

Chloe's Story

0-18 months

Looking back, there were signs that something was not quite right with Chloe from the start, though I didn't realise their significance at the time. She was my first child, born after a relatively straightforward delivery, apart from emerging into the world with the cord wrapped round her neck. The midwife dealt with this very efficiently, however, and I saw no reason to be unduly concerned.

After the birth, while still in the hospital, I was somewhat disappointed to observe that Chloe didn't appear to recognise or respond to my voice, as my reading about babies beforehand had led me to expect. As a small baby, she seemed very unhappy. My recollection of her first two months of life is that if she was not sleeping or feeding, she was mostly crying. When she woke up, she would want feeding immediately, so that she was feeding every two and a half hours or so, which was quite exhausting. She was also extremely sensitive to sudden noises. Even quite innocuous sounds, such as a drawer being shut, would make her jump, almost literally. Her entire little body registered the shock.

After the first couple of months or so, Chloe seemed much more settled though, and generally made good progress. By six months, she was babbling 'ma-mam-ma', and could sit up. I did notice, though, that trying to look at baby board books with her did not yield much of a response.

However, she sailed through her 8 month developmental check, and generally seemed to be doing well. She was quite an active baby who enjoyed crawling and walking round the furniture. I also noticed at this time that she liked feeling different textures - of clothing, paper, furniture etc. She would quite purposefully run her hands up and down things that attracted or interested her. She also developed a phobia of the vacuum cleaner for a while, which meant that I would have to try and do the vacuuming while she was asleep. Otherwise she would scream quite vehemently.

She walked unaided at 12 months and 1 week, and gave up crawling quite quickly after that. She babbled a lot at this time but there was no sign of recognisable words. Other mothers I knew reported realising that children began recognising and understanding some words around this age, but I could not see any sign of this. At about 14 months, she started saying 'tea' for mug. As she did not drink tea herself, this seemed odd, and I was not convinced then that it was a real word, though I now think that it probably was. The first word I was convinced was a 'real' word did not come until she was 17 months. At her 18 month developmental check, the health visitor expressed concern that her language development was behind, but as she seemed fine in every other respect, did not seem to think it was anything to worry about. In view of later events, I now feel that Chloe's language should have been monitored much more closely over the next few months, but of course it's easy to say with hindsight.

18 months to 3 years

Over the next year, things became increasingly difficult. Chloe's language improved but only very slowly. She gradually learned more words, and at 22 months produced her first 2 word phrase. I recorded this in her baby book as the first time she had put 2 words together, but I later realised that she was not in fact putting words together but reproducing a 2 word phrase that she had learned as a set phrase, a pattern that would persist for some years. As her language appeared to be improving, and I knew very little then about normal language development in children, it did not occur to me that there might be a problem with this. What really troubled me was her increasingly difficult behaviour, and lack of play skills. She gradually grew out of the stacking toys and posting boxes that young toddlers play with, but did not really seem to move onto anything else. It was sometimes possible to engage her attention in a puzzle, book or crayons, but I could not spend all my time on this. It did not help I suppose that I also had a new baby to care for, born when Chloe was 19 months old. Other mothers of children with a similar age-gap said they'd get the older one to 'help' with the baby but I was never able to manage this. Chloe showed little interest in anything I was doing or saying and would wander off into the garden or elsewhere in the house and amuse herself pulling books off shelves or emptying cupboards. As time went on, fragile items were moved to higher and higher cupboards and shelves to keep them out of her reach, which was not easy as she could climb quite fearlessly.

When I realised that Chloe would sit still and watch television, it was a relief to allow her to watch programmes aimed at young children, and I gradually learned to fit all my chores into these times, so that I could spend the rest of the time trying to do things with the children. I was very surprised, though, to realise that Chloe, then still only 2 and not really talking much yet, knew all her colours, shapes, numbers and letters of the alphabet. Apparently, she had taught herself from watching 'Sesame Street'. At this time, if we went out, she would insist on reading out all the letters on the street name signs. Any attempts to hurry her along would cause such a howl of protest that it simply wasn't worth the effort. I did go through a brief stage of wondering if she was exceptionally bright, and unable to cope with it emotionally, and that this might be the reason for our problems.

