Identifying and Supporting Children with Very Special Educational Needs

**We need to know**
Identifying and supporting very young children with special educational needs
This chapter sets out to show that even though there is legislation which should ensure that children who have special educational needs (SEN) should be identified at a very early age, their educational needs met and their parents supported, there are great discrepancies in actual practice.

How are children’s special educational needs identified when they are under 3 years old? What are the responsibilities of educators? How do parents react to learning that their children have special educational needs? Why is it that the experiences of both parents and children with SEN can be so different?

There is general acceptance that early detection of special educational needs is important in order to improve a child’s quality of life, by making early intervention possible. This chapter argues also that early diagnosis or clarification of a child’s special needs, provided it is conveyed appropriately and accompanied by support, is essential not only to a child’s development but also to parents’ feelings and capacity to support the child. Clearly, the ability to identify SEN, understand the nature of a child’s difficulties and suggest appropriate methods of intervention is also of great significance to all those who work with young children.

**Special educational needs and children under 3**
In most local authorities there is a well-established network of services for the under fives, where health authorities (including NHS trusts and family health services), social services departments, voluntary agencies and LEAs work closely together to make provision for young children with SEN. Local authorities have a duty, under the Children Act 1989 (implemented in 1991) to ‘Safeguard and promote the welfare of children in need and to promote the upbringing of such children by their families, so far as this is consistent with their welfare duty to the child by providing an appropriate range and level of services’ (Department of Health 1991: 5).

Under the Children Act 1989, a child is ‘in need’ if:
- s/he is unlikely to achieve or maintain, or to have the opportunity of achieving or maintaining, a reasonable standard of health or development, without the provision for her/him of services by a local authority under this part;
- his/her health or development is likely to be significantly impaired, or further impaired without the provision of such services;
- s/he is disabled.
Although there is some overlap, there has been concern that this Act does not refer to the term ‘special educational needs’ which had been introduced in the Education Act 1981 and confirmed in subsequent Education Acts (1988, 1993 and 1996). The Code of Practice (DfE 1994) contains a section on the under-fives and includes a particular reference to children under 2. Under the 1993 Education Act an LEA may assess the educational needs of a child under 2 subject to parental consent, and must assess if requested by a parent. As a result, if necessary, a statement may be produced specifying the nature of special educational provision to be made. The Code of Practice suggests that statements for children under 2 ‘will be rare’ but makes it clear that the LEA should make appropriate educational provision such as home-based teaching (for example the Portage system), a developmental play programme (perhaps at a nursery or assessment centre) or home-based support from a peripatetic service (for children with learning or visual impairment, for example).

There is an emphasis on close liaison with the health service and the need for careful monitoring. Where a child between the ages of 2 and 5 is not attending a nursery class, school or centre, then it is envisaged that parents, health or social services will remain the major sources of referral for assessment of special educational needs. Where the child is attending a nursery school or class, however, there is an expectation that the procedures for identifying and meeting SEN outlined in the Code of Practice will be followed. This involves noting concern, notifying parents and working closely with them. There may be referral for multidisciplinary assessment involving an educational psychologist and, in particular, a child development team involving child health services to establish whether or not there is a physical explanation for the difficulty (such as hearing or visual impairment), or to obtain help and advice on the management of difficult behaviour.

Emphasis is put on parents’ rights to be informed about, and involved in, all decisions when a child is under 5. Health services and trusts are central in identifying children under 5 with SEN, and they are asked to supply parents with the names of voluntary organizations who may offer a variety of forms of assistance. Similarly, under the Children Act 1989, local social services departments must provide written information on the full range of services in their area for children ‘in need’ and ensure it reaches those who might need it.

**Identifying the SEN of under-threes**

Hall (1996) usefully distinguishes between *low prevalence, high severity* conditions which include conditions for which a pathological basis has been demonstrated or can be presumed (such as cerebral palsy, aphasia, severe learning difficulties, severe language impairment, autistic spectrum disorder) and *high prevalence, low severity* conditions in which there is a combination of genetic, constitutional and environmental factors, sometimes including neurophysiological or neuropsychological dysfunctioning (for example dyslexia, moderate/general learning difficulties). Clearly, while the former are more easily identified at an early stage, the difficulties should be seen as a continuum not a dichotomy. Four criteria may be used in deciding that a ‘condition’ exists. There must be a ‘distinctive’
response to interventions;
aetiology (causation);
pattern of presenting symptoms;
prognosis.

