



Response to the Bercow Review

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Setting the context

Amaze organised one of six parent focus groups across England commissioned by The RCSLT on behalf of the review: it was facilitated by Professor Sue Roulstone. She met with thirteen parents. Of these one parent had three children and another had four children. The children were aged 2 to 16 and they reflected the diversity of children's communication needs.

Many more Brighton and Hove parents expressed an interest in contributing to review. So that more parents could comment Amaze sent out postal and email questionnaires. These have been forwarded to the Bercow Review.

Amaze made a decision to ask families for more detail than the on-line response form. In addition to the Bercow questionnaire, we asked parents to tell us:

- How many children in the family had communication needs? And if they had more than one child with communication needs we asked them to tell us separately about each one.
- About their child's educational setting. Was it a preschool / specialist preschool setting / mainstream school / speech and language facility at m/stream / ASD facility at m/stream / HI facility at m/stream / special school?
- Each child's age and whether they were male or female
- To tell us something about their child's communication needs. Some parents gave a diagnosis: most parents gave a clear and helpful description.

To analyse and draw useful conclusions from what parents told us we wanted to understand something of the context of their experience. We wanted to see what was different about families who tell us they are happy about speech and language therapy services and those who are dissatisfied.

Who did we ask?

It's important to think about whether the parents we contacted reflected the experience of the whole community of parents who have children with speech, language and communication needs and be clear about whose views we may be missing.

The parents we asked to give evidence to the review have children on the Compass database. The Compass is the children's disability register, in Brighton and Hove. It is held by Amaze. It holds records of 1200+ children.

- All children on the Compass have statements of SEN, or are in receipt of Disability Living Allowance, or both.
- We randomly mailed about 400 parents whose Compass records tell us their children had some speech, language or communication need. 52 parents replied.

We did not contact parents of children on our helpline database. This broader database includes the children on the Compass as well as others who are more likely to have unidentified or emerging needs. This database includes the details of children whose parents ring the helpline and have concerns that their child might have some special needs. It includes records of children at early years/school action and school action plus and children who are not getting Disability Living Allowance. Some of these children will inevitably have un-assessed speech, language or communication needs. The children must live or go to school in Brighton and Hove.

So, the views we gathered did not include the experience of parents whose children:

- Are not getting Disability Living Allowance and
- Are at early years/school action or school action plus or
- Have fallen through the net altogether because their parents are not aware that their child has delayed or disordered speech, language or communication, or
- parents concerns have not been listened to
- parents of children with EBSD.

With more time and resources Amaze would like to find out about the experience of these families.

We think it's likely that speech, language and communication needs are under-diagnosed. Why do we think this?

It's hard to for many parents to acknowledge their child has any difficulties and to act on their concerns. It's easier to listen to friends who say 'don't worry, lots of children don't talk until they're four' than the friend who says 'do you think your child's got a problem? One parent reported making a complaint about her child's health visitor for wanting to make a referral to services: others just found the whole process very painful.

To begin with we were very defensive as we thought there was no problem and he would just take his time and catch up.

I felt like locking myself inside I wanted to be on my own thinking about all the bad stuff

For some parents it feels like there's no safe place to talk about their children, where they don't feel judged: feeling they might be blamed makes some parents reluctant to seek help. Initiatives like Sure Start, which may offer these sorts of opportunities, are struggling to sign up the hardest to reach and most deprived families.

Speech, language and communication needs are 'invisible' and they emerge over time. It's difficult for parents to describe these sorts of problems, and not unusual to hear parents say 'he just doesn't listen to me' or 'she doesn't do anything I say' or 'he just talks rubbish.'

Parents don't have the vocabulary or the manual. The words practitioners use to describe speech, language and communication needs are unfamiliar and even parents who are articulate and literate struggle with the terminology. Parents don't have the right words to describe their child's communication and don't know the right questions to ask or where to get help. They aren't yet in the 'special needs arena.'

What if we have different expectations of some children? Let's suppose there is an expectation amongst practitioners that at 3 years old, many children in the most deprived areas of the city have the speech and language skills expected of 2 year olds in other areas. Unconsciously, this might not be regarded as something requiring intervention, more that this is just how it is.

Less concern about identifying children with delayed speech and language in the most disadvantaged parts of the city might be 'justified' by an

assumption that these children 'catch up' by the time they start school. Or if they haven't school will sort it out.

Unless a child has significant global developmental delay, concerns about their communication are unlikely to be on parents' or practitioners' 'radar' until a child is well over 3 years old. Children who have disordered speech and language, specific speech and language impairments or autistic spectrum conditions may well be picked up much later in the most disadvantaged parts of the city than if they lived elsewhere.