When she was two and a half, she had another developmental check, this time carried out by a doctor at the local child health clinic. It did not go well. When we went in, Chloe completely ignored the doctor, and initially did nothing that she was asked, much to my embarrassment. The doctor began talking about a speech therapy assessment, but Chloe then settled down, picked up a picture book and began naming everything pictured in the book (she had quite a large naming vocabulary by this time), so the doctor said that, on reflection, perhaps we could leave it, but that she wanted to see her again in 6 months.

I was shocked by this into re-doubling my efforts with Chloe at home, but to little avail. She would speak if she wanted to, but often did not respond to questions etc. I also began to notice that my younger child was already coming out with words at only 12 months or so, and seemed to be learning to talk so much more quickly than his older sister had, despite that fact that he'd had so much less attention because she'd been so difficult and time-consuming. This started to bring it home to me that Chloe might actually have a real problem, and that it couldn't all be my fault, as I'd sometimes wondered. Her behaviour didn't improve. She'd been dry at night for some time, so presumably had good bladder control, but she didn't seem to see the point of becoming toilet-trained during the day. She had begun to remove her nappy if I put one on her. So I began taking her to the bathroom at regular intervals. She didn't use it spontaneously though if she needed to go at other times, so we had a lot of accidents. I don't know if she was unable to recognise when she needed to relieve herself but she didn't like the sensation of wet knickers, and would take them off and fetch herself a clean pair. The health visitor thought this was rather peculiar and couldn't understand why if she could do that she couldn't learn to use the potty or toilet. About this time I gradually began to realise that Chloe really wouldn't be ready to start playgroup that September when she was nearly 3, as I'd planned, so I rang and delayed it by a term.

3 to 5 years

I was becoming seriously worried by this time, and when we saw the doctor again, we all agreed that Chloe should be referred to a speech and language therapist. I didn't know what she could do to help, or whether speech and language therapy would help at all, but I didn't know what else to try. It was about 6 months or so before we saw the speech and language therapist. By then, Chloe had started at playgroup, and within a few weeks, the playgroup leader expressed concerns about her language. So what was her language like at this point? It had slowly improved over the last year or so, but the improvement was very slow. It was still impossible to have a real conversation with her. She would only sometimes respond to anything you said to her. If you asked if she wanted a drink, she might say 'have a drink' or just help herself. If you said 'it's playgroup today', she might say 'go to playgroup'. She could not however answer a question like 'What did you do at playgroup today?' or 'What do you like doing at playgroup?', nor would she ever volunteer any information about playgroup. She only seemed able to talk about the here and now. She would sometimes make a 1, 2 or 3 word comment about something she could see, but would generally completely ignore any reply you made in response.

When eventually we had our first appointment with the speech and language therapist, she seemed a little sceptical at first that there might be a serious problem. She commented that Chloe was quite tall for her age, and that perhaps people had unrealistic expectations as a result. However, once she tried to start talking to her, she quickly realised why everyone was worried. I was quite impressed by the amount of language Chloe was producing, but the speech and language therapist asked if this was

typical of her usual speech, and said that really she should be further on than this. She also expressed real concern that Chloe did not even seem to understand what was being said to her. The speech and language therapist asked for instance what her brother was called and whether he slept in a cot or a bed. She was quite unable to respond to these questions. She was by this time a little over 3 and a half.

