

A guide for practitioners and service commissioners

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# First Impressions

Emotional and practical support for families  
of a young child with a learning disability





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The report was written by Jill Davies, Research manager with editing by Radhika Holstrom.

# Foreword

As any parent knows, caring for very small children can be extremely stressful. Poverty, the struggle to balance paid work and caring responsibilities, lone parenthood and lack of support can all make things worse. Disability throws a new element into the mix – while doubling the effect of the other factors. Families with a disabled child are very likely to be living below the poverty line, have to fight to get support or services for their child, be isolated and get unsympathetic reactions whenever they go out with their children.

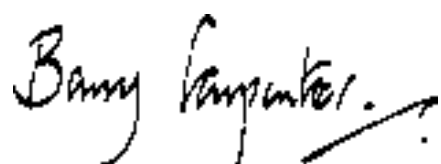
What is it like to bring up a young child with a learning disability in our society? And what support do their parents and other families get?

As parents of a child with Down's syndrome, my wife and I met professionals who were empathetic human beings and whose rich professional skills, combined with their humanity, had a powerful impact on our family life. But we met others who hid behind their professional labels, and whose interventions was a hindrance, and diminished our quality of life. Many other parents are still going through something very similar.

*First Impressions* was commissioned in early 2004, in order to look at the emotional and practical needs of families who have a small child – aged up to five – with a learning disability. It found that while some families do get a great deal of support and information, from a sensitive diagnosis onwards, others have to fight for a diagnosis in the first place and are then left to cope very much on their own. A family's experience depends on where they live – and, as my wife and I found – on the particular professionals involved.

Families need more than this. They are expected to support, and advocate for their son and daughter for the foreseeable future, but at the moment they are not getting the support they need to prepare for this. As this study shows, some parents are going through experiences which are making them depressed, isolated and confused. A day's work (and it is hard work) can start in an over-crowded house, go on to an inaccessible public transport system, and involve several un-coordinated meetings with unsympathetic specialists – all of this while coping with the physical and mental effects of continual broken nights sleep and continual heavy lifting. Even though some parents are experiencing these stresses it does not change the fact that they love and care deeply about their disabled child. But it is hardly surprising that their mental health and their physical well-being are being badly hit.

Families need to be supported, empowered, and given resources which address every family member's needs. We hope that *First Impressions* is a valuable contribution to making this happen.

A handwritten signature in black ink, reading 'Barry Carpenter' with a stylized flourish at the end.

Professor Barry Carpenter  
*Chair, First Impressions Advisory Committee*

# Introduction

There are 700,000 disabled children under 16 living in the UK (Department of Work and Pensions 2004), and this number is set to increase. More babies are surviving after being born at less than 26 weeks' gestation, 50% of whom have some sort of disability (Marlow N, Wolke D, Bracewell M, Samara M, 2005). Medical technology is now able to support these and other children who would have died a couple of decades ago: over the past 10 years the number of children who depend on equipment to provide basic care has increased by 60% (National Service Framework, 2004).

The number of initiatives to support these children has increased too; the paramount importance of early childhood intervention is now widely recognised. Over the past few years new initiatives, including the National Service Framework for Children, Young People and Maternity Services in England, have stressed the importance of early intervention. The new Children Act 2004 in England requires local areas to integrate children's services to achieve multi-agency working, and the Department for Education and Skills and Department of Health's *Together from the Start* (2003) and Early Support Programme (2003-2006) take this further.

Similar policies are being developed in the other UK countries. The consultation document for the National Service Framework for Children, Young People and Maternity Services for Wales: Disabled Child module (2003) highlights the need for more coordinated multi-agency services and for key workers for children with complex needs. In Scotland the Additional Support for Learning (Scotland) Bill (2003) also recommends key workers. In Northern Ireland the draft review of policy and services for people with learning disabilities, *Equal Lives* (2004) recommends that Health and Social Services Trusts and Education and Library Boards have multi-agency centres providing clear pathways of help to parents and develop family support plans.

Another model of family support that is available in all four UK countries is Home Start, although they may not be based in every area. Since over half the families of children with learning disabilities are living on or below the poverty line (Gordon, Parker *et al* 2000), Sure Start's role in tackling child poverty has also played a major part in the lives of families throughout the UK.

It is important to note that this report is focused on the emotional well-being of the family rather than early childhood intervention, defined by Mencap (Viewpoint 2004) as 'any activity designed to promote the development and learning of young disabled children'. Whilst the two are entwined with each other, early childhood intervention can be more effective for the child and family if they are being fully supported emotionally and practically and informed of the appropriate options available to them.

This report summarises families' accounts of their own experience, the conclusions of the literature available on the topic, and the views and recommendations from the panel of experts sitting on the First Impressions advisory committee. It sets out good practice case studies and recommends ways to improve day-to-day practice and reduce stress in the lives of these

families. The Foundation has also produced *First Impressions*, a booklet specifically for parents and family carers.

### **The research process**

The researcher conducted semi-structured interviews with 22 parents, 20 mothers and two fathers, either individually or in groups. Two had two children with learning disabilities. They were from various parts of London, West Birmingham, Berkshire, Bristol and Wales and were from a mix of ethnic backgrounds, including Asian, Middle Eastern, Black African and White.

The children had the following disabilities: Rett Syndrome, Tuberous Sclerosis, Down's syndrome, general global developmental delay and autistic spectrum disorder; and they were aged from 18 months to 13 years (so some parents were talking about past experience).