It is important to note that ‘high prevalence’ needs are more easily identified after a child has reached the age of 5+ and concern is expressed as a result of difficulty or even failure in learning. However, many difficulties experienced in later learning may arise from physical, sensory or other impairments which could be identified earlier (for example, a high proportion of children experiencing dyslexia manifest speech and language difficulties below the age of 5). While some caution must be exercised over ‘predicting’ potential difficulties, there can be no doubt of the need to identify a child’s SEN as soon as possible so that they can be enabled to make the most of their abilities. With the aid of speech therapy, physiotherapy, teaching and medical intervention where necessary, their independence, cognitive, physical, motor, social and emotional development can all be promoted. At the same time, the burden of stress on parents can be reduced, together with feelings of isolation. Financial support may be available, and the need for this should not be ignored.

In many cases, identification of SEN will be a matter of complex professional judgement which may have begun before the child was born; several local authorities have a comprehensive assessment system. Soon after birth there is a medically based assessment in hospital. This will be particularly thorough if any adverse signs have been noted at prenatal examinations. Babies showing particular conditions, Down’s Syndrome for example, will be referred to a child development centre or be visited by a senior medical officer and specialist health visitor. They will examine the baby and outline an intervention programme, often involving other professionals, such as physiotherapists. Thus the beginning of this early assessment process is medical – doctor, paediatrician, specialist health visitor.

At 3–6 months parents take their babies to the child development center for further assessment where they are likely to be seen, interviewed and the child assessed by various members of a multi-professional team. Possible members of such a team are: paediatricians, doctors, specialist health visitors, orthoptists, occupational therapists, speech therapists, educational psychologists, audiologists, dieticians, dentists, social workers, teachers and Portage workers. (Not all local authorities have such a centre, but they should provide a similar service.)

Emphasis is placed on the need for professionals to work with parents as partners and the contributions which parents can make to an informed and full assessment of their children are widely acknowledged. Despite the expectations under both the Children Act 1989 and Education Acts, parents are not always aware of their rights and often have incomplete understanding of the nature of their involvement. Gross (1996) reports on some parents in one LEA who, when asked if they wanted to contribute to their child’s assessment, wondered how much the contribution might be as they were not sure if they could afford it!
Traditionally, and even with the establishment of child development centres, assessment has taken place in settings which are unfamiliar to child and parents, and this in itself has highlighted the power differential between professionals and parents in determining outcomes. The Code of Practice proposes: ‘Young children should be assessed in a place where the child and family feel comfortable’ (DfE 1994: 99). In the same way, if parents have ‘access to other parents and to family centers and other local services, play and opportunity groups and toy libraries, then they might have direct impact on the effective implementation of any assessment process or educational programme’ (p. 99).

Simeonsson et al. (1995), in a comprehensive discussion of family involvement in assessment, emphasize that if parents and professionals are to act as partners there must be mutual awareness of respective skills and attitudes. It is important when we work with parents of young children, and are seeking their advice about a child for whom we have concern (or about whom they have expressed concern to us), that we appreciate that they enter into any interview situation with both apprehension and expectation. These will include expectations:

- as to the manner in which the assessment will be carried out;
- about the nature of information they will be asked to provide;
- of a clear diagnosis (identification of difficulty);
- that there will be proposals for intervention.

If their expectations are not met, then the involvement will be perceived as unsatisfactory and incomplete. Moreover, this experience is likely to affect their views of the professionals/services involved and any future encounters. It is worth remembering, when working in a nursery with very young children, that a negative experience with a professional involved earlier with their child may be generalized to all professionals, thereby adversely affecting your interactions with the parents. Simmeonson et al. showed that there was a strong mismatch between the professionals and parents’ perceptions of the assessment process: 62 per cent of professionals said they always asked personal questions of parents whereas only 6 per cent of parents anticipated such questions. In terms of involvement in the process:

- 44 per cent of professionals expected parents to ‘wait in the lobby’ while the child was assessed;
- 27 per cent wanted to see parents actively working with the child;
- 13 per cent invited parents to ‘validate’ assessment results;
- 13 per cent invited sharing attitudes and feelings.

Clearly, even where multidisciplinary teams do ‘involve’ parents there are different constructs of involvement and partnership, which require reconsideration. Nevertheless, more than 80 per cent of parents found the experience helpful overall. However, a significant 33 per cent disagreed with the results. In some local authorities, all children are assessed by a multi-professional team at 3–6 months, 9–12 months and again on school entry. Children who are identified as having SEN will have their development assessed and monitored by this team until
the age of 5, when they become the responsibility of the LEA and its associated health services. They may well still be seen by a multidisciplinary team but not necessarily involving the same people. Developmental plans are reviewed every three to six months. The plans may involve:
- other tests/interviews with particular professionals;
- advice as to what other professionals may offer;
- a ‘teaching/learning’ programme.

