Parents' support needs

The views of parents of children with complex needs

Presenting the results of the UK SOFTY Survey

THE
SOFTY
SURVEY
Support Over the First Two Years

Gudrun Limbrick-Spencer

handseltrust
PUBLICATIONS

Parents' support needs

The views of parents of children with complex needs

The report on the results of the UK SOFTY Survey
- a UK postal survey asking the views of parents of children with complex needs on the support that was available to them as parents or the support that they would have liked to have been available to them.

All proceeds from the sale of this publication go towards the work of the Handsel Trust.

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About the author

Gudrun Limbrick-Spencer worked with One Hundred Hours since it first began work, initially as a trustee and then as a paid worker, editing the newsletter and managing fundraising and publicity work. She conducted the second evaluation of the One Hundred Hours keyworker model of support (published as *Listening to Parents* in 1999) before becoming one of the founding trustees of the Handsel Trust.

Gudrun also works as a voluntary sector consultant - focusing on advising small to medium charities about management, publicity and funding issues - and has worked with a wide array of such organisations over the last 11 years.

Having attained her first degree from Oxford University in 1989, she is currently working to attain a Masters in Research and Social Policy at Birmingham University.

The Handsel Trust

Parents' support needs is published by the Handsel Trust as part of our commitment to encourage the dissemination of original research which adds to the pool of knowledge about how we can best support parents. We aim for research to reach parents and practitioners - the people who can put it into practice - rather than leave it in the realm only of other researchers.

The Handsel Trust is the UK organisation launched in 2000 to promote awareness of the support needs of parents and disseminate information about the keyworker model of support developed by One Hundred Hours in West Yorkshire.

The author would like to thank...

The Magic Roundabout Group in Birmingham and the One Hundred Hours parents who completed pilot questionnaires to help formulate a workable finished version.

Peter Limbrick and Sheila West who were involved in the project from the very start and who have contributed chapters to this final report.

The funders of the initial research including the Robert McAlpine Foundation, the Denton Trust and the AhjamaTrust.

I am, in fact, indebted to hundreds of people for making this survey and report possible only some of whom I have mentioned here. The vast majority remain anonymous - the parents and carers who took the time to complete the questionnaires often found the experience painful recalling traumatic times and experiences.

> *"I am grateful to have had the opportunity to complete this questionnaire. I wish you well with it and hope that the results might lead to at least one parent in the future being given the information they need without screaming, the services they want without begging and the support they need without crying."* (a respondent in southern Scotland)

Introduction

When a child has a disability or a range of complex needs, a first priority has to be to provide the child with the medical care he or she needs to minimise any pain and discomfort, and provide therapy to enhance their development.

However, this is by no means the only priority. Parents themselves suddenly and unexpectedly find themselves in the position of carer in addition to parent, and facing a different future to that they had anticipated in an unfamiliar world of medical terms, hi-tech equipment, hospital visits, specialists, operations, financial upheaval, discrimination and uncertainty. Parents need support so that, in these times of change and worry, they can care for their child, for themselves and for the rest of their family.

In the first two years after disclosure or diagnosis of a child's disability, the statutory services are there to provide wide-ranging input - health services for the child's medical and therapy needs, social services for the family's benefits, respite and equipment needs and education services for the child's education needs. Additionally, there may be input from local and national voluntary organisations.

From talking to parents around the country as part of our work with The Handsel Trust and One Hundred Hours, the organisation which preceded it, I know that this input, in the form it currently takes, is not enough for many parents. They speak of feeling abandoned and unsupported, and at odds with these services.

One Hundred Hours developed a way of supporting these families in West Yorkshire based on the keyworker (the following chapter provides more detail on this model). The question that remained to be answered was the extent to which the One Hundred Hours experience mirrored the experience of the rest of the UK. The SOFTY Survey was conceived to provide the answer.

This report presents the findings of a national survey to look at parents' needs in the first two years after diagnosis and to examine where the existing services and systems are meeting these needs or whether there is a gap in service provision.

The One Hundred Hours keyworker model

One Hundred Hours was a registered charity working during the 1990s in West Yorkshire with families who had a baby or young child with multiple disabilities and complex health needs. The initial brief was to provide ‘new’ families with a keyworker who would help the parents promote their child’s development, play and learning. From the first we adopted particular basic principles; the keyworker would work for the family, she would be responsive to the changing needs of child and family, she would acknowledge and respond to the emotional needs of the parents and she would help them join together all the separate strands from the various therapists and teachers working with the child. Her intervention would be needs-led and would be concerned for the ‘whole child’ within the family setting.

As we worked with families in this way and responded, within our adopted brief, to the needs we met, we gradually changed our focus from the child to the parents and the family. At the beginning, we did have some appreciation that the disclosure of the child’s disabilities would have a significant impact on parents and cause pain and distress. In our work in West Yorkshire, we quickly understood that, for the majority of families, the disclosure is traumatic and probably represents the biggest single event in the life of the family.

As the keyworker’s role evolved, she became in a real sense an ‘assistant parent’ and could help the parents in the tasks imposed on them by the child’s needs and the disclosure, and help them during those first months, or first year or two, when they were still traumatised and attempting to sort out their emotions and adjust family life to a whole new set of conditions. Her role was to offer emotional support to parents and other key family members, to help them get all available information about their child’s needs, to help them find out about, and access, all relevant services and to help them co-ordinate the many people helping the child.

The qualities we looked for in our keyworkers were empathy, sufficient maturity to be a shoulder to cry on, knowledge of child development and disability issues, a good listening ear with counselling skills and knowledge of local services. The keyworker would be able to develop a close relationship with the parents, to work confidentially with them, to be honest while maintaining a positive stance, to acknowledge and work with the strengths within the family, to avoid being yet another ‘expert who knows best’ and to avoid giving advice.

This became the One Hundred Hours keyworker model, a model which evolved dynamically out of our flexible response to the needs we encountered in families. It evolved without the benefit of another model to learn from and, although it reflects recent research findings, it was not a research-based model.

We were surprised that the trauma of the parents and the ways in which family life might be rapidly thrown into disarray was generally not acknowledged by those people who plan statutory services and work within them such as doctors, nurses, therapists, teachers and social workers. The exceptions were particular workers from any of the professions who recognised the parents’ plight and did what they could to help by ‘stretching’ their job description and adding to their workload. Such people have been lifesavers for many families. But lack of official acknowledgement of the needs of families perpetuated ineffective and unresponsive services for families.