By this time, I was beginning to notice other things that were worrying me. All young children enjoy a reasonable routine to their lives, but Chloe took this to excess. If we went out to the shops, we would have to go the same route, visit the shops in a specific order and always buy 6 apples and 4 oranges which Chloe counted into paper bags at the greengrocer. Many routines at home, such as going to bed had to comprise a number of elements, all of which had to be completed in order. Any attempt to vary these rituals would lead to such severe tantrums that it simply wasn't worth the effort. As it happens, I have a brother who is autistic, and I began to recognise this behaviour as being very reminiscent of him at around the same age. When we next saw the speech and language therapist, she began talking about Chloe 'building a wall between her and the rest of the world'. This sounded like autism to me and I asked whether she thought Chloe might be at all autistic, explaining our family history. The speech and language therapist said that she could not say but promised to arrange an assessment with the community paediatrician. In the meantime, the speech and language therapist suggested a few strategies to try at home, some of which did seem to be quite helpful. In particular, providing a sort of 'running commentary' on what Chloe was doing for a few minutes each day did encourage her to say quite a lot in response.

At this time, Chloe's play skills were becoming odder and odder. I was quite startled one day when she walked out of the bathroom carrying two bottles which she purposely placed in front of her and said, quite unprompted, 'Use shampoo and conditioner? Take two bottles into the shower? Not me; I just wash my hair and go', mimicking exactly a commercial that was often on TV at the time. It was also astounding, because she never otherwise produced so much language at a time. She was still at this age, not quite four, unable to use the pronoun 'I' (other than in parroted phrases), always calling herself 'Chloe'. As time went on, she began to mimic favourite videos too, and would often recite her entire 'Thomas the Tank Engine' video while pushing a toy train round and round the railway. She also loved acting out 'Goldilocks and the Three Bears' when all the family were home. She herself would take the part of Goldilocks (as she is blessed with blonde hair this worked quite well). Her little brother would have to be baby bear, and we, her parents, would have to be Daddy and Mummy Bear. She would carefully set up all the props ready (they were always the same ones). Then it would somehow be conveyed to us that everything was ready for the story to be re-enacted. We would then all have to play our parts.

That summer, shortly before her fourth birthday, Chloe attended an intensive language course run by two speech and language therapists, for two hours each morning for a week. She seemed to enjoy

going, but it didn't seem to make much of a difference to her language. At the end of the summer, we had our assessment with the community paediatrician, who was not convinced that we were dealing with autism in any form, but agreed that there was a real problem with language. She arranged a referral to an educational psychologist, who we eventually saw some months later.

In the meantime, Chloe attended another speech and language therapy course; twice a week for an hour each time. The course lasted about 6 weeks. At the end all the parents had an interview with one of the speech and language therapists who had run the course. She asked whether I felt it had helped at all. I replied honestly that it did not seem to have made much difference. The speech and language therapist agreed and recommended waiting until we'd seen the educational psychologist before resuming speech and language therapy.

I felt very let down at this point. The paediatrician felt that the problem was language-based, but speech and language therapy did not seem to be helping. After some consideration, I visited my GP and asked for a referral to a paediatrician with expertise in this type of difficulty. We were then referred to the child development centre at our local children's hospital. This entailed more waiting and a number of different appointments over time, but eventually led to a diagnosis of a mild autistic spectrum disorder, with the language difficulties described as being semantic-pragmatic in nature.

In the meantime, the speech and language therapists on the last course Chloe had attended had given us a booklet of ideas to do at home, and we tried working through this. It gradually became clear to me that it was not really aimed at the type of difficulties Chloe had. A lot of the work was around naming animals, and knowing the difference between 'big and little'. These were all things she could do, and had been able to do for some time, but the problem was she simply would not do them to order. I remember on one occasion, asking Chloe to give me the 'big spoon' from the box of different-sized spoons in front of me. Chloe simply turned away and stared into space while my little boy (then about two and a half) lifted out the big spoon and gave it to me, saying 'Here you are, Mummy'. From that time onwards, he was clearly ahead of her in language and communication skills. The one really useful part of the speech and language therapy pack was the work on prepositions such as 'in' and 'on'. There were also some suggestions for activities to practise things such as listening skills. I also developed some of my own ideas to come up with some little games and other play activities to work on various aspects of language at home.