The questions were grouped into four main areas:

- > how the diagnosis was delivered
- > what information was given immediately, after diagnosis and during the following years
- > the emotional and practical support families needed
- > the effects on the family as whole.

# Chapter 1

## Sharing the news and information

*'It took me two weeks to really get control over the whole news – everything, because you have expectations of your child. You assume they go through the so-called normal expectations of life... we didn't know what had happened.'*

There have been long-standing concerns over the way parents are informed about their child's learning disability. A number of women are told on their own, with no offers of support. For some parents, the situation is handled so badly that it influences the way they feel about any support which is offered then or later.



Initiatives such as Scope's Right from the Start (2003) template are improving the situation. But very recent experience indicates that there is still a long way to go.

### The disclosure

Around half of the parents interviewed said they were told in a sensitive manner, which suggests that procedures are improving. *'I was very happy that they told me straight away and it was very matter of fact how it was delivered – she was rather emotionless and she didn't pity me or offer condolences. If someone had offered their commiserations I would have been very upset.'* Many were also very well supported by the hospital staff, one mother described how the consultant visited her daily while she was still in hospital and turned off his bleeper so that they would not be interrupted.

Other parents had a less positive experience. One mother of a five-day-old baby was told: *'There's no beating about the bush, he's got Downs Syndrome'*. Another mother of a child with Down's syndrome asked how her baby was after an emergency caesarean and was told by the midwife: *'You'll know when you see it'*. A few parents remarked that far from being told on their own, they were told in a crowded room with far too many people around. One mother described feeling as though she was *'in a bubble'*.

Parents' experience here and elsewhere suggest that some professionals also assume that parents who do not show distress after the diagnosis are in a state of denial. *'Every time I expressed my joy to the staff at the hospital, they said, "she's denying reality". I understood the reality of my child's situation but, for me, there was another reality'* (Kearney and Griffin, 2001, p583).



## Families from different cultural backgrounds

All the families in this survey spoke English, but we also examined the literature which explores the experiences of different ethnic groups. Hatton *et al* (2003) studied the experience of South Asian families in the north of England and found that language, in particular, meant that they usually had a worse experience than white families. Two thirds of the families were spoken to in English, even though a lot of them would have preferred a different language. As a result of this poorly handled disclosure, some families may receive little or no formal support afterwards. Robina Shah's (1998) *Sharing the News* is a good practice guide and training pack for professionals working with Asian families when they are first told about their child's disability. Shah recommends that a trained interpreter works very closely with the other professionals involved to plan the wording and the approach to the family. For further information about working with an interpreter please refer to Appendix 2.

### The Sharing Concerns Portage Parents Project

Sharing Concerns is a collaboration of parents and practitioners from West Birmingham Portage Service. The group has developed a video and training module of teaching tools and guidance aimed at health, education, and social care professionals involved in disclosing news about a young child's disability or providing follow-up support for the child and family. This work has been endorsed by the National Portage Association, cited as an example of good practice in *Together from the Start* guidance and used by Scope's Right From The Start trainers.

## Learning later on

Many children are not diagnosed until they are months or years old. A number of parents described the confusion they felt when their son or daughter was not developing at the same rate as their peers, and the responses they got when they asked professionals about this. The parents of children with autistic spectrum disorders in one London borough had to fight to get their children a diagnosis: and some are still waiting for it to be formally acknowledged. Other parents wanted to know what was happening, but felt that when they asked questions they were treated as a nuisance. One child was referred for a series of blood tests but her parents were not told why. *'There are lots of different appointments in a variety of hospitals. They keep saying the tests are fine...but what is wrong with her?'* The mother of a daughter with Rett syndrome said she had to ask many questions over a year of continual hospital appointments, but got very little information in return. A mother who has two children with disabilities and a mild learning disability herself found that because the professionals refused to listen to her concerns she had to become very wary of them in general: *'You never know what they will say next'*.

## The information parents need

More than half of the parents interviewed said that they did not receive adequate information at the time of diagnosis, and were unsure where to go for information at this stage. The parents who did not get any information at all were the ones who felt most isolated. Some families who were given no information had to resort to searching the Internet, which they found overwhelming. Some information from the Internet can be alarming, even inaccurate, raise false hopes or paint too negative a picture of the child's condition.

At the same time, parents do not want to be swamped with too much information. Another parent said, *'on the first visit they gave me too much information... it's great there's so much out there but it can be too much to absorb. Even if your child doesn't have a disability you're adjusting to your life with a baby – you've just given birth, your lifestyle has changed, you're exhausted. On top of that you have to come to terms with something you hadn't anticipated; there is a danger of being bombarded.'*

### **Melanie's story**

Melanie was very grateful for the support and information she had received on a gradual basis whilst she and her child were in hospital. However, a well-meaning paediatrician went into too much detail about her child's life expectancy and propensity to dementia when he was just a few days old.

### **Action learning points**

- > Give information a bit at a time, especially if the baby is newborn.
- > Parents appreciate a leaflet or telephone number of relevant organisations or local support groups.
- > Give parents time to reflect on the diagnosis before giving more information.

We learned that parents need some basic facts straightaway: the name of their child's condition, a brief description and a contact address of the local or national support or information organisation. For example, a parent of a child with Down's syndrome said that knowing that your baby will have a learning disability, feeding problems, and floppy muscle tone is enough during the first few days. Some parents will not contact the support organisation straightaway, but they have a contact number ready for the stage when they want to ask for help.

