

However, having access to the right knowledge and expertise is vital for the child with that particular need to ensure she/he develop effective communication and makes progress. Therefore local teams have to ensure that they cover the majority of specialisms by identifying individual members to take on specialist roles and have contingency plans in place to access specialist input for those areas not covered in their own area team.

Case Study 14 describes a family's journey in finding the right specialist for an assessment and then in ensuring the appropriate input to meet the identified needs of their daughter. Case Study 15 shows how a specialism was being developed in a team and the use of a second opinion.

Case study 14: Sasha

Finding the right specialists

Sasha's mother was sure there was something wrong with her baby shortly after the birth. Her early concerns centred on her baby's tongue which seemed large and then on her failure to meet most developmental milestones. When Sasha failed to make sounds or put anything in her mouth, her mother made a referral to the Speech and Language Therapy Services.

At about 12 months, Sasha saw a community paediatrician who described her as

'developmentally delayed' and referred her to a number of other specialists; neurology, Ear, Nose and Throat Team, geneticist, but none of them came up with anything conclusive. At this age Sasha's tongue tended to hang out of her mouth and dribble ran down her chin.

Sasha's mother persisted with the Speech and Language Therapy Service and at about 18 months Sasha was given in her mother's view a '*totally inappropriate*' assessment. Sasha had two blocks of therapy, but this did not address her needs and merely confirmed that she had severe problems.

Because of her tongue and problems swallowing she was referred to a speech and language therapist who specialised in difficulties in swallowing; however this therapist quickly ruled out problems associated with swallowing. The Speech and Language Therapy Department then suspected oro-motor dyspraxia which affects the ability to make and co-ordinate the movement of the lips, tongue, larynx etc.

When Sasha was around two and a half years old, she was assessed at the Nuffield Centre who confirmed classic, severe oro-motor dyspraxia. She did not have an over-large tongue, she just never knew where it was. The Nuffield Centre recommended weekly speech and language therapy. Sasha's parents shared the report with their local speech and language service, but the most they could offer was a monthly session.

Sasha started playgroup with a statement of special educational needs, which provided for a 'non specialist' support worker at playgroup but only stipulated advice from all the therapy services. Her parents were particularly concerned and so paid for a speech and language therapist to provide weekly therapy. The specialist therapy worked well and by the time Sasha started school, she could keep her tongue in her mouth, no longer dribbled and could say one or two understandable words.

When Sasha was 5, she went to the local language unit and her parents were delighted. However, Sasha's progress was slow and parents were worried about hints coming from the unit staff that Sasha might be in the wrong placement. After two years her progress stalled completely affecting her behaviour. The speech and language therapist attached to the unit went on maternity leave and was not replaced - the children in the unit received no therapy at all for about a year. The unit staff now voiced their concerns about Sasha's placement in the unit more vocally and her parents had to fight to prevent Sasha being returned to a mainstream school with support. In fact, they were even successful in securing an increased amount of direct speech and language therapy time for her in the unit.

Outcomes

- As Sasha approaches the end of primary school, she can articulate a good range of single sounds and can say most simple words clearly. However, the clarity still tends to reduce with longer words and phrases. She has poor knowledge of speech sounds and both her spoken language and her understanding of language are severely impaired. Most of her scores are around the first or second percentile rank, meaning that 98-99% of her age group would score higher.

Costs

- Support worker at playgroup
- Language unit placement, approx £10,000 per year, for 7 years
- Various assessments and therapy interventions during the pre-school years
- Parents have paid for many private specialist assessments and specialist speech and language therapy time

Parents' comments:

'Particularly as health professionals ourselves, we are struck by how your usual expectation, that if you have a health problem everything will be done to help you, just doesn't apply to children like our little girl. On the contrary, the authorities' sole concern seems to be to get away with spending as little as possible. They don't seem interested in the child as an individual. We could afford to fill in the gaps in the system, but if we had not been able to do this...'