Not all authorities observe the above practices, as illustrated in the studies below. It is often considered that the provision and coordination of services for young children is at its best in the pre-school years. Unfortunately, there is still evidence that ‘breaking the news’ to parents is not always handled sympathetically. Thus there are reports of mothers/carers being told without the presence of a partner or family member or friend for support; of parents’ own fears being belittled; of information known to the doctors and nurses being withheld, only to be ‘let out’ inadvertently, by junior staff on some other occasion.

**Parents’ perspectives**

Since the 1970s much has been written about the needs of parents/carers of children with special needs, particularly those children with a physical, sensory or learning disability. There have been several attempts to produce taxonomies of parental reactions to learning about their child’s difficulties, and it is important not to generalize about parental reactions and feelings. The Audit Commission (1994) noted that parents are frequently the first to detect that their child is not developing normally. In their survey, 40 per cent of the sample parents were the first to identify a problem but over 50 per cent of them were not believed or taken seriously by the professional to whom they turned for advice. General practitioners were cited most frequently as failing to take the parents’ concerns seriously.

Sometimes, of course, conditions such as Down’s Syndrome are identified at birth, although it may be impossible to predict future development for some time. Parents tend to feel dissatisfied when a professional’s answers appear inconclusive or indecisive: they are anxious to know what the future may bring and may, as a result, feel that the professionals they meet
- are professionally inadequate – they don’t know enough (and therefore the parents seek ‘another opinion’);
- are trying to protect the parents from learning some ‘bad news’;
- don’t understand parental concerns;
- are patronizing them and ‘gatekeeping’ knowledge.

What parents really want is a basis for planning their lives and that of the child. It may well be, of course, that they also have some hope or need to believe, that the child will one day ‘improve’. Often this leads them to follow any suggestion about ‘methods’ which appear specifically designed for children with similar difficulties. It is important for anyone who works with very young children with SEN to be aware of
the range of reactions their parents may experience, in order to work cooperatively with those parents. The plea of ‘we need to know’ does not mean that the information given will necessarily be welcomed, although there are numbers of parents who react with apparent calm acceptance and are able immediately to plan to meet needs successfully and obtain maximum support for their child from within and outside the family. However, the following reactions to learning about a child’s disability were noted by Mackeith (1978):

- feelings of protectiveness (of ‘the helpless’) which could become overprotection;
- ‘revulsion’ at the abnormal (a strongly emotive term, but possibly experienced by some people);
- anxieties about parents’ own competence in caring for the child and about the possibility of having future children with a disability;
- feelings of bereavement – some people go through ‘grief’ reactions which have been compared to bereavement, for the loss of the ‘normal’ child they might have had. This often gives rise to anger but then is usually replaced by adjustment to the situation;
- shock – the surprise of the news – which can lead to denial of the disability or of the professional’s diagnosis, anger (general or directed towards professionals) and resentment;
- guilt – a feeling of personal ‘blame’ for producing a child with difficulties and fear that the child will blame them as parents. This reaction is probably far less common than was once believed;
- embarrassment – fears of social reaction.

It should be noted that this categorization may be misused and educarers should be wary of trying to identify reactions in this way. The final category here, for example, may not be ‘embarrassment’ but fears that society and different social groups will not ‘accept’ their child. In other words this taxonomy does not reflect a ‘social model’ of disability.

Implications for educarers
The ‘news’ that a child has a special need may produce any (or a mixture) of the above emotions, to varying degrees. Many parents may need support in working through these emotions, and workers with very young children must be aware that even where parents have known of the special need since their child’s birth, they may still be experiencing difficulties in adjustment.

Any transition point – entry to nursery and later, entry to school – marks a significant stage in their child’s development and their inclusion within, or exclusion from, social settings. For many parents, the ages of 18 months to 3 years is the period where their children’s needs are first identified, and therefore parental feelings may be at their most heightened. Sadly there are still examples, as will be shown later, where parents are not informed of their children’s difficulties in a way which shows any consideration for their feelings – in the words used to them, the time they are given or
the situation in which the information is conveyed.