It's important we think about where children live and about the characteristics of their families. Service providers and planners need to know more about the local population they intend to deliver services to. Too often data is analysed at local authority or ward level. If we do this in Brighton and Hove, we miss pockets of disadvantage and deprivation and the experience of the least well-resourced families is masked by their more affluent neighbours just a few streets away. Recent analysis at middle layer super output area (population 7,200) of data from The Compass about the incidence of ASD across the city, indicates that

- the proportions of children on The Compass that have a diagnosis of ASC are generally much lower in the more deprived areas.
- the most striking feature about families within the most deprived areas, with an ASC diagnosis for their child is that they have higher levels of literacy than other families in the same area without an ASC diagnosis for their child. And higher levels of literacy than other families on The Compass across the city. So the families in the most deprived areas with a diagnosis of ASC are unusual. They appear to have better educational attainment and this seems to be a key to accessing, information, advice and support.
- there is circumstantial and some direct evidence (Baird et al, 2006) of under-diagnosis of ASC in more deprived groups of families

Micro-geodemography is important. Jenny Broome-Smith's work at Amaze on the proportions of children on The Compass with an ASC diagnosis across Brighton and Hove, suggests it would reasonable to expect under-diagnosis of all speech, language and communication needs in the most deprived areas, among most disadvantaged families.

Better ways of working with the hardest to reach families is likely to reveal much more need. This creates a tension for services that are already under-resourced and over stretched.

We have concerns that parents from most deprived areas are less likely to be represented amongst written submissions from parents to the Bercow Review. As poorer literacy is a key feature of the most disadvantaged families, asking for written evidence is a barrier to parents who struggle to read and write and might want to contribute to the review.

Amaze hopes that particular weight is given to oral evidence gathered from focus groups and face to face contact with parents, children and young people.

What parents say: an introduction.

Parents say speech, language and communication services are overstretched and poorly resourced. Parents whose children get speech therapy report a lot of excellent practice. But few feel their child is getting enough help. There are gaps in specialist knowledge that impact on some children, especially children who use assistive technology. When speech therapy is available it is of good quality but there are not enough resources to have it delivered regularly and there are significant gaps when speech therapists are not available. Many parents say the service their child gets is intermittent, patchy and hard won.

Overall my family's experience of speech, language and communication services is that they are excellent when you eventually get to the top of a very long waiting list. The time waiting is time lost in helping your child. I'm always pushing the school for referrals etc, it's an ongoing frustrating process. Only by making a big fuss do we get the support our son needs.

Parents in Brighton and Hove who feel most positively about how their child's communication needs are met are most likely to

- be accessing services that are holistic and child centred rather than resource led
- have regular face to face contact with the same speech therapist
- have a young child with severe and complex communication difficulties and emerging skills
- have a deaf or hearing impaired child
- have a school aged child in specialist Sp/Lg, HI, ASC provision
- sense that their child is making progress
- feel confident that they can help their child

Parents whose children do not speak and use assistive technology are less satisfied.

Parents with English as their second language find it harder to access information and find out how to help their child.

Parents become more dissatisfied as their child gets older. The most dissatisfied are parents of teenagers, especially aged sixteen and over. Parents worry about their children's vulnerability out in the community. Lack of support around social communication becomes a bigger issue as young people strive to be independent like their peers.

Most parents recognise they are their child's biggest resource. They want to know how best to help and feel frustrated when they find themselves out of the loop.

Talking is embedded in everything we do.

Key message: Parents overwhelmingly say speech, language and communication is fundamental to their child's life. They want speech and language to be top of the agenda.

Government says Every Child Matters. If you can't talk, communication is an equality issue. All children have the right to tell us about the important things in their life. All children have the right to make sense of what's going on around them. Well it's hard for many parents of children with speech, language and communication needs see how that's happening.

Parents say being able to 'tell' us about simple things like feeling thirsty or hungry, uncomfortable or frightened, is essential to their child's health and wellbeing. Imagine being unable to make even the simplest requests?

The most important thing for my child is that he can now make choices and say/sign yes, no and more: a breakthrough for us all.

He says mumum, dadad and animal noises like moo baa and woof. He uses a combination of Makaton and PECS. With the help and support we have received so far he is able to make himself understood most of the time within the family and at preschool. Outside and with strangers this can be more difficult.

If everything that happens to a child is a surprise and they're never sure what's going to happen next, the world seems a very chaotic and frightening place.

The most important thing in the beginning to my child was that he needed to be able to communicate. He would just scream. Speech therapy

introduced him to a way forward. However, I think it took until my son began to self-harm, through frustration, before he was prioritized.

Children who are not confident communicators or misread other people's intentions find it hard to join in and make friends: they are also more likely to be bullied or bully other children. Some parents say their children can look as if they are doing OK when really they are struggling to make a connection and are being excluded. It's hard to be part of the 'gang' when you are different.

Talking is embedded in everything we do, its part of who we are. My child doesn't really do talking and it gets in the way all the time. They say 'she's a great observer of life'. She'd much rather join in but all the time I see her left out and left behind. The other children rush about the playground: their rules are constantly evolving as the game plays out and my child just stands there, unable to work out what's going on at all.