Case study 15: William

A second opinion

When William was just over three years old, he was referred to the local clinic due to concerns about his language development and a stammer. There was no family history of speech, language or communication problems. He was seen in a community clinic by a generalist speech and language therapist, but, fortunately, one who had just been successful in acquiring some specialist knowledge allowing her to focus on working with stammering children. William had an initial assessment that showed much strength. He had appropriate social interaction skills; appropriate use of language for commenting, describing, requesting and answering questions; appropriate basic vocabulary with language developing at the 3-4 word level; and appropriate phonology (knowledge of sounds) for his age.

The assessment also revealed some needs. He had a tendency to 'flit' between activities,

requiring guidance back to task. He also had difficulty in initiating what he wanted to say and he had a stammer which tended to fluctuate. No specific level of stammering was taken at this point, but the speech and language therapist identified prolongations and repetitions of sounds. At times William showed some frustration but always completed what he wanted to say. It was also noted that at times the way the family interacted with William was not conducive to helping fluency. His mother spoke quickly and asked quite a lot of questions, while his sister (who was 4 years older) sometimes laughed at him and sometimes interrupted him.

The first package of care followed a parent child interaction approach where William's parents identified strategies that helped him to become more fluent and then introduced these strategies into his everyday routines. This input was conducted by a generalist therapist. Initially William showed a good improvement and his parents requested a three month break as fluency was improved; however, they contacted the clinic after two months as William's stammer had become severe. This time a second opinion was requested by the local therapist and was given by a speech and language therapist who specialised in stammering. William was observed to have a severe stammer consisting of a, within clinic, measure of 52% stammered syllables with the stammer consisting of blocks, prolongations, revisions of words, facial tension and loss of eye contact. William had started school and was upset about his speech, especially as other children had started to comment on it.

A more direct approach to working on William's stammer was indicated and so the Lidcombe programme was initiated. After 8 sessions the stammering had reduced to 7.6% stammered syllables. William and his parents became less concerned about the stammer and unfortunately they either cancelled or did not attend the therapy sessions over the following 4 months. William then changed classes and his stammer had increased, manifesting itself this time as silent blocks with facial and body tensions. William was very frustrated. His parents then contacted the speech and language therapy service again.

This pattern of requesting input and varying attendance rates at clinic appointments continued as William's stammer fluctuated. As this fluctuation was often linked to issues in school, the speech and language therapist discussed the issue with the special education needs co-ordinator at the school. A teaching assistant was identified and support time allocated (three x 10 mins a week). Initially, the specialist therapist demonstrated and trained the teaching assistant in the Lidcombe approach and as time progressed introduced other strategies.

William was also experiencing some bullying and teasing and so a 'whole' class

approach was taken using a speaking circle where children offer positive feedback to each other as they practice speaking in front of the class. Over time, William has continued to have support from a teaching assistant three times per week for 15 minutes. His speech and language therapy input is now 'light touch' – generally on a half termly basis in order to set targets.

Outcomes

- William's level of stammering has reduced from 52% stammered syllables to an average 4% stammered syllables and there is now less fluctuation of the stammering during times of change/stress
- There has been a marked increase in William's general confidence and he is able to discuss his difficulties in a relaxed way with peers and adults

Costs

- Speech and language therapy input over the years but now reduced to very light touch monitoring
- Teaching assistant for three sessions of 10 minutes per week

Key questions

- Can the local speech, language and communication services meet all the specialist needs of the children referred to them?
- If not, are there agreements in place to access specialist input at county, regional or higher levels?



Key Factor 9: Inclusive educational establishments

All educational establishments should be 'communication supportive' with the workforce having the appropriate knowledge and skills to ensure the progress of children and young people with SLCN.