Appendices 4, 5 and 6 give further information relating to the One Hundred Hours model.

The SOFTY Survey

SOFTY = Support Over First Two Years

THE
SOFTY
SURVEY
Support Over First Two Years

The SOFTY Survey had a simple aim - to identify the support needs of parents throughout the UK in the first two years after the disclosure of diagnosis of their child's complex needs. We stressed that we wanted to learn about good practice - the support systems that *are* in place - as much as we wanted to learn about parents' poor experiences.

The questionnaire was very open - at no point did we define support. We were very keen that respondents should be able to come to their own conclusions about their needs and what was, or what might be, appropriate support.

Through One Hundred Hours we were able to spend 9 years developing and refining a model of support (two comprehensive evaluations of this model have been published: *When the Bough Breaks* 1994 and *Listening to Parents* 1999) and we were interested to know to what extent this model could be universal. The SOFTY Survey was our mechanism for testing this.

About the results

The Survey was conducted entirely on the basis of postal questionnaires which parents could complete confidentially and anonymously.

With 455 parents each putting their views across in the SOFTY questionnaires, it would be an impossible task for this report to be the voice of each and every one. The quotes used have been selected because they typify the responses received. Thus, while not every respondent will have had all the different experiences in all the different ways covered in the report, a significant proportion of them will.

Details about the families who contributed to the survey - the range of ages of the children, the disabilities involved and the location of the families - are given in Appendix 2, *About the respondents*.

Each quotation used in the text is followed by the broad geographical area in which the family lived in the two years following disclosure. Where words have been added or altered to make the quotations clearer or to preserve the anonymity of those mentioned in the quotations, these have been added in squared brackets.

The need for support

"I wasn't coping very well, I wasn't sleeping. He had five big fits that year which I coped well with on the outside but on the inside I was cracking up" (north-west England)

THE DATA

16% of respondents thought their initial trauma in the first days and weeks after diagnosis had been acknowledged and that this had been done well. 49% felt that their trauma had not been acknowledged at all or not as much as they needed.

40.9% felt that there had been no attempt to find out about their needs as parents during this time. A further 11.6% felt that there had been a little support but not enough.

In total, only 6.6% of respondents felt that there had been good attempts to meet their needs as parents. A further 11.6% felt that they had been met by some professionals but not all and 16.9% said that their needs had been met but not early enough.

Throughout the survey, we did not define 'support' although it was the theme of the research. This has enabled parents to define it themselves by talking about what support meant to them. For some parents, the idea of support focused solely on their children:

"The best support I felt I could ever receive was the sure knowledge that our child was/is receiving exactly the care/help he needs" (south-west England) *"I don't feel that my needs were met, but as long as my daughter was OK that was all that bothered me"* (north-east England).

Of course, this is an understandable reaction and all parents put their children's needs before their own. The vast majority of respondents, however, were prepared to talk openly about their own needs as well. Parents also talked of their frustration when they felt their children were not receiving the care they needed.

Parents talked candidly about what happened if no support was available to them. The following quotations typify what parents felt they were going through:

"If someone had asked me how I felt instead of concentrating solely on my daughter's problems, I believe it would have released the stress that built up and led to severe depression six to seven months later. My husband and I felt as if it were us against the world" (southern Scotland). *"Everything centred on our child's problems. We needed help to cope with the fact that our future had changed eg. I had to give up my career"* (northern Scotland).

Six key areas of support were highlighted by parents: emotional support, information, information about services, accessing services, co-ordination of services and the development of a ‘whole picture’ of the child. These will be covered in more detail in the following chapters. Each chapter cover parents’ general views on the topic, the consequences of the lack of support, ideas of what would have helped and examples of good practice.

1. Emotional Support

- the opportunity for parents to talk openly about their feelings relating to their situation and gain help to deal with these feelings.

"The people I came into contact with in the early months were only interested in my child, they never asked how I felt. I remember feeling totally exhausted mentally - having to accept one bombshell after another" (north-east England)

PARENTS' VIEWS

Emotional support was a key theme running through the responses of parents. When any parent's child is unwell or in pain that parent understandably is affected and has an emotional response. When the child has a disability with all that that can entail - periods of time in hospital, an uncertain future, pain etc. - the parent is bound to experience a range of powerful emotions. Through the SOFTY Survey, parents demonstrated that they were in serious need of support to help them deal with these emotions.

Some of the emotions experienced were extremely strong - to such an extent that they may perhaps seem disturbing to those who have not been through such an experience: *"My world has fallen apart since the birth of my baby girl*" (Northern Ireland). *" I felt I was an unfit mother and that my son would be better off with someone else"* (north-west England). *"There are times when it is a nightmare and you wish you or your child or both were dead. Sometimes you feel like throwing yourself down the stairs so you can go to hospital for a rest. It affects all your relationships - friends, marriage, family. Sometimes you don't go out for days because you can't face people"* (south-east England).

With emotions such as these raging, it is incredible how parents continue to function and look after their children and it is equally remarkable that so few are offered support to help them cope.

When asked the result of any lack of support, parents cited a range of emotional responses: ‘let down’, ‘isolated’, ‘devastated’, ‘desperation’, ‘unsupported’, ‘kept in the dark’, 'surviving, not living’, ‘discouraged’, ‘sad’, ‘despair’, ‘insecure’, ‘suffering’, ‘abandoned and unimportant’, ‘frustration’, ‘anger’, ‘hysteria’, ‘why us?’, ‘helplessness’, ‘grief’. And these emotions themselves bring further distress: *"I felt severe depression and guilt at my initial rejection of my son"* (north-west England).

What is disturbing about the respondents' choice of terms to describe their emotions is that many apply not to their child's disability alone but also to their relationship with the services involved: ‘let down’, ‘unsupported’, ‘kept in dark’ and ‘abandoned and unimportant’.

It is not simply a question of there being people around who are involved with the family. As one parent put it: *"I met an incredible amount of professionals but, as a mother, I felt very isolated"* (north-east England).