Key message: We need to find out what other children think. If we want children with communication needs to be included, we need to find out what other children are seeing when they look at a child in a wheel chair, come across a child who signs or have a classmate who finds it hard to talk.

He just doesn't get that a conversation's about taking turns and being interested in what the other person says. He just talks 'at you'. His pet topic right now is dinosaurs and he knows everything. But you can't join in: he just ignores any comment you make. He has no idea that the rest of us aren't as interested as he is in what he has to say. Children who know him move away, or turn their backs as he comes over. But he still loves going to the park and always looks forward to seeing them. It's really painful.

She drew a picture: three children, as tall as the page and in the corner a tiny child with tears pouring like rain from her face. The tiny child was holding a rope. They had empty voice bubbles. I said 'What have you drawn' 'boys shout pig face, smelly, stupid. You write it.' I filled in the bubbles. 'I hit 'em with my rope'. After weeks of name-calling she'd had a go at the bullies and got excluded.

Key message: Children with communication needs are at greater risk of being isolated and bullied. The ways that some children use the communication skills they do have, makes them more vulnerable.

My children look as if they can manage and appear to be coping but they have social issues: they stare...looking for cues and they keep staring even when the other person's noticed. I know what they do feels threatening and frequently they get an aggressive response.

He strikes up conversations all the time, telling complete strangers personal details.

I stopped taking my children to parks because I didn't know how to cope if my child hit another child

Communication touches every part of our lives. When our children can't tell us what they want and how they feel, they will show us, often in ways we find hard to manage. Parents say that without the confidence and skills to handle difficult situations, sometimes it feels like the best option is just to stay at home.

Key message: Children should be able to access help until they don't need it. This is not how parents experience services. Many parents report help that is withdrawn just because it's a new school year, or that it's offered intermittently.

Sure Start detected that my son was speech delayed at 18 months they gave us easy access to a speech and language therapist it was what ensued after that that became difficult. At age 5 your child is cut adrift and after that you have to fight to get any help. He was falling behind, becoming anxious and getting teased. Then he was held back a year. In desperation we looked for a private therapist. We applied for DLA and use this to pay for his speech therapist and OT. They are brilliant. Now I know how to help. Everyone can see a difference in him.

Key message: Speech, language and communication difficulties are fundamental barriers to learning. Parents say that for their children, being able to be understood, make sense of what other people are saying, join in and make friends is more fundamental to learning than other foundation skills like reading and writing.

Why is it so difficult to get services for children they are the adults of tomorrow yet the government fails to understand that better services for children may actually have a dramatic reduction on crime, drug misuse and unemployment. It should be no surprise that people who are socially excluded have problems with communication and self-expression, often stemming from childhood experiences

Key message: There needs to be a fundamental rethink about importance Government attaches to communication.

Finding out what's wrong

Finding out what's wrong is often a long and painful journey. Although parents tell us that 'it's the quickest way to lose a friend', for some, a friend worried enough to share their own concern about your child may still be the first time a parent is alerted to their own child's speech and language needs. It's easier to listen to friends who say 'don't worry, lots of children don't talk until they're four' than the friend who says 'do you think your child's got a problem.

People say don't worry. It's hard you feel vulnerable and raw it's hard to admit there's something wrong.

It's hard to for many parents to acknowledge their child has any difficulties.

To begin with we were very defensive as we thought there was no problem and he would just take his time and catch up.

I felt like locking myself inside I wanted to be on my own thinking about all the bad stuff.

When parents ask for referrals some practitioners act more quickly than others, some take more seriously parent's worries.

Process of referral took a year that's a long time in a small child's life.

Some parents report very poor communication around diagnosis, with little time for discussion and no explanation of what to expect.

English is not my first language. I never heard of autism. I asked 'what is it?' The paediatrician wrote it down and said 'look it up on the internet.

You don't want to hear everything you've been told at the time. It's useful to have leaflets to take away.

Key message: conversations about diagnosis are difficult for everyone. But they are much harder for parents when practitioners seem disinterested or in a hurry. The responsibility for getting it right lies with professionals.

Parents assume, that the system will identify and act, not that they would have to raise their own concerns with practitioners.

It's undemocratic, some parents don't know what to ask and haven't the time to find out.

Professional's expectations of health visitors to identify children seem to be really high but they don't even visit regularly now: that link has gone it's up to parents.

Getting help that is timely still feels like a lottery. Professionals don't want to tell you in case they get it wrong

T had features of ASC but people did not want to talk about that: I thought everyone was just being politically correct but I now understand why. It's just real hard to be sure. It turned out that he was not ASC. But it was only when I got upset because I didn't know what books to choose that they realised no-one had made a decision about ASC. I got a diagnosis because I wanted a book. If I hadn't gone to the JSC that afternoon, I think T would have missed out on a place at the ICAN nursery. ICAN was the perfect place for him and although everything turned out fine because a specialist speech and language centre was absolutely where he needed to be, it felt a bit like chance.