In due course, we were visited by the educational psychologist, who was very helpful and appeared to have a good understanding of Chloe's needs. She felt that she would benefit from an immediate placement in the nursery section of our local language unit, and recommended this to the LEA. The LEA turned this suggestion down on the grounds that the forthcoming relocation of the language unit from its then location on a hospital site to a school setting would be too disruptive for Chloe. They did, however, initiate the statutory assessment process, at that time still under the old 1981 Act, and in due course, Chloe was given a statement and place at the language unit.

Infants School

Chloe started at the language unit in September 1992, shortly before her fifth birthday. The unit at that time catered for about 15 children between the ages of 3 and a half and 7. It was staffed by two full-time teachers and a co-ordinator, who spent half of her time there, and half of her term working for the peripatetic service that supported children in mainstream schools. There were also two support assistants and a speech and language therapist who was there every day between about 10.00 and 2.30.

When I collected Chloe after her first day, she just said 'playgroup' as she left the building, and then looked over to the dining hall and said 'dinner'. She was still quite unable to answer any questions about school, but quite often she would 'parrot' conversations that she had heard that day, and even acted out entire schooldays, reproducing very convincingly the noise of a school playground. In this way, I gradually learned the names of the staff in the unit, and the names of the other children, and gleaned some idea of what actually happened at school.

After Chloe had been there a few weeks, I had my first parents' evening appointment. This was my first opportunity for a detailed discussion with the speech and language therapist. She explained that Chloe's language was very uneven and disordered. Some aspects of her language were still at the level of a two year-old. So what she was having to do was go right back to a level Chloe had mastered, and then start building up from there. She also commented that Chloe did not seem to know what language was for, and that this needed to be worked on. She told me that Chloe was having three formal speech and language therapy sessions a week, one on her own, and two in a small group with two other children with similar problems. She warned me that Chloe was likely to need a lot of help for quite a long time.

Chloe proved to be a bright child, who found schoolwork quite easy. She picked up reading very quickly, so much so, that there was soon a risk that she would be reading more than she could actually understand. As a result the school kept her on one reading level for about a year, working through a range of different books at the same sort of level of difficulty, while they worked on her language. The school did not send books home to practise reading, as she did not need to do this. Instead they sent books with pictures and few, if any, words for Chloe and me to talk about to encourage her language.

After she had been at the unit for about 6 months, Chloe's language began to improve noticeably. Her behaviour also began to improve and she slowly lost some of her quirkier little habits, such as making odd little facial expressions, and moving crayons up and down in front of her face. Up until this time, Chloe had spent all her time at school in the unit, but now, in the third term of her first year there she began spending one afternoon a week in a mainstream class, mostly engaged in play-based activities.

Before we knew it, she'd been at school a year, and it was the summer holidays. This was a long break from the sustained intervention Chloe had been receiving, and I did feel that she lost some ground. We were all, including Chloe, pleased when September came round again, and she returned to school. She quickly caught up again, and continued to progress. Her play skills also began to improve noticeably. She now began to engage in imaginative play with her brother in a way that she hadn't done before, though she could still be quite inflexible (the game had to go as she planned it!). She even began to make up little storylines for games for dolls and other toys in a way she hadn't before, though they still tended to be the same storylines done over and over again.

By the end of that school year (Year 1), her language was only about 6 months behind, though she still had significant pragmatic difficulties that were not easily measured by the conventional testing. When she moved into year 2, she was initially timetabled to spend half her time in a mainstream class, with support. This worked well and was gradually increased until by the end of the year she only spent a few hours a week in the unit. At her annual review at the end of year 2 Chloe's language scores were all age-appropriate. Her pragmatic skills were still poor, though, and so it was agreed that she would remain attached to the language unit in the junior school.