'Communication supportive' establishments offer the optimum conditions in which to support language development. They will:

- Encourage speech interactions through positive approaches such as visual support, modified adult language and awareness of children's language levels so that appropriate responses can be made
- Ensure all staff have a basic knowledge about how to encourage the development, or further development, of speech, language and communication skills in all children. Such skills are particularly important in the early years and primary years of education
- Use the Early Years Programmes and the Inclusion Development Programme to help develop the skills of staff
- Take measures to improve the acoustic quality of the establishment as poor acoustics disadvantage all children but those with special educational needs in particular
- Establish effective working links with specialist professionals. Where there is good liaison and interaction between the speech and language therapist and the staff in the setting, the child generally makes significant improvement. Further progress is also made when the speech and language therapist has spent some time in the classroom assessing the child's needs and providing advice and training to the school staff

Case Study 16 describes how a child's learning was turned around when the speech and language therapist went into the school and into the classroom. Case Study 17 describes how a London borough took a strategic approach to developing communication supportive environments.

Case study 16: Rose

Getting into the classroom

Rose is 10 years old with learning difficulties and complex communication difficulties, who attends her local mainstream school. She was not making satisfactory progress or experiencing an inclusive education as she was increasingly withdrawn from the class to work in one-to-one situations.

Rose was failing to meet the speech, language and communication objectives within her statement of special educational needs and not receiving the therapy input as outlined in her statement. Therefore the local authority purchased speech and language therapy time. In addition to providing one-to-one therapy to Rose for half an hour every two weeks, the speech and language therapist was also asked to provide training to the teaching assistant and the class teacher. The therapist also advised on how Rose could be included in classes. The therapist was given half an hour every two weeks (or equivalent) to work with the class teacher and assistant. A monthly communication meeting with Rose's mother, the therapist and the school staff was also established.

The therapist introduced the school staff to a symbol supported curriculum to help Rose record her work and recommended particular supportive software packages. Rose responded well to their use.

The monthly meetings helped to set more realistic and attainable targets for Rose so that she could experience the feeling of success. Both parents and school are clear about the targets and on how to help Rose achieve them so she experiences consistency of approach.

Outcomes

- Rose is now spending most of her time in the mainstream classroom and feels included
- Rose is progressing up the P-scales
- The teaching assistants and class teacher feel more confident and empowered to respond to Rose's needs

Costs

- One hour of speech and language time every two weeks (half an hour with Rose and half an hour with the staff)
- Teaching assistant support of 20 hours per week

Parent's comments:

'Empowering ourselves and the school staff by team working with the speech therapist was a breakthrough for us. Everything that went before this was haphazard working with the child and led to very little progress.'

Case study 17: A London borough**A strategic approach to ensuring communication supportive environments**

A London borough in West London has made improving the speech, language and communication of all children a strategic priority. The local NHS and the local authority with I CAN have developed a joint commissioning approach to Speech and Language Therapy Services. There is joint funding of speech and language therapy posts. A steering group meets regularly to progress the development of speech, language and communication services in the borough including representatives from the three organisations.

Over the past 4 years the *Early Talk* programme has been delivered providing pre-school practitioners with the knowledge and skills to encourage all children's speaking and listening skills.

The borough has implemented the *Every Child a Talker* (ECAT) programme through the deployment of two Early Language Consultants. The consultants provide mentoring and training and help to 30 early years settings to develop action plans and staff skills. The settings have received *Early Talk* training and are now working towards accreditation.

The local NHS and the local authority have a vision that goes beyond the Early Years. They have plans to trial I CAN's *Primary Talk* programme which enables school staff to work with the full range of children from the very confident communicators to those with severe or complex speech and language needs and by piloting I CAN's *Secondary Talk* in secondary schools in the borough. Youth justice is another area they intend to explore.

Outcomes

The joint commissioning approach to speech and language services has really helped to integrate children's services and increased the profile of speech and language services.

Feedback from staff at *Early Years* settings has been extremely positive regarding Early Talk, e.g. *'Early Talk is fantastic, especially the focus on how children develop their speech and language skills. It should be essential training for all staff in early educational settings.'* It was noted in an annual review how *Early Talk* provided staff with a clearer understanding of children's language needs and allowed them to do better observations on children and identify any SLCN earlier.