Although the process did feel like it flowed and was joined up sometimes I remember the feeling that because my child did not have a label I felt unsure who to ask for help. For example I didn't apply to Amaze for a while because I felt somehow our needs were not severe enough.

Information is not easy to find

Parents say finding information and advice is really difficult. Some say it's only by chance and talking to other parents they find out about things that might help their child. Throughout the focus group parents were exchanging information and contacts.

Most of the advice and guidance I have received has come from a friend in a similar position and Amaze. F's SENCo has acted as translator (about S&L speak) and has been really helpful.

Although I was sent the results of two assessments carried out in year one. The language and scoring mechanism meant I didn't really understand the significance of the results. Also he came across as having higher than average comprehension and expressive language. This was utterly bewildering as his peers and teachers have great trouble understanding him. I am still trying to find support that is simple and straightforward that I can do with him at home.

'The information is probably excellent if you are another speech and language therapist who knows what the 'raw score' 'standard score' and percentile' means.'

Key message: parents say it would be useful to have an introductory leaflet explaining exactly how the speech and language service works, with advice about where to get further information and support.

I first found out about Amaze for example from an information pack supplied by the Jeanne Saunders Centre. ICAN had lots of books and loaned them to parents as well as encouraged us in to have talks from linked professionals who also came well prepared with lots of info for us.

Key message: it helps when services work collaboratively

Key message: parents want access to an advice line for queries and concerns

Key message: it helps if assessments are followed up with a thorough written explanation in plain English and a chance to discuss this.

Key message: parents want suggestions for simple and fun exercises that can be done at home. Some suggest an interactive website similar to the literacy website ICT.com

I would have quite liked a web-based resource with lots of links off to places.

There aren't enough speech therapists. So what happens?

When resources are scarce, services are forced to make tough decisions about who needs help the most and how to use resources most effectively. Parents say that to meet the needs of just some children, under resourced services set artificially high thresholds or seemingly random criteria. Parents come across rules that aren't overt and others that seem nonsensical.

Many parents of preschoolers report piecemeal 6 weekly sessions then long gaps of 3 months blocks without any therapy. It doesn't make sense to them. Parents say it takes weeks for a child to build a trusting relationship, so just as their child feels comfortable enough to get a lot from the sessions, they stop again.

It's not clear to parents how evidence about need affects decisions about thresholds and service provision. In Brighton and Hove over the last few years parents have seen 'goal posts' move. There have been times when the only school aged children getting a service in mainstream schools were

- in a cluster of primary schools in one identified part of the city
- in reception and year one
- stated AND the primary need was speech and language
- in a Speech and Language, Hearing Impaired, or ASC facility

Most school-aged children are only able to access speech therapy as an advisory service. This is often very different from their experience of pre-school services.

We had a fantastic experience pre-school, but now it's gone to the wall.

My child has been to ICAN (nursery) so he had a lot of help in early years. Later I was told other more needy children had priority. There seems to be a notion that children make the most progress up to 5 1/2 years.

Key message: Provision should reflect needs rather than seeming to be tailored to fit under resourced services.

Hove Polyclinic has only just started to accept children who need help beyond school starting age. I would like to say that I am delighted this service has been extended as children like my son do need expert S&L support through their schooling.

ICAN was brilliant. But I felt they were put under pressure not to put children forward for a statement because they had to prove they were cost effective and had made a difference. It took another year to get him a statement.

Parents of children with physical and medical difficulties encounter particular barriers trying to get the right help for their child.

If your child is in the medical system, speech and language is the last thing that gets addressed, they are so wrapped up in getting your child to survive a year but if your child can't move and they are always going to have to rely on other people. Isn't it all the more important they can tell us what they want?

Where are the therapists who understand the technology? Had a lot of input around swallowing, eating and drinking and finding a 'yes' and a 'no'

and sorting out a communication book but no one wanted to take responsibility for adding more symbols. So I do it myself.

We were introduced to PECS by our paediatrician but his school put it on the back burner: they use the Chailey Communication System. It's a thick book: my child couldn't use it without help. All of a sudden he had no say over his own communication. There had been no discussion or negotiation: it seemed as if one size should fit all. An amazing explosion of behaviour got us shunted off to CAMHS. They realised it was to do with his frustration struggling to communicate. Then his school did Sign a Long and PECS.

VOCAs Voice Output Communication Aids are expensive. The CAPS project had finished. I had to lobby our MP and The Children's Commissioner to get one. But children who need them, really need them.

Key message: Speech and Language therapy is an educational need for many children but it is too often seen as a non-educational need.

Children learn best when they feel secure and confident. When children cannot easily make themselves understood or make sense of what other people say, school is miserable and learning is too risky.