### **Anne's story**

Anne's daughter was diagnosed with an autistic spectrum disorder when she was three years old. Anne could not take anything in after the initial diagnosis and said how useful it was to have a follow-up appointment just a week after her daughter was diagnosed. She had time to think about it and write a list of questions for her next appointment.

### **Action learning points**

- > A follow-up appointment soon after the disclosure to give more information is valued with the professional present at the initial diagnosis.
- > Written information about the child's disability should be given at the time of diagnosis, such as the name, a brief description and a contact address of the local or national support or information organisation.
- > The National Autism Plan for Children (N.A.S. 2003) contains guidelines for professionals who work with children with autistic spectrum disorders.

## The next stage

Follow-up is as patchy as diagnosis; and poor follow-up is often the direct result of poor information at diagnosis. Families do not always know which services are available to them. Some children were referred directly to the local Special Educational Needs, Portage or similar service at an early stage, while others had no follow-up appointments or were placed on long waiting lists. Some parents said that the quality of information and services on offer depended on which paediatrician and/or health visitor they were allocated.

Parents said they had been helped by health visitors, Portage home visitors and staff from early years centres or pre-school services. Those in areas with no access to Portage, pre-school provision, or support from voluntary organisations often reported feelings of isolation and high levels of anxiety, and a number of mothers said they had taken anti-depressant medication at this time.

Parents also said that meeting other parents was one of the best sources of information, and the literature reflects this: *'It's through word of other parents and you might hear a conversation and think I might be entitled to that'* (Redmond and Richardson, 2003 p210).

Overall, parents highlighted six areas where they wanted support:

- > emotional support
- > information about their child's condition
- > information about services
- > accessing services
- > coordinating services
- > developing a 'whole picture' of the child.

They all said that it would be useful to have a key worker to help them with these six areas – a suggestion echoed in the Softy survey (Limbrick-Spencer, 2000), which asked parents to identify their support needs during their child's first two years and recommended key workers to help them with this.

### **Roma's story**

Although initially Roma and her husband were shocked to find out about their daughter's disability, they felt hospital staff gave them the right amount of information at the right time. Following the diagnosis a Portage worker visited them, explained their role and gradually introduced them to a number of support agencies.

### **Action learning points**

- > A local identified person should support the family immediately after diagnosis to offer information, advice and support.
- > Be aware that some people need support to be put in contact with local support groups, pre-school services or parents in a similar position, rather than expect them to do it of their own volition.
- > For families living in England, services should implement the Family Service Plan – a written summary of assessment outcomes, specifying services, support and stating the name of the key worker.

## Chapter 2

### Emotional and practical support

*'There wasn't much support between birth and access to Portage, just friends and family, so some constant professional support would be useful.'*

From interviews and the existing literature, it is clear that some families benefit from support from a wide range of sources including Portage services, early years centres, specialist nurseries, health visitors, social workers and other parents. Others get no support at all. Often this depends on where they live (a point emphasised by Helle Mittler in her 1998 international study).

The parents interviewed who appeared happiest with the services provided to them were those who had received good support and information from the beginning. Mothers who attended pre-school special play sessions or early years centres with their child felt less isolated and supported by the staff and fellow parents. Conversely, a number of parents reported a gap between diagnosis and receiving a Portage home visitor (and a group of mothers with children on the autistic spectrum did not have access to Portage or a specialist pre-school service at all). Many of them were angry and upset about this – *'I felt belittled whenever I asked for help and was fed-up of being turned away whenever I requested something'*.

#### Emotional well-being

These feelings of isolation and frustration can lead to poor mental health. In one group interview half the participants said they had taken anti-depressants when their child was very young. We also heard from a GP and paediatrician who reported high numbers of mothers taking such medication.

Although not all families of children with severe disabilities are at risk of developing high levels of stress, there has been much research interest in its effects on the whole family, particularly in contributing to depression in primary carers. Olsson and Hwang (2001) found that the severity of the child's disability contributed to higher depression scores in parents. Single mothers of children with disabilities were found to be more vulnerable to depression than mothers living with partners. This is not surprising, given that the factors associated with maternal depression



include poverty, receiving means-tested welfare benefits, and experiencing more than one potentially stressful life event (Emerson, 2003). However, in another study (Manuel *et al*, 2003) the researchers did not find that severity of disability predicted maternal depression, but did find that the level of social support was an important factor.

Some parents said they felt isolated when their child started at a special school because there were fewer opportunities to meet up with other parents due to the school not being in their local area. A parent of a child in a mainstream school spoke of her son's isolation and her sadness because he was never invited to his classmates' birthday parties.

There has also been some research interest in the effects of early intervention on mental health in families. Pelchat *et al* (1999) looked at the effect of an intervention programme which began at birth. Compared to parents in the control group, who received only the usual services, the parents in this group were more confident receiving help from others, experienced less emotional distress, anxiety and depression and perceived more emotional support from their partners.

### **Day-to-day practicalities**

Negotiating day-to-day life is also difficult for families with a disabled child. Finding a suitable parking space and an appropriate shopping trolley, using public transport and sourcing a strong enough buggy when the child outgrows their pushchair, all creates stress. Public transport is particularly inaccessible for disabled children and adults.

Finding a sympathetic GP who will make instant referrals to appropriate services when moving to a new area can also create stress which other families do not have to think about. One mother of a child with Rett syndrome described great difficulties in finding a new GP who would take the family on and write quickly to the range of specialists her daughter needs.