Tea and sympathy

A 'there-there' purely emotional response isn't appropriate and gets short shrift from parents: *"The health visitor was really useless ... she felt sorry for us but seemed to have no more understanding than a man on the street"* (south-central England). *"The health visitor had no real knowledge and I felt a bit patronised and pitied"* (south-east England). One parent, after joining a play group for children with special needs, gave the reasons for it being beneficial as: *"it was a positive community which listened but never pitied me when the rest of the world seemed to pity us and just see the problems"* (south-central England).

Informal support

It is not uncommon for professionals to believe that there will be adequate sources of informal support within the family and that external input is not needed. Respondents to the SOFTY Survey did not always feel that this was the case. In many cases, the respondents felt they needed to protect those closest to them: *"I felt I was asking too much of my friends"* (central England). *"I needed to talk more to someone openly about how I felt. I always felt/feel that I was putting too much on other people, especially my husband"* (south-central England).

With equal weight, parents talked of their family simply not having the reserves to cope with parents' emotions – everyone was too busy coming to terms with it themselves: *"The family was too shocked to help"* (south-west England*). "I would have been helped by being able to talk about my feelings and fears but I only had my husband and mother-in-law and they were broken anyway"* (north-western England). In many cases, it is simply too emotionally difficult to talk about the real situation and real feelings: *"It was very hard to tell people as everyone got upset. I would pretend that everything was alright"* (south-central England).

Respondents also talked of not being able to confide in those who are traditionally closest to them – their partners: *"I felt alone, especially from my husband. He felt overwhelmed and I was left to cope alone"* (eastern England).

For many couples, marital problems ensued: *"My husband and I split up because we blamed each other and the anger tore us apart*" (north-east England). *"I coped on my own but I had to help my husband as well ... My husband will probably never quite cope and has since left"* (south-eastern England). Other couples were more fortunate and received appropriate help to keep them together: *"we needed the counsellor to defuse the stress between us two parents"* (eastern England).

THE CONSEQUENCES OF A LACK OF SUPPORT

There are long term consequences of a lack of emotional support which parents readily acknowledged: *"I never really got over my feelings of despair*" (north-east England*). "My feelings of guilt and loss were never dealt with"* (south-central England). *"I suffered depression for three years following my son's birth*" (south-east England*). "I was finally put onto anti-depressants ... after two years of suffering terrible depression"* (southern Wales*).* Being depressed is certainly no help to running a family and bringing up a child with complex needs.

At times, the depression manifests itself in physically harmful ways: *"My partner found it hard to come to terms with our child's disability and became aggressive, violent and suicidal until counselling six months later"* (north-east England*). "I became dependent on alcohol"* (north-east England*). "Because of the lack of support by the time my child was six months I had a breakdown"* (southern Scotland).

Far from there being support in place, parents reported that their needs were not even acknowledged: *"After three years of therapy* [for the child] *and trauma, a health professional asked me how I felt for the first time"* (north-east England*). "No-one noticed that I didn't sleep for five weeks in the hospital"* (central England).

WHAT WOULD HAVE HELPED

The message came through very strongly that parents wanted someone to talk to - in fact it was the strongest need expressed throughout the survey. But this person could not be just anyone. It had to be someone with understanding and many respondents also suggested that they would need counselling skills:

"I could have done with professional counselling to take the pressure off my husband and family but I could not get this (it wasn't suggested)" (north-west England). *"Some respite, counselling and a befriender would have made me feel more like human being"* (north-west England). *"I felt very frustrated, angry. Someone who understands and could listen to me would have been a great help*" (north-west England). *"Counselling to come to terms with the child you lose and to accept the child you are left with. Someone who will listen without judging*" (eastern England). *"We were left with extreme emotions: our son would be better off dead, we will never be happy again. A total fear of the future. Someone to talk to who said 'this is normal and it will pass' would've helped"* (south-east England).

Parents often felt that they were left in limbo. If their child had died, they felt they would have been offered grief counselling. With their child alive, such counselling was still needed, but not available: *"I felt that if my child had died I would have been offered grief counselling but no one really acknowledged the grief you feel for the healthy child that you have been promised through your pregnancy - only to find ... your baby is born brain-damaged"* (central England).

EXAMPLES OF GOOD PRACTICE

The parents who had received emotional support were very positive about its impact: *"When my child was 13 months* [old]*, a counsellor came to my home about once a month or whenever I needed to talk. I found myself telling her everything. Things I couldn't even tell my husband. She never once looked down on me in disgust at the things I was saying."* central England*).* *"I feel understood when I talk to* [the physio]*."* (London). *"She* [the pre-school counsellor] *has been every two weeks since our son was diagnosed, working with him and offering a great deal of support to me, a listening ear, a shoulder to cry on and a person to show there is light at the end of the tunnel"* (south-central England).

2. Information

- providing information about the child's disability and its implications and, more generally, providing answers to parents' questions, including those about benefits (providing information about services is covered in the following chapter).

"Being a parent of a child with a disability is like going to another planet, and there is no guide book" (south-east England)

PARENTS' VIEWS

As one parent put it: *"Having a child with a disability knocks your confidence, you are in a world that you have no experience of"* (north-east England). The SOFTY Survey showed clearly that one of the most common responses to parents finding themselves in this new world of disability is a hunger for information: information to help them understand their child's condition and why it occurred; information to help them get the best treatment/ therapy for their child; information to help them assess their child's probable future potential and information to help them regain their confidence and hold their own with health and education professionals. *"I felt in the dark. I wanted to know what I could be doing to help my son develop"* (south-east England). "[Our son's] *medical needs for his spina bifida were quickly dealt with but the information for us to cope was very very poor"* (eastern England).

And the information is not just that needed at the point of disclosure or diagnosis, parents talked about the need for information throughout their time with their child and at the different stages of family life. One topic about which parents commonly expressed frustration is benefits and, specifically, the poor information they received about their entitlement to financial support: *"Information about benefits and help available should be more easy to get hold of"* (south-west England). *"Whether or not you hear about the benefits your child is entitled to is totally hit and miss. It is usually left to parents to tell other parents"* (mid-Wales).

Accessibility
Of course, the information is invariably out there somewhere. What parents said they needed was <u>accessible</u> information – particularly as they were busy dealing with their child and could not spend a great deal of time seeking out information themselves: *"I had a premature baby who needed feeding every two hours day and night I was totally exhausted and worried, and had another child to look after"* (central England).