Two of the *Early Talk* specialist provisions in the borough were accredited in June 2009 with a 96% pass mark. The accreditation report highlighted several outstanding aspects of the service and summarised as follows: *'The service at I CAN specialist provisions in the borough is of high quality, characterised by professional, skilled staff who together provide an excellent example of collaborative practice in Early Years education for children with speech and language impairments.'*

Costs

Specific costs across the range of the services described are not currently available.

Key questions

- Do you have a co-ordinated strategic plan to ensure that all your educational establishments are 'communication supportive'?
- Is the need to develop communication supportive schools reflected in the local authority's Accessibility Strategy?

Key Factor 10: Access to technology

Knowledge, or the ability to access knowledge of technological solutions to communication should be available to all children who need this level of support.

The case studies show how the use of augmentative and alternative communication (AAC) aids can successfully promote a child's social, emotional and educational development:

'The best thing about my communication aid is that people now understand me and realise that I have a lot to say for myself.'

In many cases, acquiring these aids appears problematic. Some areas seem to have a minimum age for being assessed for communication aids. In some areas there is a long wait to be assessed and/or a long wait to identify the right aid and acquiring the funding. The waiting can vary from a few months to over two years. This is excessive given that the aid is so critical to a child's development and progress.

In many cases the technology needs to be accompanied by a training programme for the child, the family and education staff so that they all become confident in its use and so gain maximum benefit. As the child becomes more proficient, packages need to be developed and changed and so it is equally important to have ongoing monitoring and support from AAC specialists. Unfortunately, support after acquisition of the communication aid can be minimal.

Case study 18 describes some of the delays experienced in acquiring communication aids and then in customising them. Case Study 19 shows how well the process can work.

Case study 18: Janie

Delays in accessing the technology

Janie is 19. She has cerebral palsy and a profound hearing impairment, which was diagnosed at about 15 months. She has no useful function in her hands or her feet; any sitting balance and very little head control. She uses a wheelchair and requires full support with all her daily activities.

Shortly after diagnosis, the family received very useful support from a teacher of the deaf who was experienced with children with multiple and complex needs. She was confident of Janie's ability to learn and communicate and encouraged her parents to

raise their expectations. Janie uses two hearing aids and attempted speech within a few months of receiving them. Janie learned to understand sign language, but her lack of hand function meant that she would not be able to use signing for expressive communication.

Janie's early communication was mainly through eye-pointing, which remains useful but limited in scope. The combination of severe cerebral palsy and profound deafness means that her speech sounds are only intelligible to those who know her well. Janie attended a special school from the age of two years. She does not have a learning disability, but her attainment has been limited by physical and sensory impairments, making it difficult for her to demonstrate her understanding and produce written texts.

Janie was assessed for a communication aid when she was about 5 years old. However she did not receive the equipment until she was 7 when a local bakery funded a Dynavox 3100 (a high tech voice output communication aid). Later a replacement DV4 was purchased by the school through external fundraising.

Janie experimented unsuccessfully with a variety of switch systems before her father suggested a throat microphone which was custom made. She has now used this for 8 or 9 years, with single switch scanning. Although it is slow and laborious, she has developed a good command of basic English and is able to conduct simple conversations; compose extended sentences and produce short texts using picture word power software. However, her spasms mean that the switch is often activated by mistake, and every mistake requires 3 correct hits to delete. Currently she is using a V-Max (another type of voice output communication aid), funded by the local authority in January 2009, but she is awaiting the outcome of a bid for a new microphone switch which would give fewer 'mis-hits' and for eye-gaze software, which might, with practice, allow faster access.

Janie has made most progress when supported by a speech and language therapist who could identify objectives and provide a structured approach to progression in her AAC aid use. Unfortunately, such support has not been consistent throughout her education.