His peers and teachers have great difficulty understanding him, but it's been decided that he doesn't qualify for any support

Children with needs that don't meet the threshold have to struggle along. Parents say it often feels as if it's been forgotten that their child was ever assessed as having speech and language difficulties. They say that for some children this leads to isolation, lack of achievement, anti-social behavioural and exclusion, emotional distress and mental health issues. Very often no one tracks how they are doing and children don't come to the attention of services again until they become disaffected and challenging or anxious and withdrawn. Services like CAMHS, ACE, Sorted4School, YOT, Triple P et al try to help but cannot fix the root cause, which is that some of these children continue to have unmet speech, language and communication needs.

I am really disappointed. H's last assessment stated that he was above average in sentence structure and expression. I really wanted to dispute this view, as it is generally acknowledged by everyone that H's speech and language is very behind his peers. He is often hard to understand and has problems using narrative language. Because of this assessment H's profile did not meet the criteria for therapy in year 2 and he was discharged. So at this crucial stage in his development, he had no support. This has led to a certain amount of social exclusion, culminating in verbal and finally physical bullying last term. Consequently his confidence is taking a bashing. This has been acknowledged to be directly affecting his

work. I spoke directly to the S&L therapist, who whilst sympathetic, could only suggest I got him a private therapist. This of course is financially completely out of the question. A term has elapsed (or 6 months in real time) and I understand that at my request the SENCo has re-referred him and at some unspecified time he will receive nominal weekly support.

Other parents reported lots of monitoring but never any help.

I grew to hate the word 'monitoring' He was monitored until 5 and then handed over to school how can he slip through the net when I've been on the case for years? How bad is 'not bad enough?'

Parents whose children do get a service feel frustrated that speech and language therapy input is piecemeal.

The service seems to be short staffed to the point that we did not receive speech therapy for a year when my child was 7 yrs old and now again she is 9 yrs old and at the moment we have not received any speech therapy for the past 3months.

I was told the group wasn't suitable so they couldn't offer her a place. It seems like a child can have too complex or specific needs or not severe enough needs, either way you don't get a service. I think every child should get what they need.

Key message: Parents say there are not enough resources to have regular therapy and there are large gaps when speech therapists are not available.

Key message: Lots of parents report that having a statement or attending a special school is no guarantee of getting help. Parents of children in provision for pupils with severe and complex needs are as unhappy about the lack of speech and language therapy provision as parents of children in mainstream schools.

'I feel utter confusion. I have been told that it (where speech and language therapy appears on a statement) is almost pointless as there isn't much support even if you are successful in getting your child a statement.'

My son has ADHD. He has limited social awareness: he struggles to understand non-verbal communication and social cues. He has a Statement but speech and language is not written into any part of it and he has never received any speech and language in this area.

My son goes to an independent special school. Currently my son does not receive therapy from a qualified Speech and Language Therapist,

although it's in section 3 of his statement. This is because there is a lack of qualified therapists and the school is unable to recruit one. There is access to an assistant however this does not suit his needs.

Some parents feel their child has been let down and their life chances diminished by lack of speech and language therapy services. This is not in keeping with the Every Child Matters.

I am SURE that if she had received intensive regular speech coaching throughout her school life as PART OF HER EDUCATIONAL NECESSITY AND CURRICULUM instead of for example FRENCH then she would be communicating better now and would have a better chance in the outside world.

Getting help pre-school

Some parents reported previous authorities as a black hole of despair.

The information I needed to find out about support for my child was not initially easy to find as we lived in London. As soon as we moved here to Brighton our GP and Health Visitor were extremely supportive and helpful in finding help for us.

Once we get in contact with Amaze we went on a course for parents of children with special needs in which we received most of the information required to access different services. In addition, we received emotional support to understand the diagnosis and to assimilate it in a positive way.

Prior to 3 years old only two assessment sessions were offered by referral community paediatrician, followed by speech therapy at pre school assessment centre. This was good but terms are very short and speech therapy is delivered in school time without parents' involvement so it becomes very difficult to support children with practise at home. This is also the case when a child continues into a special school.

At first it seemed like a long wait to see the specialists because our son was very young when I first brought his development delay to our GP and Health visitor's attention. They put us on a waiting list and as soon as our son was about 18 months, the system just took over and we were seen at first on a 6 weekly basis building up to weekly visits after his play skills sessions ceased. The play skills specialist was also helping our son with Speech and Language before that stage, linking in with her colleagues and pushing for our son to get more help as he was showing excellent signs of response.

Excellent – is how I rate what happened to our family once he went to ICAN. The team were amazing from the first introductory session before term started right through, encouraging parents in to watch chat and learn. The brilliant communication and home support were excellent. The transport and chaperones were also wonderful and meant that my little boy always wanted to go to school.

My son receives an excellent service. Perhaps more group sessions with other children, such as Chatterbox (which we cannot attend anymore as our son attends nursery on that day). More courses on signing would be useful, not just for parents but for those people who also support children with speech and language difficulties.