Parents talked of being given information that was simply not in an accessible form: *"We were given a copy of a complex medical editorial which we could not understand and there was no-one to talk to"* (south-west England) or having inadequate opportunities for follow-up: *"Instead of just giving leaflets out to explain the problem, I think it would have been better if they stay with you and went through the leaflets with you"* (eastern England).

Professionals' control of information
Part of the frustration was the feeling that professionals were controlling the information flow – they had the power to give the information but, for whatever reason, they chose not to: "[Our child] *was in special care for two weeks and, apart from us being told what was wrong with him, no-one told us anything about Downs, what it entailed or what his*

capabilities might be. We know now that there are different levels of Downs" (north-west England). *"It's not knowing anything which is the worst part. Nobody jumps up to help you, you feel so let down by everyone*" (north-east England). *"Professionals seem to think they have a right to withhold information for fear of distressing parents so, despite very early indications, no concrete information re my son's future was given until he was nine months old ... Professionals seem to feel that a dawning realisation of problems will be better than a short sharp shock. Unfortunately all this does is delay the inevitable grieving process and give parents months of distress and uncertainty"* (central England).

The timing of information
Parents demonstrated that there are no rules about how much information should be given at what time. There seems to be no substitute for the information provider being someone who is getting to know the family, their circumstances and their ability and desire to take in information. *"I felt it was too early to be piled with so much information, I would have liked time to come to terms with it all"* (central England). *"I found that consultants and SCBU nurses were reluctant to fulfil my need for general information - I think in case we didn't cope with it"* (north-east England).

CONSEQUENCES OF A LACK OF INFORMATION

Parents frequently equated having inadequate information with feeling like being physically lost: *"We stumbled on so many services by chance, like walking around in a fog"* (south-east England). *"It was as if we were feeling our way in the dark*" (southern Scotland). Parents also spoke of an initial lack of information having long-term consequences. *"I am still only discovering some of what's available* [three years after diagnosis]*"* (eastern England).

WHAT WOULD HAVE HELPED

Parents talked of the need for a person who would be able to give information: *"Perhaps an after-care worker employed within the hospital at the children's outpatients clinic available to any parents using the clinic to go and see after an appointment would be a good idea"* (north-west England). *"Advice came from all different sources and at times it was mind boggling. There needs to be a central information source"* (south-west England).

EXAMPLES OF GOOD PRACTICE

Parents cited examples of good practice highlighting the following key characteristics:

Being able to understand the information -
"The best support we received was being able to talk to our GP and health visitor and being able to understand them" (eastern England)

"[The hospital doctor] *arranged for us to go to his local clinic and gave enough advice but in small quantities so we could digest everything."* (north-west England)

Being treated with respect -
"We were kept informed right from the beginning and treated like responsible adults" (north-east England).

Being kept up-to-date -
"We've been kept informed of our son's (almost daily) progress from the start. This has

instilled confidence in us" (north-east England)

Taking time to explain things -
"The consultant paediatrician came to see us at home and spent an evening talking to us about the syndrome and the support available. He visited us the same day our daughter's blood tests came back. He was very supportive" (north-east England)

A speedy response -
"Our consultant paediatrician was excellent and offered lots of support and sound advice. Any concerns of ours were quickly addressed and explained" (north-west England).

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3. Information about services

- providing information about relevant services to parents and enabling parents to access those services

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"Our whole world felt like it had ended and we didn't know where to go or what to do" (eastern England)

The data

34.8% of respondents said that no one, during the entire two years after acknowledgement of their child's needs, had helped them through the maze of services. This percentage rose to 47.2% for families of children with autism.

PARENTS' VIEWS

Links with appropriate services for the child are vital in support terms for the parent, as well as in medical terms for the child. As one parent typically stated: *"feeling our child is receiving the best care available is the best help for us"* (north-east England). Unfortunately, the parents who have the confidence that this is the case from the early days were in the minority throughout the SOFTY Survey.

There are very few completely comprehensive ‘one-stop-shops’ and it is inevitable that parents will have to move between services to get all their family's needs met. As the family's needs change (for example, as the child with complex needs grows older), the family will move onto different services. Respondents to the SOFTY Survey saw the need for information about available services as being extremely important for the family's well-being: *"You spend all your time coping with daily life and the last thing you want is dealing with all the professionals"* (south-west England).

Some parents attributed their success with finding out about services only to their own personalities: *"If I wasn't so outgoing I don't feel we would have found out so much"* (north-east England). For others, the very act of having links to forge gave them the sense that they were actively doing something of benefit: *"It is very important to be informed of all the possible organisations, services, systems available and contacting a huge number of these gave me a valuable focus and then support"* (London).

The general impression given by the SOFTY Survey respondents is that parents want to be told what is available and supported in taking it further rather than the task being taken away from them completely.

CONSEQUENCES OF A LACK OF INFORMATION ABOUT SERVICES

Parents without such support commonly talked of their frustration at simply not knowing what was available to them: *"I felt alone. I was badly depressed. I didn't know what to do or what equipment I needed for my daughter"* (south-east England). *"I felt very unsupported at the beginning and wish I'd been told about support available right at birth as, if I'd got it* *earlier, it may have stopped me becoming so desperate"* (London).

The typical story was one of parents eventually finding out for themselves after a gap of months or years in which they were floundering: *"It would have been lovely to have someone who could have led us through the available services in our area instead of us still finding them two years on"* (central England). *"I have only just found out social services could help me"* (eastern England).

Parents can often feel that they only found out about services, which later became vital to them, by chance: *"I feel it was more by chance I was told that other services were available to us and then it was a very long haul to get referred to them"* (north-west England*)*. This feeling that things are happening accidentally and not by design, can increase feelings of insecurity and not being in control.

The gap between hospital and home

The single most significant time for linking services over these first two years after diagnosis was highlighted as being the time between being in hospital and bringing the baby or child home: *"The worst time was being discharged from hospital with lots of support, to home with none."* (north-west England). Parents were incredulous that links between hospital and community were so poor: *"For some reason our original hospital consultant neurologist did not make any contact with people working in the community"* (north-west England)

WHAT WOULD HAVE HELPED

The suggestion for improving parents' ability to find out about and link with services was a keyworker who was able to offer all-round information and advice: *"I really needed one worker who was able to offer emotional support and advice on all areas of disability ie. health, education, and social services"* (London). *"I feel that parents should be given all the support they need and one keyworker to ensure that it is anticipated rather than casting about trying to find out what is available in a crisis"* (central England).