Many parents mentioned the impracticality of attending so many appointments. One mother had to attend four appointments in the same hospital in one week. Not only was this time consuming, it was also expensive, she had a 16-mile return journey and had to pay a parking fee at the hospital car park. Life could be made easier if appointments were better coordinated, especially if more than one child in the family has a disability or if the child needs to see a number of different professionals. It could also reduce the amount of time parents spend briefing new specialists.

### Emma's story

Emma had to take her six-week-old son to see a physiotherapist at the local hospital. She was exhausted because she was a new mother, adjusting to the news that her son had Down's syndrome and was unsure where the department was (and she was carrying a heavy baby car seat). Emma said *'you are at the stage where it is hard just to get out of the house.'* It would have been great if the physiotherapist could have seen her at her own home for that first appointment as Emma would have been less stressed and absorbed more information.

### Action learning points

- > Consider the needs of the parents when making appointments.
- > Better coordination of appointments – as recommended by the Disabled Child Standard, National Standards Framework for Children, Young People and Maternity Services (2004, England).
- > Parents do appreciate it when professionals can visit them at home when possible.

Going back to work was not an option for many of these mothers, but a number said they would like to be able to. Those parents who received short breaks from their child, even for just a couple of hours, appreciated this very much especially as it gave them the chance to spend quality time with their other children. We did not hear of any parents using Direct Payments as a way of funding such breaks, although one parent had been informed about them by her social worker.

### Fathers

Very little research has looked specifically at the experiences of fathers of children with severe disabilities. Carpenter and Herbert (1994) record that services do not always recognise fathers' grief in the same way as compared with mothers. Some studies have indicated that fathers are less likely than mothers to seek help and support.

As only two fathers were interviewed it is not possible to discuss their support needs in any depth here, but they said they felt very involved in their child's life. One was a shift worker and the other did not work, so they were often present when the Portage visitor came to the home and could attend appointments with their partner. Carpenter (2002) acknowledges that most support services for families are offered during work hours, and that it is probably impossible to change radically, but suggests that appointments are offered well in advance (so that working parents can book time off) and that some evening visits are offered.

A mother of a very young child with Down's syndrome said that whilst she was being fully supported emotionally at the hospital following the birth, she was worried for her husband. *'He is not a talker and he would have been overwhelmed by me wanting to talk about it. He was fearful of people and having to say things to people at work and I feel there isn't much support.'* However, she said she could think of no easy solution to help men during the first few years.

### Key workers and emotional support

Once again, everyone expressed the need for a single, stable professional to give on-going support from the start and help navigate them through the system: a message reinforced by successive studies.

Some areas do provide key workers. The Handsel Trust have helped to develop models such as *The Team Around the Child* (Limbrick, 2001). Professionals from different services work together to provide education, therapy and treatment and each family is allocated a key worker, who can mediate with the family and specialists to coordinate appointments, services and therapy programmes – and is also able to provide emotional and practical support (Limbrick-Spencer 2000).

Most key worker models are currently targeted at children with very complex needs, however families of children with less severe disabilities are also subjected to fragmented services, lack of information, lack of family balance and conflicting advice – all of which create unnecessary stress and confusion.

These models have also been highlighted in a number of policy documents including the Welsh and English National Service Frameworks, *Together from the Start* (DfES and DoH, 2003), the Early Support Partnership Programme (2003-2006) in England and the Additional Support for Learning (Scotland) Bill (2003).

### **Bromley Early Support Programme**

The Bromley Early Support Programme is based at the Phoenix Child Development Centre, where 26 multi-agency services for babies and young children with special needs and disabilities are co-located. The programme ensures families of young children with more complex needs and disabilities have a key worker, multi-agency meetings enabling coordinated and supportive family led services and a family service plan developed in partnership with parents and services.

### **Flexibility**

Finally, it is important to acknowledge that parents also need some choice over the way they take up support. Some prefer home visits, others want clinic appointments. Some want to attend support groups or want to meet parents of disabled children; others simply don't feel the need to or are not ready to do so at the beginning.



## Chapter 3

### Impact on the family

*'Life revolves around the child with a disability and can take the emphasis off the other children in the family.'*

Today, we are encouraged to take a positive view of the birth of a baby with a learning disability. At the same time it is important to recognise that the birth of a disabled child can affect the relationships between partners, siblings and the extended family and friends. Similarly, difficulties with housing and finance may arise. There is a strong link with poverty (Dowling and Dolan, 2001, Emerson 2003) and other inequalities. Contact a Family's 2003 survey on parents' relationships identified that 17% were single parents, and several studies have shown that single parents in particular are far more likely to experience poverty, stress and isolation and have fewer work and/or leisure opportunities.



#### **Stress**

Ellis *et al* (2002) found that families with younger children were particularly under pressure. Many children had problems with feeding, toileting and especially sleeping – a lot of them woke in the night or early in the morning. Robinson and Richdale (2004) also found that although sleep problems are common and chronic in children with learning disabilities, parents may not recognise it as a problem and often do not seek help. Instead, they continue under the considerable pressure of consistent, repeated broken sleep long after other parents can count on a good night's sleep. Siblings sleep can also be affected, particularly if they share a bedroom.

Another small-scale study, undertaken by McLean *et al* (2000), confirms the extra burden of caring for a child whose life is constantly threatened. They compared families of premature infants who were on home oxygen therapy with ten families of premature infants who were not and found that those using oxygen therapy felt the care required had a significant effect on the family. Mothers reported significantly less vitality and more mental health problems.