Children often have to wait for the right help. Even so experience pre-school is often a more positive experience than what happens at school age.

Key message: Children make better progress when the service they get is tailored to meet their needs.

'Initially we had a very tough time, D was about 2 and would not cooperate, the sessions with two other children were a nightmare for us both. Recognising this was a problem D was switched to one to one and he accepted this much better and it allowed the person working with him to tailor sessions specifically to his likes and interests.'

Unfortunately when my son was seen and accepted as needing S&L therapy, he was put into a group that was not right for his needs so he had a further wait until a space became available in a suitable group that targeted his needs. This group was wonderful and my son made huge progress. Currently however, due to further problems at school, he has been referred again to this dept just before the Christmas break, as of yet we do not have an appointment.

I feel that the services at Hove Polyclinic are excellent, but that waiting times are long and spaces are limited. Therefore I feel that there are always more children requiring help than is immediately available. I am currently waiting for my son to see this dept again so I hope it won't take too long. His school referred him before Christmas as of today (14/01) he does not have an appointment.

How should speech and language therapy be delivered at school age?

Most parents of school aged children want speech and language therapy to happen at school An advantage if a child gets help is that they don't need to take time out of school to travel to appointments. But parents say getting help feels like a lottery.

Key message: parents believe that for inclusion to work, classes need to be smaller

Many parents praised the commitment and hard work of schools. But parents worry that too much is expected of teaching staff and that some may be resentful of the extra work. Too often, speech and language programmes are delivered by support staff with no formal training. They may not understand why it's important to be consistent and make time for particular activities. Your child's teacher may be intuitively able to work with a child with S&L needs but it's a matter of luck.

I was dismayed that the teacher needed to be told even basic stuff like to look at my child when talking.

Parents say key strategies that get diluted and aren't delivered consistently make less difference. Programmes are supposed to be carried out in school however there is enormous pressure for other targets to be met. Unless strategies are implemented everyday, and woven into the curriculum they won't make much of a difference.

Parents report very different experiences. Some schools have a 'can do' approach, while others come up with endless reasons why the help a child needs hasn't been put in place.

Key message: Parents believe speech and language therapists have a key role in promoting inclusion. When speech and language therapists are given the profile and resources they need to work effectively in schools they can help children make friends and access the curriculum. Different schools give different priority to inclusion.

It would be help my daughter if her school embraced Makaton signing. Schools should have adequate training around communication difficulties so they can implement strategies for language differences in the classroom and whole school activities. I think this would prevent individual children being removed from the classroom so frequently and place more focus on promoting difference positively amongst the pupils. This would be a huge stride towards respect for difference.

'My child is part of the community there: the other children and staff need to learn how to communicate with her. What's good practice for my child is good for the whole class'.

At my child's mainstream school everything is taught through Makaton: it's a centre of excellence. Her school has picture timetables which are great for all the children.

Key message: Parents say we need many more speech therapists working alongside teachers in schools and more LSAs with speech and language training.

Key message: Small clusters of schools could share a speech therapist but a special school or a school with a high proportion of children on the SEN register should have its own speech therapist.

What matters most is that everyone works together.

Her school was always trying to provide that which the speech therapists could not in order to fill the gaps for our Kids, to make sure they were getting something! Also when we did have therapists they were always excellent at trying to ensure people followed the programmes, and how to, without their input, so the teachers could function when they were not there. It is never their fault that they were short staffed and pressured. My point is that this should be a necessary and freely available part of their learning as is the ordinary curriculum! The teachers have a great deal to do without also trying to do speech therapy.

But parents tell us getting speech and language therapy through school has some disadvantages. Disadvantages are that they don't really feel involved, despite the regular written communications from the speech therapy service.

It would be nice to sit in on a session now and then to experience it directly.

Does a Statement get your child speech therapy?

Key message: Speech and Language therapy is an educational need for many children but sometimes it is still seen as a non- educational need. Children learn best when they feel secure and confident. When children cannot easily make themselves understood or make sense of what other people say, school is miserable and learning is too risky. Parents say:

- It's a myth to think that children with statements get speech and language therapy.

We had to fight for every bit of speech and language therapy, it made no difference that it was a major part of her statement. Before she was Statemented my daughter was supported by SLSS, they were brilliant because they helped teachers with ways to work with her but the minute we got the statement it was taken away! My child is now in a special secondary school but she still doesn't get SALT! We get no support or help with her communication needs.

It's a myth that children in special school get speech therapy and expertise but it's not so, my child is in a group of children with very diverse needs.

It took a lot of fighting to get weekly therapy in his statement, but although the funding was agreed they couldn't find anyone.