EXAMPLES OF GOOD PRACTICE

Parents cited come examples of good practice and highlighted the following key characteristics of this support:

All-round information –
"A family support worker from the children with disabilities team was appointed to us. This was a turning point. As well as offering me personal support, she organised benefits, opportunity group placements etc." (south-west England)

Direction without taking away control -
"The children's community nurses gave us a number of suggestions about ways forward and we used this to make our minds up as to how we as a family were to cope" (eastern England)

Immediacy -
"The nurse from the CDU came to see us on SCBU to explain the services and help available the day after our daughter was diagnosed" (north-east England)

A knowledgeable helper -
"Our portage worker is very good and takes time to chat to us about our lives. She is extremely knowledgeable and makes it her job to learn about other services. She helps steer our way through all the services" (south-east England)

4. Accessing what is needed

- enabling parents to be proactive in accessing the services they want

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"Why should we have to fight for services to enable us to keep our children with us? In the last two years I feel I have had to fight for everything for him including adaptations to the home, DLA, respite, education" (central England)

PARENTS' VIEWS

Apart from information, there are two other issues related to linking with services highlighted by respondents. The first is advocacy, in terms of accessing services, and the second is the co-ordination of services. Parents' views on the latter are covered in detail in the following section. Both generated strong words but, interestingly, there was far less detail written about advocacy than care co-ordination – no examples of good practice were cited about advocacy and few detailed suggestions were made about how it should be provided.

Parents talked of their struggle to access appropriate services in fighting terms*: "You have to battle to get the help needed but are often judged badly for this ... At times I am overwhelmed by coping and having to fight for the right help"* (south-central England*). "It is a constant battle to get the right and appropriate services and support for your child"* (south Wales*).* And this is taking place at a time when parents already have enough to cope with: *"I feel that it is very unfair that the parents of disabled children have to fight for help and support - especially when there is already a strain there for coping with a child with disabilities"* (mid Wales). Many talked of their belief that no help was available unless the family had reached a crisis point: *"There are not enough services anywhere and we have to have a crisis before we can get a service"* (London).

WHAT WOULD HAVE HELPED

Suggestions focused on the idea of a single helping person who knows the child and the situation, and the services available, and can thus access appropriate services on the family's behalf: *"I feel you need someone in your corner to back you up. I didn't even know you had to push for speech therapy. You think because your child is disabled people are going to be knocking on your door saying 'Oh, your child needs this. Your child can go to this class or a certain therapy would help your child lot'. This is not the case. I needed someone to ask me if my child was having speech therapy or play therapy or physio etc. and if my child wasn't then they would help me find out how I could get it and make sure I got the therapy, physio etc. early enough. I found it is left to me all the time"* (north-west England).

"I think there should be one person who is following the needs and supporting the child and family, giving them information about groups and help they can receive. Helping them with appointments and fighting for their needs" (southern Scotland).

Respondents were aware that this helping person would have to have an appropriate relationship with the various services and workers involved in order to be able to work effectively on the family's behalf: *"A keyworker to liaise with all the professionals would be wonderful but would have to be qualified to have respect and recognition from medicine"* (south-west England).

5. Co-ordination of services

- putting together a whole (agreed) picture of the child and the family to ensure that everyone is working towards the same goals and that there is a realistic programme of therapies, and timetable of appointments.

"My son doesn't receive a co-ordinated package of therapies. Many 'experts' see him and deal with their part of him and send him back to me for re-assembly" (north-east England)

PARENTS' VIEWS

The ideas of care co-ordination manifested themselves in several different ways in the views of the respondents to the SOFTY Survey. In its broadest sense, a lack of co-ordination left the parents faced with an array of institutions and individuals which they needed to make sense of: *"I felt very alone and totally responsible for my daughter's medical care ... everyone had a different opinion. Life would have been a lot easier if there was more co-ordination between the different hospitals and departments"* (north-west England*). "There are too many different departments with different budgets and ideas"* (south-east England*).*

More specifically, a lack of co-ordination leaves appointments unco-ordinated, knowledge not shared and a confusion of goals and aims.

Managing appointments
When a family has succeeded in accessing services, the sheer volume of visitors can be daunting: *"At times it did feel a bit like we were running an 'open house' - physio, portage, child psychologist, aromatherapist, health visitor etc."* (north-east England). And this input brings problems of its own: *"Professionals visited our home almost daily (physio, speech therapy, portage etc). We were grateful for their presence but also found they added to the problems (interrupted feeds etc.)"* (southern Wales).

Simply co-ordinating appointments would be of great benefit to families who are trying to get on with their ordinary lives at the same time as bringing up a child with disabilities: *"It is frustrating that services aren't more integrated - we have weeks with no appointments and weeks which are full of them and we are asked the same questions over and over again"* (north-east England).

Of course, when the visits are not home- but hospital-based, the family has to travel which brings its own problems particularly when there are other young children to care for.

Exchanging knowledge
The common cry throughout the SOFTY Survey was the frustration of parents having to say the same things over and over again: *"Further down the road I'm tired of all the agencies involved and number of observations and assessments - I cry out for a co-ordinated approach to cut down on duplication and my time spent repeating the same things!"* (eastern England). It is easy to imagine, not only how tiresome this must be, but how painful it may be to recount a child's pain or decline. On a very practical level, this is also a great waste of valuable time for the workers involved.

THE CONSEQUENCES OF A LACK OF CO-ORDINATION

In very simple terms, a lack of co-ordination invariably represents a poor use of time for everyone involved – the workers, the family and the child: *"Dealing with the pain when you discover your child has complex special needs is hard enough to bear without having to deal with, in my case, five different agencies to provide services. I didn't have time to deal with my pain and I suffered as a result"* (southern Scotland).