Redmond and Richardson (2003) explored the service needs of mothers caring for young children with severe to profound and life-threatening disabilities in Ireland. Results showed that a large majority (88%) were experiencing increased levels of strain and 71% encountered

higher levels of unhappiness and depression. However, many mothers also expressed positive feelings, particularly about their children, and none of them wished to have their children cared for anywhere other than at home. *'We wouldn't take a normal child to an institution, and we say we want to keep their life as normal as possible, so why should we take them to such a place?'* (Redmond and Richardson, 2003 p209).

Several researchers point out that parents have also have to adapt to sharing their lives with professionals (Todd and Jones, 2003). Although the network of professionals is there to help and support, families can still find it very difficult to work out who is meant to be responsible for what, and to manage the different people involved. *'When Tim came along, all our experiences as parents counted for nothing. Here was I bringing my beautiful baby – my third baby – home from hospital and his Dad and his brothers and I weren't going to be good enough for him. We weren't going to be able to embark on this adventure on our own and we would have to bring assorted strangers along for the ride'* (Redmond and Richardson, 2003 p209).

In terms of physical stress, lifting and the associated back strain is one of the biggest problems. Again, most parents do not regularly carry a child who is much over two, whereas disabled children often need to be lifted or carried long beyond this.

## Housing

Oldman and Beresford (2000) studied the effects of unsuitable housing on families with a disabled child living in the north of England and found that four out of ten families reported that this was a problem. For example several parents believed their children's conditions were worsened by poor heating. The costs of adaptations, higher heating bills and higher mortgages were a great source of worry – while at the same time neighbours could become abusive about their apparently 'preferential treatment'.

This and other studies show that lack of space is also an issue; children who need to use walking aids cannot get about at all in a small house or flat and children with sight problems bump into the furniture. It is not always feasible to put siblings in the same room. One mother described how her family had had to move house in order for their toddler with autism to have a bedroom of his own, as he was disturbing his siblings' and parents' sleep. They also had to fit double-glazing into their new house in order to prevent their son from escaping or harming himself. This family had increased their mortgage, with no financial support. Another family had been re-housed by the local authority in order to have more space. The mother of a child with Rett syndrome had a lift installed into the lounge as her house was too small to adapt a ground floor room into a bedroom; this will make it hard to sell the house if they move on.

Ironically, adaptations can limit space even further, although many professionals do not understand this. The amount of medical equipment in some homes makes them look like a hospital.

## Relationships

Relationships between partners can also come under great strain following a diagnosis. Fathers can find it particularly difficult (especially as most support is targeted at mothers). A number of mothers reported that their partners initially found the diagnosis difficult to cope with, and a very small number said that their partners were still in denial, which put extra pressure on them. *'It can have a devastating effect on your relationship ... I was angry with my husband for being self-centred, self-indulgent ... it's difficult for blokes because they don't have the same sort of bond – especially if they're not physically there.'*

Pelchat *et al* (2003) report that fathers find it more difficult than mothers to talk about their parenting role, and that their concerns are more with the world outside the home while mothers took on the major role in childcare. Mothers are likely to find discussing their emotions helpful while fathers were more likely to use cognitive strategies. Interestingly, mothers reported that their husbands rarely talked about their feelings, whereas the fathers felt that they did: perhaps an indication of different perceptions of the same event.

### **Work opportunities**

Some of the mothers interviewed mentioned that they wanted to go back to work but did not feel they had the support, or the time to do so, mainly because they did not know who could look after their disabled child during school holidays and after school hours.

Parents also stressed the need for employers to be sympathetic about time off to look after ill children or attend appointments. Research has shown that some working parents have reduced overtime options or have been refused promotion because they have spent so much time caring for a disabled child (Smyth and Robus, 1989).

The need to work was not just financial. Those parents who worked (mostly part-time) said the main benefit was to get out of the house and *'not think about learning disability for a while'* – and some other parents did a little voluntary work, demonstrating the therapeutic rather than the financial benefits of work. This is borne out by research linking maternal employment to well-being (Hautamaki, 1997).

The benefits system is another barrier to going back to work. One mother had to refuse offers of employment at a school because once she works more than a certain number of hours she is no longer entitled to Invalid Carers Allowance. *'If I'm working I still have to care for her'*.

### **Siblings**

*'Life revolves around the child with a disability and can take the emphasis off the other children in the family'*.

Other children in the family can find it very difficult to accept all the attention their sibling with a disability receives. Some parents said their children had become jealous of their sibling and desperately wanted some parental attention. One mother of a son with autism said, *'I have to be with Michael but my other children want to be with me. Even if I go to the corner shop they take turns to come with me, but never have quality time – always in a rush.'* Other children, however, had become more understanding in general.

Parents of children with autistic spectrum disorders may also be worried that younger siblings are also affected. Research is currently taking place in the USA concerning the possible increased risk of autistic spectrum disorders in the younger siblings of children with autism. The results of this research are not yet available.

### **Lia's story**

Lia has four children. The youngest, Michael, is nearly three and has autism. Her elder daughter, Emily, was becoming increasingly frustrated with Michael because no matter how hard she tried to play with him he often disregarded her. Lia discussed this with the Portage home visitor who suggested she speak to Emily about what autism is and gave her exercises to do with Michael, just like her mother and father.

### **Action learning points**

- > Professionals and home visitors need to take into account the needs of brothers and sisters.
- > Involve siblings in any intervention if they show interest.

A number of parents said they were unable to do certain things as a family group, such as going to the cinema or museum and often had to do things separately. On a positive note some families were issued with free family passes to Legoland (for those living nearby) from their social worker, so the whole family enjoyed perks such as jumping queues at the theme park.