In some cases, teachers and nursery nurses may be the first to voice concern to parents about a child’s difficulties, and indeed they are requested to do so in the Code of Practice. It is important to plan carefully how to do this, giving thought to the timing and setting of the occasion and the language used and the support offered. This should show you have thought of possible action that can be taken and where appropriate advice and support is available. Educarers should also be prepared, not for one of the earlier reactions, but for some relief to be expressed by a parent who might have had concerns and been afraid to voice them, or who, as in the case of one of the mothers described later, had not been listened to by another professional. When there are other children in the family the effects on them also need to be considered, as the case studies later in this chapter show. Parents will be concerned about the amount of attention and time which are inevitably spent on meeting the needs of a child with SEN and which might adversely affect the intellectual, emotional and social development of other children.

Where there are older siblings, then there will probably be a certain amount of jealousy and expectations of ‘looking after younger brothers and sisters’. How is the family to decide what is normal and what is placing undue burdens on all members of the family? I know of several families where older children feel that their teenage years were fraught because they were expected to spend a lot of time helping parents to care for a younger brother or sister with severe learning difficulties. They echo the teenage mother of a child with SEN who said, ‘There’ll never be a time when I’m young and free!’

They have to test out their friendships by seeing whether or not their friends can ‘accept’ their brother or sister; they may also feel guilty if they express frustration or resentment even to themselves. The birth of a baby with special needs (or the existence of an older brother or sister with SEN) may begin affecting parental interactions with the ‘normal’ 2- to 3-yearold child in a nursery: and educarers should not become so preoccupied with their responsibility for recognizing and meeting the needs of a child with SEN and their parents, that they ignore the fact that they may be teaching the siblings of children with SEN.

**Identifying young children with SEN in the nursery**

Not all children under 3 entering nursery provision will have had their SEN identified by health authorities and child development teams. Responsibility for early identification and assessment therefore lies with nursery staff. Assessing very young children and predicting their future development is made extremely difficult by the very varied nature of normal human development. All that can be said for certain is that while there should be a general increase in complexity and integration of behaviour and sophistication of problem solving abilities, the normal development of any one child will show much individual variation, at times
appearing to stand still, at others to show very rapid advance. Emotions will come and go. Children with SEN may show either general developmental delay or ‘disordered’ development usually resulting in a ‘spiky’ or uneven profile. Thus some may have poor spatial or motor abilities yet have an extensive vocabulary and advanced use of language. Some may seem uncommunicative yet demonstrate comprehension far beyond their use of expressive language. Some may build towers and bridges with blocks, but appear unable to recognize a rhyme; some may sit and look at picture books, happily turning pages or ‘share’ a story with an adult; others squirm and run away before the first page is turned. It is important not to take too simple a view of ‘general developmental delay’.

At no time does development take greater strides than in the first three or four years of life. We therefore need to expect greater diversity in levels of development of children aged 2 to 3 without affixing a label and assuming a set of ‘expectations of development’ will automatically follow. Hall (1996) refers to the following rates for particular problems in pre-school children:
• waking and crying at night – 15 per cent;
• overacting – 13 per cent;
• difficulty settling at night – 12 per cent;
• refusing food – 12 per cent;
• polymorphous pre-school problems – high activity, tantrums, disobedience, aggressive outbursts, tearfulness, clinging – 10 per cent of 3-year-olds.

In many cases these disappear and most can be managed successfully, but Hall points out that nearly half the psychiatric disorders in 14- to 15-year-olds represent conditions which have existed for many years. What is important, therefore, is to note ‘concern’ about children’s difficulties, devise intervention strategies and monitor progress. The Code of Practice provides useful guidelines.

The key to assessment of children under 3 lies in close observation, which includes listening to and interacting with children in all their activities, including play. Particular attention should be paid to their development of language and communication skills, physical and motor development, self-help skills and increasing ability to interact with other children and adults. Where progress gives rise for concern then the child’s teacher or key worker should prepare a written report setting out the child’s strengths and weaknesses and noting evidence for the concern. The use of parent assessment material and developmental checklists should be considered. Parents should be fully informed and the child’s name should be placed on the nursery’s SEN register.

Many nurseries already have their own systems in place and have often been supported by health visitors and special schools or support services in devising checklists and guidelines. Where the difficulty persists over five or six weeks (or is very severe) then the nursery may either devise an individual programme and place the child at stage 2 or 3 of the Code of Practice or refer for external support or further assessment. Because the child is so young, this will nearly always involve contact with health services and a hearing and sight examination.
It is possible to obtain statutory assessment which may lead to a statement for children under 3. Where a child over 2 is attending a maintained nursery or school then the LEA expects that Code of Practice procedures are followed. Many very young children, however, attend provision made by social services or voluntary or independent sectors. They are urged to share concerns and involve appropriate services and the LEA as early as possible.