Janie uses her communication aid for work and social communication at school; prepares work or writes text on it at home, and sometimes uses it socially with family or friends. However, she is often frustrated by people's lack of understanding of the inherent slowness of the system and their reluctance to wait while she composes her message. She enjoys using it at 1 Voice, where she has a supportive peer group and positive role models.

Outcomes

- Despite the technology, communication remains very hard work for Janie, however, she is a motivated, confident and effective communicator

Costs

- Provision of three communication aids in past 11 years – the first two through fundraising via school, the third provided by local authority. (Approximately £2000-£4000 per aid)
- Attendance at out-of-county special school, including transport, for past 17 years. Speech and language provision has been through school
- Early input from local authority peripatetic teacher of deaf, who visited weekly for 8-9 months (from diagnosis till Janie took up her assessment place in nursery at special school)
- Two hearing aids (currently digital post-aural). Ongoing audiology monitoring and periodic replacement of aids
- 1 Voice events: has attended about ten family and teenager weekends over last ten years, subsidised by 1 Voice fundraising
- Equipment related to her physical disabilities: 5 foam curve wheelchair seats, bed, foam toilet/shower chair, mobile hoists

Case study 19: Jason

The complete support package

Jason is 17 years old. He has Aperts Syndrome, which is a complex craniofacial condition. He has a moderate visual disability and a severe learning disability. He finds it difficult to hold a pen and is unable to write independently. His severe speech disability makes it difficult for him to be understood. Those who know him well have to act as an interpreter.

Without augmentative and alternative communication (AAC) he is unable to communicate independently. Prior to using AAC Jason was frustrated at not being able to articulate fully his thoughts, feelings and wishes. He experienced isolation from his peers and a reduction in his personal autonomy. In a recently published journal Jason explained his joy at receiving a high tech communication.

'I met a specialist teacher in communication who assessed me for a high tech aid which spoke the words I needed to say. It was great! Suddenly people started to understand me and I could ask for things I needed independently'.

Jason's communication needs were assessed by an AAC teacher and an alternative

communication plan was put in place. Initially, Jason was provided with a communication book, which comprised of pages of picture symbols arranged in category areas. He was taught how to indicate his needs by pointing to pictures on a page. It became evident that Jason had the capability to develop more literacy and communication skills. Trials were undertaken with a range of high tech devices.

At first Jason used a simple picture based high tech aid (Eclipse) and then he progressed onto a more sophisticated symbol based system (Dynamite). Ultimately he was able to use a device based on letter spelling and word prediction (Light writer).

The school set up a communication team to support Jason comprising of:

- Specialist teacher for AAC
- Speech and language therapist
- Teaching assistants who were trained in the basics of AAC and particularly in the programming maintenance and technical aspects of the device

Jason was provided with regular, additional teaching and training:

- One-to-one support for one hour each week with a specialist teaching assistant (working under the direction of an AAC consultant)
- One hour each month one-to-one with the AAC consultant who monitored and evaluated his progress and set targets.

A clear recording system was put in place with SMART (specific, measurable, achievable, realistic and timed) targets. Jason was encouraged to participate in the setting of these targets which were presented in a child friendly and accessible way and initially they used a sticker style reward card.

Jason was actively involved in producing his own record of achievement which included the production of his own DVD showing progress and a magazine style Record of Achievement which also acted as a transition document as he moved throughout the school and interacted with other professionals. Very importantly, opportunities were provided for Jason to meet with other people who used assistive communication in order to provide role models and support.

Jason's family and key workers were provided with training in the use of the technology. Jason's writing skills were also assessed and it was decided to introduce a laptop computer with specialist word predictive software (Grid 2). Over time Jason developed his skills to the extent whereby he was able to write independently; use word prediction; and access all multimedia functions such as email and text.