### **Siblings Workshops**

Sunfield School, Worcestershire is a residential school for children with severe and complex learning disabilities. It places great emphasis on the needs of siblings and runs a series of events for siblings of all ages to strengthen the relationship between them and their disabled brother or sister who is living away from home.

Their workshops use the Sibshops model devised by Don Meyer in the United States. For further information see Conway and O'Neill (2004).

### **Hernes House Sibling Social Support Group.**

Hernes House respite service, Oxfordshire, organises social events twice a year for users' siblings, so that they can meet and make friends with other children who have similar experiences. Fun events such as ice skating or going to the cinema allow children to socialise freely without worrying about their sibling.

### **Extended family and friends**

There were mixed reactions from extended family and friends. They can be a great source of comfort and support, but some parents also find that people they used to be close to become awkward and distant. They may also not understand the child's difficulties. One mother of a child got round this by asking her National Childbirth Trust coordinator to tell the mothers in her group that her son had Down's syndrome. She was then more comfortable when she next met up with them.

However, it takes time to sustain friendships and many parents of disabled children are too tired or busy to maintain regular contact with friends. It can also be difficult to make new

friends. One mother experienced isolation from other parents on the school run when they realised she had a disabled daughter – *‘it’s like being invisible’* she said.

Clearly, there needs to be a change of attitude for some, and more understanding and practical changes in service provision if families are to be truly supported.

# Chapter 4

## Recommendations

Throughout the report we have listed some key action learning points linked to examples of good practice. Below are additional practical and strategic recommendations that can improve the emotional and practical support for families with a young disabled child.

### **Information at diagnosis and during the early years**

#### **For Government agencies, planners and local commissioners:**

- > Ensure that someone in each area, such as a key worker or family support worker, is responsible for giving parents information and pointing them in the direction of help.
- > Include plans to deliver appropriate information about the full range of local services for parents of disabled children in all Children's Service Plans and plans designed to provide support for parents and carers.
- > Audit all the local services supporting families. If services work well for disabled children and their families, they will work better for everyone.
- > Train midwives and primary care staff in the health needs of disabled children, such as feeding difficulties in children with Down's syndrome.

#### **For paediatricians, midwives, health visitors and other healthcare professionals:**

- > Adopt the *Right from the Start* (2003) template endorsed by England's National Service Framework for Children (2004). This template provides the framework for developing a locally agreed protocol for sharing the news about disability.
- > Give all parents Contact a Family's help line number.
- > Give the family information about and/or referrals to the other local sources of support they need.
- > Inform families of the Early Support Family Toolkit (DfES 2004, England only).
- > Maintain good contact with families, especially at stages such as the move on to solid food and toilet training.
- > Warn parents not to rely on the internet alone, but point them in direction of reputable websites such as [www.nelh.nhs.uk](http://www.nelh.nhs.uk).

#### **For social care, education and voluntary organisations:**

- > Provide more information about educational support and the statutory assessment procedures.
- > Refer parents to the local Parent Partnership Network, which supports parents in getting educational support for their children, and do this while the child is still well below school age.
- > Help parents make contact with other parents.

- > Include information about services for disabled children, including local sources of emotional support in Children's Information Services, based in every local authority.
- > Distribute leaflets to hospitals, child development centres and similar places to publicise the range of services available.

## **Emotional and practical support**

### **For Government agencies and local commissioners:**

- > Provide one consistent key person/lead professional in the early years for support, including emotional support.
- > Ensure that families have access to a special needs health visitor.
- > Improve public transport to make it more accessible to disabled users.
- > Ensure that staff has the necessary capacity and competency to offer the full range of support to families with a disabled child.

### **For education, healthcare, social services and voluntary agencies:**

- > Offer home visits in the early days.
- > Coordinate appointments and offer them at times that suit the whole family.
- > Inform parents of the local Childcare Information Service, which will have a list of local resources.
- > Inform parents about Direct Payments as a way of funding extra support in the form of short-term carers.
- > All agencies should provide good, up-to-date information in all places that parents use.

## **Impact on the family**

### **For Government agencies and local authorities:**

- > Review the benefits system, so that parents can choose the combination of work and family commitments that suits them best.
- > More flexible working arrangements and appropriate childcare arrangements so that parents can go back to work if they wish to.
- > Plan services and leisure facilities for the family as a whole.
- > Consider the financial and practical need of families, such as free passes to leisure centres and more economical childcare facilities.
- > Ensure that there is a range of support to assist family carers, for example, funding for short-term breaks or leisure opportunities.

### **For local agencies:**

- > Provide more inclusive activities such as play-schemes so that the disabled child and their siblings can attend together.
- > Offer workshops to empower parents, especially in talking about their children's disabilities.
- > Inform parents of Direct Payments as a way of buying in support and help.
- > Take the needs of siblings into account, particularly by engaging them with activities or exercises to do with their brother or sister.

- > Offer siblings and other members of the extended family genetic counselling where this is appropriate.
- > Provide more training for childminders and other childcare providers.

**For research bodies:**

- > Conduct more research into the needs of fathers.