With an unco-ordinated approach, there are frequently discrepancies in what is being aimed for and how it should be achieved. *"In* [this] *area, a more co-ordinated effort is needed between GP and paediatrician, health visitors and therapists, as all seem to work to different goals and do not put all the needs of the patient first" (north-east England).*

Ultimately, of course, there is only one child, and so regardless of the myriad care programmes, the parent has to make sense of the information and services reaching the family and can find themselves taking on the role of co-ordinator: *"I think the various professionals really need to communicate. To the parent it seems confusing how little they know about each other. I feel I am my daughter's keyworker - I find myself explaining to different staff what the others do and who they are. It's quite a responsibility when you've got enough to cope with already"* (south-central England).

WHAT WOULD HAVE HELPED

The solution to the problem of co-ordinating appointments was seen to be: *"If one person could take control and try to co-ordinate appointments so that you don't see different people at the hospital on different days."* (northern Scotland). Of course, this is not the only aspect of co-ordination needing development.

EXAMPLES OF GOOD PRACTICE

The examples of good practice cited by parents were very varied in nature and would seem to cover a great diversity of co-ordination – from co-ordinating meetings: *"We requested monthly meetings of all professionals and were given this facility"* (southern Wales) … to 'one-stop shops' of all services: *"The CDC had every kind of professional help available and, after my son's diagnosis and assessment there, they were 'available' if I needed to talk to someone"* (central England).

Other examples stressed the need for one person to co-ordinate all the services who had a good all-round knowledge of the situation and all the services that may be involved: *"My health visitor has been very good and has arranged appointments etc. for us. One person like this who knows all the details of our case is vital as is consistency in the professionals who deal with a case"* (south-east England). *"The family support team working in our area is a great idea. It is a group of health visitors and social workers working as an <u>independent</u> team. They co-ordinate all the professionals dealing with a child ie. linking education or health"* (mid Wales) (Respondent's emphasis).

6. The Whole Picture

- the existence of a complete picture of the child within his or her family and home situation.

"Nobody looked at her as a whole - just the individual bits … The fact that, with an older brother,* [our daughter] *needs to be part of a family, was overlooked" (eastern England)

The data

30.3% of respondents had no-one who they felt had the 'whole picture'. This percentage increased to 41.8% for families of children with autism.

A further 10.3% had a family member, friend or charity as the only 'body' with the whole picture.

PARENTS' VIEWS

No child with disabilities is brought up in isolation – the child is in a family/home environment, the members of which and the functioning of which can be greatly affected by the child's disability. And likewise, the family and its activities will affect the child: *"The impact of a child's severe disability is far-reaching on the family - exhaustion of the parents, poor sex life, financial insecurity, poorer relationships with the siblings (an exhausted parent is not the best parent), lack of sleep, lack of opportunity to get out of the house ... fathers need more help in adjusting to the tremendous impact. Many prefer to work long hours to avoid the stressful situation at home - and this puts even more stress on the mother"* (north-west England).

Many parents spoke of their frustration that the family as a whole was not considered by those dealing with the medical aspects of the disability: *"The hospital doctors were concerned as to how my ill daughter was to be treated. They did not consider how we were going to cope as a family with the situation"* (eastern England). *"I think consultants and doctors should take more time to realise what an impact having a child with such problems has on the whole family and not just on the child himself"* (north-west England).

Taking the trouble to find out about matters relating to the family is also seen as a caring act in itself: *"No-one has ever asked me about my husband or the other two children. For all the doctors knew my husband could have left me - no-one knew what the situation was like at home"* (London).

Some parents were aware that attempts were being made to keep one person informed about all aspects of a child's care but these were not always adequate or appropriate: *"it is only my GP who has copies of everything as he is always copied in by everyone. But he has only ever met my daughter two or three times"* (London*).*

THE CONSEQUENCES OF A LACK OF A WHOLE PICTURE

There are a number of practical implications to a lack of knowledge about the whole picture. The first manifests itself in fear that something will be missed if no one individual has access to all the information about a child: *"No health professional seems to have an overall picture of what's going on which is frustrating eg. having to repeat child's history at each visit and sometimes concerned that something will be missed"* (south-central England).

The second is that the home or family situation may mean that it is unrealistic for families to act on all advice. *"If I dealt with all the 'home therapies' advised, we would have no time for just being a family"* (north-east England*).* If professionals leave a family believing that the family is going to undertake certain tasks – say a set amount of physiotherapy – and the family is unable to do so, it could have implications for the child's progress and can be yet one more cause of feelings of guilt for parents.

WHAT WOULD HAVE HELPED

As with co-ordination, the answer, as respondents saw it, is very easy – focusing as it does on a single supportive individual who gets to know the whole family: *"We needed one person who knew us all* [the family] *and could be more pro-active in helping us help our child"* (south-west England).

EXAMPLES OF GOOD PRACTICE

The good practice cited demonstrated the need to focus on the whole family and not just the child's disability as was explained by one respondent in relation to the paediatrician: "*He listens to me and he recognises the effects on me and the family of* [my daughter's] *complex needs"* (south-central England). *"The community nurse definitely gives us our best support. He helps us get what we need, gives good and informed advice, knows and cares about the whole family"* (north-east England).

Some parents felt that they had met with individuals who made it their business to ensure that they had the whole picture but that this was more the result of their personalities than their roles: "[The best support I received] *was from the paediatrician. She showed great interest in and concern for my own personal circumstances rather than just dealing with the medical needs of my daughter. This was down to her personality"* (south-east England*).*

Recommendations

1. Elements of effective service

It is clear through the SOFTY Survey, that parents need support in all the elements discussed. However, the respondents' input did not stop there. Recommendations were also made in terms of how existing and future services should be offered - both support services for the family and services specifically for the child.

Through selecting the recurring themes in the examples of good practice and discussion of what had not been helpful, the following list of recommendations has been developed:

1. Partnership

Parents should be enabled to play an active and valued role in discussion and decisions about their child's care and treatment

Generally speaking, parents are the primary carers of their children and they are also the people who know their children best. As such, respondents demanded input into the decision-making process affecting their children's care. *"I'm also getting angry at feelings of being 'just the parent' - lip service paid to 'parental partnership'. I feel very much out of control and flattened by the (failure) of services to give me exactly what I need to help me and my family" (*eastern England*).*

Even on a very basic level, far from being in an active partnership, parents felt excluded: *"Professionals quite often spoke to each other about our son but seemed to leave us out of the conversation"* (north-west England).