Children with very complex needs may be given a statement (in some LEAs this may be necessary to access a particular service). A statement must include:
- all available information about the child, with a clear specification of the child’s SEN;
- a record of the views of the parents and any relevant professionals;
- a clear account of the services being offered, including the contribution of the education service, the educational objectives to be secured and the contribution of any statutory and voluntary agencies;
- a description of the arrangements for monitoring and review.

The LEA should ensure regular review of any specific educational targets. There should be close collaboration with non-educational service providers to ensure good record keeping and to ‘avoid duplication of investigations when the child is over 2 years’.

Statements for children under 5 are subject to review at least every six months to ensure that provision is appropriate to meet the child’s needs, in addition to carrying out annual review in accordance with the regulations.

Special educational provision for children under 3

This might include full- or part-time attendance at a nursery school or class playgroup or opportunity playgroup. For a description of one such ‘opportunity group’ see Brenda Kyle’s chapter in *Working with the Under-threes: Responding to Children’s Needs*. There may be additional support from a learning support teacher who may give one-to-one help, or from a peripatetic hearing or visual impairment service. In some cases there may be a home-based learning programme – the Portage system is used in several LEAs – or a locally devised teaching service, perhaps based on ‘play’ and involving parents in teaching their child. In cases of behaviour difficulties, support may be available from an educational or clinical psychologist or a peripatetic support service. In some cases, there may be access to non-educational services: speech therapy is by far the service most often identified for young children with SEN.

So far, the chapter has considered what provision there should be to identify and meet children’s SEN, emphasizing the importance of procedures for assessment in order to obtain access to health and educational services. The chapter has highlighted the need to work in partnership with parents and to identify children’s SEN early. Two case studies give contrasting examples of practice.
Mark Smith

Mark is the second child in a family of three children. His elder brother Daniel was just over 3 years old when he was born. His mother was a nursery nurse who had stopped working when Daniel was born. His father works in a bank in the large industrial town where they live.

Mark developed normally until he was about 15 months old, by which time he was walking, had normal language development and showed a lively curiosity. His mother cannot remember exactly when she became aware that Mark had started walking around with his head down, and started bumping into chairs and the doorway, and falling over things. ‘I remember one day suddenly thinking that’s the fourth time today I’ve told him to look where he’s going.’ Her husband tried to allay her fears by saying ‘It’s just a habit’, but agreed that Mark should be seen by the doctor.

Their GP immediately referred Mark to the local hospital for further tests. Mrs Smith recalls that she was fortunate in having her own parents living nearby who could look after Daniel while she began what seemed like ‘a nightmare of not knowing – not knowing whether he was brain-damaged, blind, or both; not knowing whether he would “get better” or whether the condition could be cured by an operation’.

The family was fortunate in that the hospital was also the location of the regional child development centre, which made a full assessment, suggesting that the eye condition was only temporary, and arranged a return check-up visit for five weeks’ time.

On return to the hospital, the specialist prescribed an ointment to be administered four times daily. Mark’s mother had great difficulty applying this, because Mark cried and tried to fight against it. His father administered it in the morning and evening before and after work. But there was no improvement. Mark’s mother noticed that Mark began to sit in one place and hardly move. He showed no interest in his toys, even when handed them.

At this stage, Daniel, nearly 5 years old, started primary school, and Mrs Smith took him to school, pushing Mark in a pushchair. On the way she talked about things she could see, trying to draw Mark’s attention to them. She began, however, to feel guilty that Daniel was being neglected during this very important period of his life because she could only think of Mark. Mark was now about 18 months old.

After using the ointment for six weeks, with no improvement, Mark was referred to the nearby city’s Royal Eye Hospital, where infantile glaucoma was diagnosed. Mrs Smith describes her feeling as ‘one of relief’. ‘Although it may sound strange, I thought at last I’ve got someone who knows what he’s doing. I’d heard of glaucoma, although only among old people. I was told that he would have to have an operation to reduce pressure.’

Mrs Smith then went through a stage of apprehension and anxiety about how lonely Mark would feel in hospital. There was open visiting for parents and a lot of support from hospital staff.
Mrs Smith’s parents cared for Daniel, in his own home, to try to reduce the stress on him and his parents. Mrs Smith recalls trying never to cry in front of Daniel and making great efforts to help him learn to read, and playing with him whenever possible: ‘I remember screaming at John, my husband, “that’s just what Mark will never do”.