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# Appendix 1

## **Members of the Advisory Committee**

Chair: Professor Barry Carpenter, Chief Executive and Principal, Sunfield School, Worcester

Ruth Beckman, Down's Syndrome Association

Jenny Bugden, Special Needs Health Visitor, Suffolk

Lesley Campbell, Children's Officer, Mencap

Jill Davies, Research Programme Manager, The Foundation for People with Learning Disabilities

Vivian Freeman, Children with Disabilities Team, Westminster Social Services

Alison Giraud-Saunders, Co-Director, The Foundation for People with Learning Disabilities

Elaine Holmes, Right from the Start, Scope (served until October 2004)

Dr Lisa Honeyman, Clinical Psychologist

Dr Daphne Keen, Consultant Paediatrician, St George's Hospital, London

Tracy Linehan, Right from the Start, Scope

Gillian King, West Birmingham Portage Service

Dr Graham Martin, GP

Richard Mills, Director of Research, National Autistic Society

Helen Norris, Phoenix children's Resource Centre, Bromley

Philippa Russell, National Children's Bureau

Robinah Shah

# Appendix 2

## Working through an interpreter

written by Robina Shah (2004): adapted from *Sharing the news* (1998)

### Introduction

Trained interpreters are used to help reduce language problems and to provide clear and correct information for people whose first language is not English. However, working with trained interpreters is a skill and for successful interpretation to take place the professional needs to understand how to work with them effectively.

### Getting Started

Where there may be one or more persons requiring an interpreter or interpreters, it is important to be aware of the following arrangements. For example:

- > understand the issues involved in working with an interpreter
- > be able to distinguish between a lay interpreter and a professional interpreter
- > identify helpful and unhelpful approaches of working with an interpreter
- > learn the importance of pre-planning and post interviews in preparing both the interpreter and parents with language needs in understanding how the consultation will run for them
- > learn the importance of identifying language needs
- > understand the role of the professional in the consultation format
- > understand the concerns of interpreters and the parents with language needs.

It is very important to point out that some parents can speak English but might feel the assistance of an interpreter helpful. This is because some times they may feel that they can discuss their emotions more comfortably in their first language than in English.

### Sensitive issues

It is important to recognise that working effectively with a trained interpreter develops over time.

Emphasis should be placed on getting the process right which in turn saves time, money and most important of all allows parents with language needs to gain a clearer understanding of their child's diagnosis and care plan arrangements.

In all aspects of communication there maybe cross cultural concerns. Be guided by the parents, and if relevant, by the interpreter for assistance and do not be afraid to use common sense.

## Working through an interpreter

### Check list

- > Try and find out whether there is a list of interpreters available at your place of contact.
- > Ask the parents whether they would like to have an interpreter present at the consultation. For some this gesture will be very welcome because it demonstrates your sensitivity to their needs. However, there may be some parents who do not wish to have an interpreter present, choosing instead to use a member of the family. In this situation it is important for the health care professionals to establish how best their information needs can be met and therefore should not be pushed into requesting a trained interpreter. Here it is important to explain why trained interpreters are used as part of good practice and that they are seen as integral to ensuring that the information shared is understood in both context and intention.
- > Acknowledge that for some parents sharing information about their child can be very emotional. Parents may need to feel comfortable with the presence of a stranger in a very private situation.
- > Check whether the interpreters and translators have been assessed for their competency in spoken interpretation or written translation. Clarify whether the interpreter or translator has a Diploma from The Institute for Linguistics, which is the accreditation body for professionally trained interpreters.
- > Check that the interpreter and the parent/s speak the same language or dialect.
- > Where relevant bear in mind the gender and religious preferences of parents when arranging for an interpreter
- > Allow time for a pre-interview discussion with the interpreter in order to talk about the content of the consultation and the way in which you wish to facilitate it.
- > Discuss the terms you will be using before the session so that the interpreter can familiarise themselves with them and check back with you for clarification and or misunderstanding.
- > Encourage the interpreter to ask questions and to interrupt you if necessary. This can be very difficult when facilitating but in some situations it might be important.
- > Use straightforward language and avoid jargon.
- > Actively listen to the interpreter and the parent by trying to maintain eye contact with them and not with the interpreter.
- > Allow enough time for breaks in the session.
- > Observe your body language and try not to hurry the interpreter or to speak loudly.
- > At the end of the session check whether parents have understood everything. Encourage them to ask questions or to write them down in their own language to be discussed the next time you meet.
- > Have a post consultation discussion with the interpreter to check that the session went according to your needs and to find out whether any changes need to be made.
- > To ensure continuity between consultations try and work with the same interpreter each time.

### Communication and Language

It is important to identify whether there is a language need so that arrangements for an interpreter can be made. Where people with language needs are illiterate they can usually identify the script of their mother tongue and this will help staff arrange for the appropriate interpreter. It is always important to identify the languages spoken locally so that an assessment of the spoken and written language needs for a particular area can be established.

# Appendix 3

## Useful Organisations

### Siblings

Sibs

Tel: 01535 645453 or 01904 550029

[www.sibs.org.uk](http://www.sibs.org.uk)

### Early years support

Early Support Programme (England only)

[www.espp.org.uk](http://www.espp.org.uk)

Department for Education Northern Ireland  
Parents' Special Educational Needs website  
[www.deni.gov.uk/parents/special\\_ed\\_needs/guide\\_parents/d\\_under.htm](http://www.deni.gov.uk/parents/special_ed_needs/guide_parents/d_under.htm)

Parentzone website (Scotland)  
[www.parentzonescotland.gov.uk/specialneeds/index.asp](http://www.parentzonescotland.gov.uk/specialneeds/index.asp)

Enquire (Scotland)  
Tel: 0845 123 2303  
[www.enquire.org.uk](http://www.enquire.org.uk)  
Provides independent advice and information to families of children with disabilities who need extra help at school.