In contrast, those parents who were involved appreciated having their input encouraged: *"Our son has numerous consultants for the different aspects of his condition. The majority treat me as an intelligent human being and include me in decisions"* (central England). *"If your child has a problem, they are viewed by various professionals. Then they and the child's parents get together to discuss your child. We found that this helped - to be in a group with everyone giving their opinions and finding the best way to proceed. This made us feel part of the whole"* (north-east England).

2. Parent-led service provision

Parents need to be able to control what services they want and when they need them

Given the role of primary carer taken on by parents, the respondents talked of the need for parent-led services - the opportunity to dictate which services they wanted: *"The help has to be what the family needs, not what others think we need!"* (southern Wales). And to dictate the timing of support: *"I could approach her* [portage worker] *about any problem at my own pace ie. put things off until I was ready to deal with them rather than be swept along by 'helpful' people who may have had plenty of useful advice but they were not the ones living with the problem"* (south-west England).

Being a parent of a child who has a disability which warrants the input of a host of external people is frequently very disempowering for parents. Respondents to the SOFTY Survey spoke of those times when they appreciated having control of that input: *"We coped alone when we could and it was our choice to do so. When we needed extra support I always* *contacted my outreach nurse"* (north-east England).

No-one likes to have 'help' imposed on them when it is not wanted. No matter how well-intentioned, it can have the opposite effect of the supportive act it was meant to be*: "I am a very independent person. I only get help when I ask for it. That's the way I like it"* (eastern England).

3. Involving the partner/rest of the family

Partners and other key family members need to be included in support provision

Respondents talked frequently of the need to involve the rest of the family in any support mechanism: *"The professional support ... relates only to the mother of the child whilst in hospital and at home during the day. No support whatsoever was available to the father"* (mid Wales).

Siblings also need to be included: *"My husband has never had any support, nor have any of my other four children who have ongoing problems coming to terms with our little girl's disabilities and are resentful of the time I give to her"* (Isle of Man).

4. Knowledge

Parents need access to knowledgeable helpers

Parents stressed the importance of having someone who is knowledgeable about the child's disability and situation: *"Although my health visitor was sympathetic, she didn't have much knowledge about my son's special needs*" (north-west England).

Respondents did not have unreasonable expectations of people's knowledge levels and respected efforts workers made to keep themselves informed: *"Parents would have far more respect for professionals who admitted when they didn't have the knowledge, go and inform themselves or at least recognise that sometimes parents really are the experts"* (south-west England).

Workers who made no effort served only to frustrate parents: *"Most people we come into contact with didn't understand our child's condition as it is complex and rare but made only vague attempts to get a better understanding despite our giving them relevant addresses and leaflets to read"* (eastern England). *"The health visitor was fairly supportive in the initial days ie. visiting regularly and listening. However, she had little knowledge of disability or how to find the answers to questions I was asking"* (south-central England).

5. Not having to ask

Support for the family and services for the child need to be made available without the parents having to ask

A clear message from parents is that it is important that services are made available to them so that parents can use them as and when they want to. It is very difficult to know what services to ask for when you don't know what might be available. *"A lot of the time, I didn't know myself what my needs were - and there was not a lot of help to identify them"* (north-west England*). "Because we weren't pulling our hair out and banging walls, I think people thought we were coping better than we were and because everything was new to us, we didn't know who or what to ask about anything"* (north-west England*). "At times it has been* *my own fault that I have had no support as I am not pushy and hate to put onto people so I won't ask. I think if you are like this it is hard"* (north-east England). The only person who can genuinely offer this level of service is a person who is knowledgeable both about the family and its needs and the services that might be appropriate.

6. Feedback

Parents deserve effective feedback mechanisms relating to the services they receive

Parents talked of their inability to criticise services they received - a criticism compounded by a lack of alternatives: *"I feel parents feel indebted to professionals for any input, however small ... we are very unlikely to complain about their conduct for fear of putting child's treatment at risk. Also often they definitely do close ranks so a complaint about one professional is likely to have repercussions amongst all involved in child's care"* (south-west England). Such negative perceptions, whether always based on fact or not, are damaging. Great effort is needed to counter it.

7. Respect

Parents demand to be treated with the respect they deserve as the people who care for and know their own children

Many respondents felt that workers had, at times, dismissed them as being over-anxious or neurotic: *"When* [parents] *feel something is wrong, even if it isn't, they should be listened to and believed as they really do know best, instead of being fobbed off as over-anxious. Please start to listen"* (north-west England).

8. Accessibility

Support provision and services for the child need to have realistic and effective accessibility, including outside office hours

Parents cited good practice as having their workers accessible at any time: *"My health visitor and social worker were always there on the end of the phone anytime."* (eastern England)

The consequences of not having this accessibility were cited as including needless hospital visits: "*The nurse could be paged between 9-6 on weekdays. Out of hours support is almost non-existent often resulting in visits to hospital where people are unfamiliar with your child and their problems"* (south-west England).

Importantly, respondents wanted to feel that it was OK to call out of office hours and that they were not hassling the worker concerned: *"It was good because we could phone at anytime of the day and night for advice, and never felt we were being a nuisance"* (eastern England).

9. Honesty

Parents deserve honesty in matters relating to their child

Honesty was seen to be important in both directions. Parents appreciated honesty from professionals, even if the truth was not always easy to say or accept: *"she made me feel like I was not alone. She was not patronising. She knew* [our son] *would not be 'alright'. She understood"* (north-east England). And, in the other direction, parents appreciated opportunities to be honest about how they felt: *"honesty about the worst feelings helped us* *feel understood"* (south-east England).

Honesty was also important in terms of people doing what they said they would: *"Was let down by the district nurse and health visitor who said they would be there to support me through her heart operation – both were nowhere to be seen*" (southern Scotland). *"Doctors always gave you the feeling that they would sort everything out and they did not"* (southern Scotland).

10. Gap-free care

Parents need seamless services - without gaps in which they or their child are left simply waiting for services to start

Parents talked of there being periods of time during which they received no support for themselves and no care for their child: *"My child was put on a waiting list for assessment for 5 months during which time we received no further support*" (north-west England). These gaps were often at times of great anxiety and uncertainty: *"I feel that there was not enough support during the period of tests etc. ... which is often the hardest time"* (eastern England).