At this time she was contacted by a visiting teacher from the peripatetic support service for the visually impaired. This teacher had been alerted by the local child development centre, and visited Mrs Smith before Mark’s operation and arranged a visit to follow the operation. Of all the professionals, doctors, consultants, nurses and psychologists encountered by Mrs Smith during these months of uncertainties, she found the visual impairment (VI) support teacher, Mrs Lee, the most helpful and supportive. ‘She was very matter of fact and never tried to offer false hopes. What she did, however, was start to make me plan for the future. She told me what was available.’

Mrs Lee carried out an assessment of Mark’s development, within the home, using the Sheridan and Oregon checklists. She offered suggestions for improving motor and language skills and began to visit weekly. She also began procedures for assessment which might lead to the provision of a statement of SEN. Mr and Mrs Smith were able to contribute to the assessment and a statement was completed within three months. At the age of 2, Mark was given a place in a mainstream nursery school near Daniel’s primary school (which unfortunately had no nursery provision) and provided with a special support assistant (a trained nursery nurse).

The head of the nursery, the teacher and special assistant all met with Mr and Mrs Smith before Mark started, and discussed the parents’ concerns for their son. While at the nursery, the VI support teacher visited weekly to monitor progress and advise staff. Mark settled quite well at the nursery after a tearful first week. The nursery staff discussed a toilet training programme with the mother and this was put into operation within three weeks. By the middle of his second term he was completely trained, wearing normal pants and was proud to be ‘a big boy’.

By this time he became more independent in dressing. The VI teacher taught him the positioning of the main pieces of furniture so that he could move around the room. Although there were some difficulties when children were enjoying floor-play or equipment was left on the floor, staff and other children became far more conscious of the need to enable Mark to gain confidence in moving around, and he was taught to use particular paths to the main resource areas. He began to talk to other children and be included in their play. Advice

A report on Mark aged 2 showed:

*Physical development* Average height and weight for age.
*Social skills – self* Feeding skills poor – uses fingers adequately.
Tries to feed self but not well coordinated. Help
needed at meal times from special support assistant. Not toilet trained – still in nappies. Informed mother/NNEB after the event, i.e. wee-wee/pooh meant that he had done it. Can’t dress self fully, but can put trousers, jumper, socks on. Trouble with shoes.

**Social skills – others** Seems to enjoy being with other children. Play – has soft toys – all have names and he can identify them all. He also plays with toy cars and lorries.

**Learning skills** He knows what a book is and likes to be told stories. ‘Tactile’ books/pictures were enjoyed.

**Language development** Good for age – can use some whole sentences, asks questions, some baby talk words. Intelligible and articulate. Knows a few simple rhymes, for example ‘Round and round the garden’.

was given to the nursery nurse on how to be vigilant and how to increase Mark’s independence, as there was a tendency for him to rely on adults. Mark loved being told stories, and by the age of 3 could retell stories and invent them. He learned to identify and name objects by feel and touch. He located people by listening to their voices and finding the direction by sound. The VI teacher emphasized the need for him to keep his head up and directed to the front of his body, to try to prevent him from picking up any ‘unusual’ mannerisms which might impair social interactions.

The aim was to transfer Mark to a school with resourced provision for children with VI as soon as he was 3. There he would not have one-to-one support, but there would be a high adult–child ratio and an environment where special resources could be found to meet his needs. Mark had very little residual vision, although he distinguished light and could see and name some colours. A priority area would be to start on pre-Braille (and then Braille) teaching and mobility skills. Mark had developed normally in terms of language and ability and it was anticipated that when he went to primary school he would be given access to the full National Curriculum. Although Mark’s parents still find it very hard to accept the limitations faced by Mark, they now accept his difficulties and feel that Mark is being helped to achieve his potential.

Mark’s parents believe that good educational provision has been made for him in his very early years and that this has led to good emotional and social development as well as fostering his independence. Once more he plays with toys, and his intellectual and language cognitive and linguistic skills are well developed.

**Anna and Charlotte**

Anna and Charlotte, twins, were born when their sisters Gemma and Hayley were 3 1/2 and 2 years old. The twins were delivered normally after an uneventful pregnancy of 40 weeks. Their mother recalls that they were ‘very good babies’ for the first 12
months, and that although they made noises, they did not cry much. When they were about 18 months old, their mother was concerned that it was difficult to start toilet training and also that although they were walking, they spoke no recognizable words. Finding this unusual after her experiences with Gemma and Hayley, she reported it to the health visitor who said that late language development was quite normal for twins who often developed their own form of communication. Their mother was uneasy about this as she had not observed any signs of communication between them.