Outcomes

- Jason has achieved independent communication and exceeded the expectations of his initial assessment
- Through developing appropriate communication skills he has been able to access education and move through the National curriculum P-levels now working at level one in most subject areas
- His written language skills have advanced from
 - 2002: makes a mark on paper (unaided)
 - 2006: writes first name and copy writes some letters
 - 2010: produces legible writing, writes in sentences, sends emails

Costs

The costs are over a **10 year period** and are in addition to the provision of attending a special school:

- | | |
|--|---|
| • Low tech system | £500 |
| • High Tech systems | £2000; £6000, £3000 |
| • 3 Specialist assessments | £1500 |
| • Support from AAC Consultant | £300 (annual cost for 10 visits of one hour per year) |
| • Support from AAC teaching assistants | £720 (Two hours per week for 36 weeks – indicative) |

Key questions

- Are there staff members in your teams with sufficient knowledge of low tech and high tech AAC:
 - to carry out assessments for technological aids to communication
 - to provide the necessary ongoing support and training?
- Are technological solutions to communication needs available to all the children who may need them in your area of responsibility?
- Are funding streams clearly identified for providing such communication aids as may be necessary?
- Does the local authority's Accessibility Strategy adequately cover access to communication technology?
- Are educational establishments responding appropriately and liaising with speech and language therapists when children have specific speech, language and communication needs?



Key Factor 11: Social support networks

Many parents of children with SLCN value the opportunity to be part of a parental support group.

Many children and young people with SLCN, particularly those in mainstream schools, value the opportunity to meet together. A recurring theme in many of the case studies centres on the need for peer support both on the part of the children and their parents.

Apart from gaining information and solutions, parents stressed the importance of emotional support knowing that they were with people experiencing similar challenges and who understand the difficulties.

Children also benefit from meeting others with similar needs helping them deal with the loneliness they experienced particularly if they are the only child in a mainstream school with that particular need.

Many voluntary organisations provide opportunities for children with similar needs to meet together and/or opportunities for their families to come together. It is important that the value of these groups is recognised and that they are included in a local area's overall list of services.

Rather than select one case study to illustrate this key factor, quotations from children and their families are cited below.

'Contact with other parents and families, both informally and through parent workshops and email groups, provides mutual support and allows us to learn from the experience of others.'

'The other major factor for us was meeting other families in a similar situation; once again by pure chance we met a family (at a folk festival!) with a child about a year older but with very similar needs when both kids were pre-school age. Turned out they live 25 minutes from us. So we have come along the journey together... kids both at mainstream (different schools), same LEA, lots of same issues etc.'

'...participation in family weekends and teenager projects over past 10 years has provided J with enormous encouragement in using her communication aid by offering motivating reasons to communicate, a peer group of friends like herself, a team of volunteer workers who understand the difficulties of using AAC and support and encourage young AAC users, and above all a group of inspirational adult role models who encourage higher aspirations and confidence about future possibilities. J has now

become a teenage role model, and is very serious about her responsibility to support younger children in their use of AAC; she has given presentations to parents and families at 4 events and is keen to do more.'

'It (parent group) is unparalleled by any other means - sharing information and getting support from people who really know what it's like to have a child without speech, and the true impact that has on a family.'

'It has been invaluable to us to meet other AAC users, older and younger, and see that the world really can be your oyster if you can communicate effectively by some means or other!'

Key questions

- What opportunities are there in your area for parents of children with SLCN to meet?
- What opportunities are there for children with speech, language and communication difficulties to meet children with similar needs?

The Communication Trust is committed to sharing good practice around service provision for children and young people with speech, language and communication needs. We are collecting case studies from frontline staff, parents, service managers and organisations across private, voluntary and public sector provision. To tell us your experience of effective service provision please contact enquiries@thecommunicationtrust.org.uk.

The Trust recognises that the effective practice outlined in this booklet relies on having staff and volunteers with the right combination of skills and experience to best meet a child's needs. To support this the Trust has developed the Speech, Language and Communication Framework – a competency framework and audit tool that helps staff identify their training and development needs www.communicationhelppoint.org.uk.

The Trust runs a number of programmes to support front line staff. For more information please contact enquiries@thecommunicationtrust.org.uk or visit the website www.thecommunicationtrust.org.uk.