Junior School

By now, the language unit had expanded to include a junior school section. It was run more as a base than a unit. The children spent most of their time in their mainstream classes and were withdrawn for additional support. Initially, Chloe was withdrawn for four sessions a week. This gradually decreased to just one a week by the time she left the school. The main focus of support for Chloe was on her pragmatic and social skills, which were now her main area of difficulty. For example she would sometimes speak to other people in an inappropriate manner, e.g. she might talk to the headteacher as though she were another child. She also still sometimes ignored people who spoke to her. She had a few friends by now, but still the teacher in charge of the base often expressed concerns that she seemed very much on her own at lunchtimes. She sometimes talked to her about it, but Chloe always insisted that she was all right and perfectly happy. Perhaps slightly more worryingly, her brother, who by now attended the same school (we were fortunate in that the language unit was attached to a school within easy walking distance of our home) reported that Chloe would sometimes barge into and take over a game played by younger children. Gradually, as she moved through the school, Chloe's pragmatic skills slowly improved though it remained a problematical area.

Academically, however, she was fine. She was one of the brightest children in her class (and knew it), and needed no curriculum support. Eventually we had to start thinking about secondary school placements. By the time Chloe finished junior school there was a secondary school language unit in our area, but everybody agreed that she no longer needed this level of support. Chloe herself very much objected to being 'special needs' and was not happy about being withdrawn from class for supplementary work. So it was decided that she should go to a mainstream secondary school.

Secondary School

Obviously, we felt a certain amount of nervousness about the transfer to a mainstream secondary school, especially at the start, but in the main, it's worked pretty well. The staff at her secondary school have worked hard to support Chloe, though I rather suspect they haven't really understood the nature of her difficulties very well. I gave them some information before Chloe started there, but they may have found it difficult to relate to Chloe as her difficulties are now so subtle and high-level.

The first issue that arose was around speech and language therapy. This was still specified on her statement as the school and I pointed out to the LEA. This posed a difficulty, as the local NHS service did not provide speech and language therapy to children of secondary school age. Eventually, the LEA agreed to arrange for a speech and language therapist to come and observe Chloe, and give guidance to the staff on strategies to use to support her. This seemed a reasonable compromise, as Chloe herself did not wish to be singled out as special needs.

Initially, the school did try including targets to aid Chloe's social development on her IEP, but she proved very resistant to them, not enjoying the extra-curricular activities she was encouraged to join. So they were gradually dropped. This has not proved too problematical an area for Chloe at secondary school anyway. At lunchtimes she has always been able to go to the library or computer room, so hasn't been so conspicuously on her own as at primary school. She has gradually joined in various clubs and other activities at school. Although she does not have many close friends, she has over time made some, and she generally seems to be well-liked by the other girls at her school. She has even been voted form captain a couple of times. As she is very organised, and thrives on being given responsibility, this has suited her very well.

The academic side of secondary school has perhaps been a little tougher. The standards of work demanded have obviously been higher than at primary school. Chloe has not found this too difficult in itself. She has, however, sometimes found it hard to concentrate in classes that did not interest her very much. She does not always respond well to criticism or correction, even when it's intended to be constructive, and has at times taken a rather rigid approach to her work, insisting on doing it in a certain way, even when her teacher has explained why she wants it done differently. These difficulties led to a few detentions in her first years at secondary school, but the school have worked hard to explain to Chloe that they are trying to help her do well in her exams, and she has gradually learned to be a little less inflexible. Throughout her time at secondary school, she has had weekly tutorials with her head of year, which have come to focus mostly on improving her classroom performance. Inevitably, as she has moved through secondary school, academic performance and public examinations have taken on greater importance. Now that she is halfway through year 11, the focus is now very much on her GCSE's. We are confident that she will do herself justice in the summer when she takes them, and feel that this is really a success story, considering how bleak things looked 10 - 12 years ago, when Chloe seemed to have so many problems.

This shows what can be achieved if children with speech, language and communication needs are given the right support, and how important it is that they should get that help.