Parentsnet website (Wales)  
[www.learning.wales.gov.uk/parents](http://www.learning.wales.gov.uk/parents)

Home Start  
Free information line: 0800 68 63 68  
[www.home-start.org.uk](http://www.home-start.org.uk)

Sure Start  
Tel: 0870 000 2288  
[www.surestart.gov.uk](http://www.surestart.gov.uk)

### General

Carers UK

Tel: 0808 808 7777

[www.carersuk.org](http://www.carersuk.org)

Contact a Family  
Free Helpline: 0808 808 3555  
[www.cafamily.org.uk](http://www.cafamily.org.uk)

Council for Disabled Children  
Tel: 020 7843 1900  
[www.ncb.org.uk](http://www.ncb.org.uk)

Disability Rights Commission  
Helpline: 08457 622 633  
Minicom: 08457 622 644  
[www.drc.gov.uk](http://www.drc.gov.uk)

Relate  
Helpline: 0845 130 4010  
[www.relate.org.uk](http://www.relate.org.uk)

### Key working and early support

Care Co-ordination Network UK  
Tel: 01904 321959  
[www.york.ac.uk/inst/spru/ccnuk.htm](http://www.york.ac.uk/inst/spru/ccnuk.htm)

### National organisations

BILD (British Institute of Learning Disabilities)  
Tel: 01562 723010  
[www.bild.org.uk](http://www.bild.org.uk)

Capability Scotland  
Tel: 0131 313 5510  
[www.capability-scotland.org.uk](http://www.capability-scotland.org.uk)  
Scotland's leading disability organisation.

Cedar Foundation (Northern Ireland)  
Tel: 028 9066 6188  
[www.cedar-foundation.org.uk](http://www.cedar-foundation.org.uk)  
Provides support to people with disabilities to be fully included in their communities.

Down's Syndrome Association  
Tel: 0845 230 0372  
[www.downs-syndrome.org.uk](http://www.downs-syndrome.org.uk)

Down's Heart Group  
Tel: 0845 166 8061  
[www.dhg.org.uk](http://www.dhg.org.uk)  
Offers support and information to families who have a member with Down's Syndrome and congenital heart defects.

Enable (Scotland)  
Tel: 0141 226 4541  
[www.enable.org.uk](http://www.enable.org.uk)

Foundation for People with Learning Disabilities  
Tel: 020 7803 1100  
[www.learningdisabilities.org.uk](http://www.learningdisabilities.org.uk)

The Fragile X Society  
Tel: 01371 875100  
[www.fragilex.org.uk](http://www.fragilex.org.uk)

Mencap  
Free Learning Disability Helpline:  
0808 808 1111  
Minicom: 0808 808 8181  
[www.mencap.org.uk](http://www.mencap.org.uk)

National Autistic Society  
Helpline: 0845 070 4004  
[www.nas.org.uk](http://www.nas.org.uk)

Rett Syndrome Association  
Tel: 0870 770 3266  
[www.rettsyndrome.org.uk](http://www.rettsyndrome.org.uk)

Scope Early Years (England and Wales)  
Tel: 01432 370860  
[www.scope.org.uk/earlyyears](http://www.scope.org.uk/earlyyears)

Scope National Office (England and Wales)  
CP Helpline: 0808 800 3333  
[www.scope.org.uk](http://www.scope.org.uk)

Unique  
Tel: 01883 330766  
[www.rarechromo.org](http://www.rarechromo.org)  
A rare chromosome disorder support group.

## Parents with Disabilities

Change  
Tel: 0113 243 0202  
[www.changepeople.co.uk](http://www.changepeople.co.uk)  
Supports the rights of parents with learning disabilities to be parents.

Circles Network  
Tel: 0117 373 7010  
[www.circlesnetwork.org.uk/crowley\\_house](http://www.circlesnetwork.org.uk/crowley_house)  
The Crowley House Project supports disabled parents at risk of social exclusion.

## Pre school learning and Education

Advisory Centre for Education (ACE)  
Advice line: 0808 800 5793  
[www.ace-ed.org.uk](http://www.ace-ed.org.uk)

IPSEA (Independent Panel for Special Education Advice)  
Tel: England and Wales 0800 0184 016  
N. Ireland 0232 705654  
Scotland 0131 665 4396  
[www.ipsea.org.uk](http://www.ipsea.org.uk)

Enquire (Scotland)  
Advice line: 0845 123 2303  
[www.childreninscotland.org.uk](http://www.childreninscotland.org.uk)

National Portage Association  
Tel: 01935 471 641  
[www.portage.org.uk](http://www.portage.org.uk)  
A national network of parents looking towards properly resourced inclusive education for children with special needs.



Network 81

Helpline: 0870 770 3306

[www.network81.co.uk](http://www.network81.co.uk)

Parents for Inclusion

Helpline: 0800 652 3145

[www.parentsforinclusion.org](http://www.parentsforinclusion.org)

National Parent Partnership Network

Tel: 0207 843 6058

[www.parentpartnership.org.uk](http://www.parentpartnership.org.uk)

Pre-school Learning Alliance

Tel: 01954 232327

[www.pre-school.org.uk](http://www.pre-school.org.uk)

We use our research and projects to promote the rights of people with learning disabilities and their families.

We do this by:

- Identifying work that is needed to overcome barriers to social inclusion and full citizenship.
- Communicating our knowledge to a wide range of people.
- Turning research into practical solutions that make a real difference to people's lives now and in the future.

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Tel: 020 7803 1100  
Email: [fpld@fpld.org.uk](mailto:fpld@fpld.org.uk)  
[www.learningdisabilities.org.uk](http://www.learningdisabilities.org.uk)

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