Busy with four children, the eldest of whom started at school when the twins were 18 months old, the mother did not worry unduly. When the twins were just under 2, and Gemma and Hayley were at a local nursery, their mother joined a mother-and-toddler group, but because Anna repeatedly tried to leave the room, this was discontinued and the twins gained places at a nearby nursery, attending mornings only. Here they were placed in separate classes because staff believed separation would enforce communication skills. Both were still in nappies. At first they appeared to settle well (staff reported that they didn’t cry when their mother left!) but within a week or so problems were reported. Anna destroyed the paintings and work of other children, threw water around and would not sit still for stories or games. Charlotte appeared to be less trouble, but mother thought that this was because she was allowed to wander round the classroom unchecked by the teacher. Their mother recalls ‘I hated going to pick them up, because there was always a complaint. I felt they [the staff] thought I was a bad mother because I couldn’t control them. They never offered any help, just told me what a relief it was when I arrived.’

At home, other problems emerged. The twins began to smear faeces over their bedroom; they tore wallpaper and broke ornaments and their sisters’ toys. Parents removed all ornaments and pictures from within the girls’ reach. They still had no speech. Their mother telephoned the health visitor who came and ‘reassured’ the parents that this was all ‘normal behaviour’ for twins and they would ‘grow out of it’. (This attitude towards parental fears has been noted in literature on professional–parent relationships.) However, after four weeks, the parents felt they needed more help and contacted the health visitor again, who sent the health visitor responsible for SEN. She was immediately concerned about their language development and arranged for them to have speech therapy for half an hour each week in a group with three other children. She also arranged for them to have a hearing test. The local authority in which she works does not have a child development centre, but there is a team of designated professionals working across local clinics and hospitals to provide child health services.

In the meantime the mother had been asked to remove the children after five weeks in the nursery; they were now attending a ‘Scallywags’ group. She noticed that the twins did not appear to recognize the differences between objects: dolly, teddy bear, pretend foods were all treated the same and any could be given as a response to a request for any one of them. The experiences of the previous nursery were repeated – the twins interfered with the activities of other children, threw objects around and bit other children. Eventually the children were separated and Charlotte was sent to a different nursery. In a few months, the children had attended three or four different pre-school groups.
After failing an initial hearing test, they were retested and their hearing found to be normal. A consultation with a paediatrician was arranged. During this session, Anna remained silent, but Charlotte kept saying, ‘stuck, stuck’, which was her word for food. During the consultation, an attempt was made to assess each child independently. When Charlotte, who had been outside with her father, came into the room, crying, her mother picked her up and cuddled her. ‘What did you pick her up for?’ queried the consultant, ‘You’re reinforcing her bad behaviour.’ The mother considered this a most unsympathetic response, and lost confidence in the consultant and any of her later deliberations. The specialist health visitor and speech therapist were all consulted, but no ‘cause’ was found for the twins’ delayed development.

At the age of 2 1/2, although they attended the Scallywags nursery, no one had specifically mentioned ‘special needs’ to the parents. The twins were still in nap-pies and continued to misbehave. Their mother said, ‘Picking up Charlotte was like before – I dreaded going. I felt they thought it was my fault – that I wasn’t a good mother.’ Anna developed the habit of beating her head on the floor. No one at any of the nursery groups ever alerted the mother to any difficulties in ability, understanding or learning, or made any reference to intellectual, perceptual or motor development. All comments were concerned with ‘misbehaviour’. The health visitor devised a ‘discipline programme’ for use in the home, but it was deemed a failure.

If the twins’ difficulties had been identified as ‘special educational needs’ then even aged 2 appropriate provision could have been sought. No one informed Anna and Charlotte’s parents of their rights: they were, in fact, grateful for what they saw as some attempt to find out ‘what was the matter’.

When the twins were 3, a teacher from a local special school visited at the request of the health visitor. The LEA agreed, without the need for a statement, to provide parttime attendance (mornings only) at the special school. A taxi, with attendant, collected and returned the twins. At about this time, the mother’s sister (who was taking an NNEB course) brought her a book which contained a description of autism and autistic behaviour. After reading it the mother said, ‘It’s just the twins. I knew then, really. We didn’t mention it to the doctor, she’d said it was just language delay. It was the end of everything – they were never going to be normal, there was no future for them. My husband only read two or three pages. He couldn’t bring himself to read it all.’