- Provision is often unspecified on Statements
- Wording may be amended when there is no evidence that needs have changed.
speech and language work undertaken by classroom teachers and ANCILLARY SUPPORT STAFF within a structured language programme drawn up and monitored in consultation with speech and language therapy services
- Some parents of children with Severe Learning Difficulties, Autism, and Down Syndrome report that speech and language therapy is not written into section 3 of their child's statement. It's hard to imagine how it is not an educational need for them.
- Parents have appealed successfully to SENDIST to have speech and language therapy retained in section 3 post 16

- Some parents of Statemented children tell us speech and language needs are not written in at all. Even though they can clearly describe their child's speech, language or communication needs.
- One parent reported that she was encouraged to agree that speech and language therapy be removed from a statement, to give their child a better chance of getting into a particular special school. A significant number of the pupils at that school are on the autistic spectrum.

Parents are a child's biggest resource.

Key message: Parents want to help but without the advice and support of a speech and language therapist, they don't know where to start

Parents want to do as much as they can to help, but babies don't come with instructions! There are a few simple rules about communication that all parents can learn and are good for all children. If this is your first baby, parents say you don't know when your baby should be babbling. Parents need early information about what to expect from their child's speech and just as important, about pre verbal skills like mirroring our child's expressions, taking turns, pointing, and shared attention. All parents need to know this stuff!

Many parents tell us they need very specific skills to help their child. Parents may need help to support their child's attention and listening, their understanding, their speech, signing or use of assistive technology, to help make sense of their child's behaviour, to help their child play and make friends. Parents also tell us they want support to manage their own feelings and expectations. Whatever the challenge, parents want information, advice, opportunities to observe good practice and have a go for themselves: **parents want training that's 'fit for purpose'**.

He couldn't suck: he was drinking from a tiny cup. The therapist taught us exercises to teach him how to suck and at just a few weeks this was amazing.

The VOCA is my son's gateway to communication but the therapist doesn't work with the special school who maintain it. I've only had two sessions of training in two years, along with the special school staff. It's left to me to programme. I don't know enough: it could be so much more useful to him.

Parents want to sit in on sessions so they can pick up tips. Parents ask what difference is an hour going to make if you aren't given advice about what to do for the rest of the week?

I would very much like as a parent to have more input and support in my child's development around communication by being offered ongoing signing courses and support with helping her to read and information on IT software that could support her with homework etc

I really didn't know what I was doing and how to help him initially. The services we have received have been excellent, the speech and language therapists really know what they are doing and have helped us enormously. They have been dedicated, caring and very understanding. The main thing that stands out is that they have gone at our son's pace and not rushed into anything.

Having a therapist visit at home and demonstrate practical ideas was brilliant.

Our therapist has identified specific things for us to work on in the home, at his nursery with his 1-1 carer and with Portage. This has been of significant effect over the past 4 weeks as we are all doing the same things – e.g. exaggeration of mouth/face movement when speaking, making sure he is looking at what our mouths and tongues are doing and Makaton signing which in itself has been a huge help for my son. Without her expertise I don't think our son would be doing this well.

The most helpful thing was the Hannen programme which empowers parents to help their children. It eased a lot of frustration.

Key message: its important parents understand why therapists do what they do.

I just didn't understand what they are doing and why. What is the playing all about? What has rolling a ball got to do with speech and language? It was ages before I had the courage to ask what it was about. And it was about turn taking, and getting my child's attention.

They used Makaton and at first I was concerned this may delay his speech further but it has become key to making himself understood. Being able to communicate his basic needs like I need a drink was a real breakthrough for him and helped build his confidence.

We was introduced to PECS by Sue Crane who I feel has been the most influential support for him so far, at the time his motor skills were poor and we didn't think he would be able to rely on Makaton alone. He now uses a

combination of the two. He has a very visual memory and can cope with lots of images at once. This has helped us to see the depth of his comprehension and helped him to express himself and his needs in much more detail.

We have been on the beginners Makaton course run by the MacKeith centre and it has been a real learning curve. At first we felt quite self-conscious signing in public but as we saw the results, we have also gained in confidence. Each new sign makes a new and exciting connection. The course was also one of the few instances where I met other parents of children with similar difficulties / uncertain diagnosis.

Parents need all round support because the implications of speech, language and communication are so broad and can have an enormous impact on behaviour:

I got no help: with support I'd have felt less like a failure. I felt humiliated by his behaviour. He hit children. At the time I didn't realise he was just trying to play. Looking back was I too harsh? I didn't know he didn't understand.

We signed up to PECS at great expense: to a course and to be trained, when we got there it was like teach us something we don't know!

Key message: Parents should not have to pay to learn how to communicate with their child. Whether the practical help parents' need is generic or specialist, more effort and resources should be put into making workshops accessible and free.

Key message: School terms are short and many parents want therapy sessions throughout school holidays.

What will make things better?