A month later, the consultant arranged for an assessment at the school. The mother’s memory of this consisted of the girls coming into the room one at a time: Anna touched her mother’s legs and then wandered docilely round the walls. When Charlotte came in, she sat on a ‘horse-thing – she loves animals’. There was some discussion of the difficulties and then, as the parents got up to go, the doctor said, ‘I think they show characteristics of autism – no communication, and behaviour difficulties.’ With that, they left. The letter they received said ‘signs of infantile autism’. ‘We just came home thinking – our life’s over. They’re never going to get better. You try and be strong, ’cos it’s coming up to Christmas, but you know it will just mean wrecked toys.’
The family now has support from social services: someone to ‘watch’ the children from Monday to Friday from 2.00 to 4.00 p.m., and every other Sunday someone comes from a voluntary service. On Wednesday, a carer from the Crossroads scheme stays with the twins from 6.00 to 8.00 p.m. so that the parents can take the other children out.

These parents only started accepting that their children had difficulties between the ages of 2 and 3. Confirmation of the problems and support has come only after the age of 3, and even then it is not adequate. The effect on the older girls is as yet unknown; major problems occur because the twins destroy their belongings and take a tremendous amount of attention. Moreover Charlotte has killed the family guinea pig – ‘loving it, squeezing it and dropping [or throwing] it’. Anna has squeezed the hamster so tightly that it died. Neither girl is toilet trained. Anna is described as ‘docile, laughing a lot, twirling until she is dizzy and imitating what you say’.

Charlotte is very ‘bossy and stubborn’. Since the diagnosis, the parents have been in touch with other parents through the National Autistic Society and have found this contact very supportive. However, their mother does feel bitter about the lack of information and support when the children were under 3. She says: The health visitor should have listened to me and known there was something wrong when the children were smearing and had no speech . . . The main problem with doctors is they should listen to parents a little bit more . . . Playgroup and nursery teachers should pick up problems earlier and inform parents. They shouldn’t treat you as if you’re not a good parent. We needed to know earlier. No one told us. The mother has to do all the running – I had to contact the health visitor and say ‘you’ll have to come’ . . . We knew something was wrong but we didn’t know what . . . There’s a special school in a nearby town, but [there is] a two-year waiting list – now we might not get a place. It helps to know what’s wrong. We need to know.

These two case studies illustrate how much any system depends on local applications and the quality of the professionals. Both sets of parents experienced similar feelings of distress, loss and confusion. Both families were subjected to stress because of inaccurate diagnosis and incomplete information in the early stages. However, Mark had a condition which, while causing a permanent and severe disability, meets all four of the criteria for a syndrome. It also creates a disability which comes high up on the scale of ‘social accept-ability’. His LEA had good, focused services for visually impaired pupils and the support service had sufficient time to provide an excellent level of support.

The twins, in contrast, had a condition which was, in its early stages, at the far end of a continuum of infant behaviours. Far less is known about autistic spectrum disorders than visual impairment. The point at which behaviour should be considered as sufficiently ‘different’ to warrant being considered as needing special support and intervention is a matter for multi-professional judgement. However, even when the concerns of the parents were taken seriously and a consultant paediatrician became
involved, there was a clear failure to coordinate the multi-professional work. No one appeared to find the time or inclination to listen to the parents seriously and see what was happening from a family perspective. No one coordinated all the contributions to make a complete picture. What happened was a series of individual actions none of which could, in isolation, be an effective response to the special needs of Anna and Charlotte. Certainly, no one addressed the feelings of the parents that ‘their life was over’. Many of the obligations placed upon local authorities and area health authorities went unfulfilled. Voluntary organizations were found by informal means, reports were delayed, parents were less than fully involved in assessment procedures and they were left in the dark about what the professionals were thinking.

The stories of Mark, Anna and Charlotte, their parents, and other family members remain unfinished, but from these early beginnings we can see just how significant early identification is for children with SEN. There are important implications for the role of all those involved in educare for the under-threes and the way they impact on the future lives of children with SEN and their families. An interesting issue arising from the second case study concerns attitudes towards SEN. While children with language difficulties, a sensory impairment or physical disability may often evoke a sympathetic response from teachers and nursery nurses, those presenting challenging behaviours do not. Autistic spectrum disorders vary considerably, but some are manifested as behaviour difficulties. All too often the response of professionals is to seek the removal of such children, or, in the case of very young children, ‘blame’ parents: they do not make the same supportive response that they would for a quiet, socially conforming child whose learning may be impaired. All those working with children need to examine their own attitudes towards the nature of behaviours presented by children with SEN.

In the same way, a further problem is related to our beliefs about ‘maturation and development’. While an earlier cautionary note has been expressed about individual differences in development, the study of Anna and Charlotte provides a warning against believing a child ‘is going through a phase and will grow out of it’.

References

The views expressed in this Chapter represent those of the author, and not necessarily those of the DfES.