- A fundamental rethink about importance we all attach to children's communication.
- Better data collection: local commissioners need to know how many children have speech, language and communication needs
- Thinking about where children live and about the characteristics of their families, before setting up services.
- More money for SLCN
- When decisions about thresholds and service provision are based on evidence about needs
- Provision that is flexible and reflects needs rather than tailored to fit under resourced services.
- Better pay and better career pathways for therapists
- More specialist SALTs
- More prompt assessment after referral.
- Everyone has a 'can do' attitude
- Local practitioners who understand each others services
- When services work collaboratively with each other
- Seeing the same therapist consistently over a long time
- Schools prioritising children's communication needs
- Many more speech therapists working alongside teachers in schools and on the staff of the school
- More LSAs with speech and language training.
- Recognition of the skills other practitioners and services bring to the SLCN arena
- Small clusters of schools sharing a speech therapist
- Special schools and schools with a high proportion of children on the SEN register should have their own speech therapist.
- Children get the help they need for as long as they need it
- A one stop shop so parents can access information advice and support: access to an advice line for queries and concerns
- Help to claim benefits like Disability Living Allowance
- Parents kept in the loop: able to observe sessions and pick up tips
- Therapy sessions throughout school holidays
- Free and accessible training and workshops for parents: children with communication needs don't come with a handbook
- Parents who feel confident they can support their child's communication

Tips from parents to each other

Keep a diary

Once I started the fish oil supplement I started to keep a book. I didn't write in it every day – progress was too slow! But I did jot down any progress or sign of communication. It might have been a pointy finger trying to share something, or a sound, or the beginning part of a word, or a book he enjoyed. I then summarized this once a month or when I started a new bottle of fish oil. What this gave me was a small sense of moving forward. When you are in the thick of it, it sometimes felt like things were getting worse not better and by jotting things down I was able to celebrate small achievements. The other time I found this incredibly useful was when his intervention started. I did a timeline and used my summaries of what he could do i.e. a “t” sound for Thomas. This was really useful for the speech therapist, paediatrician and for me because it's hard to remember great detail all the “when did he” questions at these appointments.

Make a Visual timetable

This is a brilliant way of letting your child know in pictures on a time line what's happening throughout the day. It can be photographs, pictures, Makaton symbols or words. You laminate them and put some Velcro on the back.

On my wall I had a long narrowish board on which I could Velcro the symbols to match the morning plan breakfast – get dressed – play time – go out in car etc

Watch what your child eats

Cook using fresh ingredients. Avoid colourings and additives. Try fish oil. Parents recommend Eye Q – fish oil. See www.durhamtrial.org.uk, the Equazen website at <http://www.equazen.com> and <http://www.fabresearch.org>

I am convinced EyeQ helps. They have lots of options and the one most recommended is the vanilla flavoured oil which you can pour onto Ribena if your child won't take it off the spoon. You usually have to refill the cup at least once to catch all the oil stuck to the sides! I am sold on this.

Useful websites:

Talking Point at www.talkingpoint.org.uk This is the site developed by ICAN. *They send you a good pack.*

Makaton Vocabulary Development Project. Tel 01276 681368
www.makaton.org *I contacted them about courses, in the end I didn't go but I wrote a list of the key thirty or so signs I wanted to learn and asked my child's speech therapist to teach me one to one.*

Something Special at www.bbc.co.uk/cbeebies/ is a brilliant site with signing and Makaton symbols. Just go to the website and click on Mr Tumble, he looks like a clown. *TV Programs like something special shown on CEBEEBIES also has been a help in getting parents and children outside the SEN system to understand a bit about Makaton and occasionally use signing themselves.*

See, do and learn at www.dotolearn.com/games/learninggames.htm. is a web site providing activities to promote independence in children and adults with special learning needs *This site has some good free games and things.*

Winslow at www.winslow-cat.com 0845 2302777 is a company that supplies special needs resources.

Brightminds at www.brightminds.co.uk is a catalogue resource with loads of great stuff. *I bought some of their speech therapy software which my child's just getting into.*

Amaze is an invaluable resource if you live in Brighton and Hove www.amazebrighton.org.uk tel 01273 772289 *It is free and fantastic. Children registered on the Compass get special cinema trips and free swimming at any Brighton pools. Any Amaze parent gets access to a help line, handbook, fact sheets, a great newsletter with lots of info on playgroups etc. workshops and 1:1 help with education and benefits. And it's all free!*

Books

AFASIC publications are useful: they explain terms

Making the connections that help children communicate. The Hanen Program (from Winslow)

It takes two to talk Ayola Manolson (from Winslow) *a *** great book. This was the one that made so much sense and worked for us.*

How to talk so kids will listen and listen so kids will talk (Adele Faber and Elaine Mazlish) ISBN 0-380-81196-0 (better for slightly older children)

The Late Talker: What to do if your child isn't talking yet.

The Small Group Book – prepared by Jeanne Saunders Team (Brighton)**
fantastic resource £10 from Brighton Presens team.

How to understand and support children with Dyspraxia by Lois Addy
(from Brightminds)