At times, parents felt that long waiting periods jeopardised their child's health and development: *"Things should have been put in place as soon as* [our daughter] *was diagnosed, instead of waiting for her health to deteriorate - we would have been more in control and prepared"* (eastern England).

Where seamless services were provided, it was noticed and appreciated by parents: *"We were discharged by a wonderful staff midwife into the care of a special care midwife who was a tremendous support"* (southern Scotland).

11. Continuity of care

Parents needs to be able to rely on supportive services and have supportive individuals replaced should they leave

Parents spoke of their frustration at supportive people ending their support at times not at the behest of the family. Support was withdrawn because the child moved on to a different service, or the individual left their jobs or simply because the service offered was changed. When there was continuity of care, parents found it to be a significant benefit: *"also very important is the continuity of his care. He came to see me after* [my daughter] *was born ... and he still does"* (south-central England).

It was not uncommon for support to change when a child died. All the previous support was withdrawn because the child was no longer in need of services. However, this can be a time of great need and emotional stress. One parent told a typical tale when asked what support would have helped her: *"having support from the day she was born and having the people who did eventually help stay around after she died instead of all backing away"* (eastern England).

Many of the problems of continuity arise because of a common feeling that helpful people are helpful because of their personalities and not because of their roles. And so, when the helpful person moves on to another job, parents cannot rely on their replacement being supportive: *"My health visitor was very supportive but then she was moved to a new post. I felt then that we just had to get on with it"* (north-east England). *"Midwives offered support/ opportunity to talk although this was variable and seemed to be influenced by their own life* *experiences rather than professional training"* (south-central England).

Needing continuity of care does not mean that parents want services without end: "[The community nurse and therapist helped] *by supplying us with all the information and literature required. Daily visits at home just to be able to chat and ask questions if needed, which then went to once a week, then every few months as we no longer felt we needed them"* (eastern England). *"I could call the community sister anytime and she would come back to me that day. Once I felt I was coping, it was up to me to say how often I wanted her to come"* (central England).

12. Visits at home

Where it is possible, parents want home visits

Home visits were appreciated when they were available. The benefits were seen as being twofold. Firstly, it gave the workers a chance to see the child in their own environment and to gain an idea of the family's situation: *"Having someone visit at home is invaluable as they get the full picture.* [The health visitor and social worker] *visited the home and were in the best position to see what your needs are."* (eastern England).

Secondly, home visits alleviated the stresses of having to take a child (and siblings) to appointments: "*parents are expected to travel. I honestly don't think they realise how difficult it is to get a severely handicapped child to appointments etc. plus siblings need attention."* (eastern England)

13. Being positive

Parents need positive alternatives to the problem-focused medical approach

"Most of the attention we got was medical and therefore focused on the negatives" (south-central England). This was a typical comment, in this case from parent who generally saw (health) workers as having to concentrate on the medical problems and the child's anticipated limitations rather than a whole child who has so much more to them than problems and limitations.

Parents talked of support helping them get beyond these negative perceptions: "*Having other 'normal' children and knowing their milestones, it was hard to see any reached by my child. With support you learn to celebrate any successes and not have expectations"* (eastern England).

Parents also made it clear that having a child with disabilities does not mean that you lose your sense of humour. Fun is still important as one parent made pointed out in her explanation of why the pre-school teacher counsellor was supportive: *"Easy to talk to and fun. Not all doom and gloom!!"* (south-central England) [respondent's emphasis].

Being positive also involves assuring parents that they are doing a good job: "[Our son's] *hospital doctor has been really complimentary to us as parents and thinks that we are coping very well. This in itself is a great support to us"* (north-west England).

Recommendations
2. The keyworker

Respondents, throughout the survey, talked of strong emotional responses to the disclosure of their child's disabilities, and frustration with the information flow and access to services. With only 6.6% respondents feeling that their needs had been met well, it is apparent that we are seriously letting down this groups of carers.

The idea of the keyworker was not brought up in the survey literature and questions nor was an indication given of the definitions of support. But the voice of the respondents could not have been clearer - overwhelmingly, they wanted emotional support, greater access to information and services and a co-ordinated approach which took account of the whole picture of the child within the family.

These are not new ideas and represent nothing more than a common-sense approach to support for parents and carers. Respondents were by no means demanding the unreasonable.

Additional to these major needs, respondents made requests for other methods of working with them and their families, which are outlined in the list of *Elements of effective service*. These included such issues as working in partnership with parents, involving other key family members rather than the mother alone (The Handsel Trust's publication *Just A Shadow* by Sheila West covers this in greater detail), home visits, continuity of care.

The One Hundred Hours keyworker model of support successfully brings all these elements together providing the family with an individual who is there for them to respond to these needs. Importantly, the keyworker is someone who gets to know the family and the child and so can offer support appropriately - an issue which respondents stressed was important in giving emotional support, information, and co-ordination of care.

This was summed up in typical fashion by the following: *"I feel that having one person to turn to would have helped me a lot more. There are so many different people involved with us as a family now. Having one person that I could call to scream to occasionally, someone outside our family and friends would be really nice. Someone that totally understands about the needs of my child, and also my husband and myself. At the same time though we do need to be a family the same as other people so I would not like someone that pushed themselves upon us all the time! I think that a link worker would be a really good idea. Somebody that understands each of the different aspects of our child's care (ie. physio, speech therapy) not as a replacement for these people but just an understanding friend that can help put things in their place and help you, your child and husband live a normal family life"* (north-west England). And this support needs to start as early as possible: *"When you first find out there should be one person ... assigned to help with the emotional and practical issues"* (southern Scotland).

Part of the role of the keyworker has been suggested to be co-ordination of the services working with the family. This of course, demands multi-agency co-ordination - enabling the keyworker to do his or her job and also to create the seamless service requested by respondents.

The keyworker system of support is not a new idea. The chapter on research in keyworking, by Sheila West, looks at these recommendations in the context of other research.

Support from other parents

"At 2½ years our daughter happened to be in a hospital with another girl of the same age and problem. It was this* [child's mother] *who told us about benefits etc. We'd lost 18 months of claiming" (eastern England)

The data

54.6% of respondents had had the opportunity to talk with another parent.

12.7% had had the opportunity but decided not to take it up.

59.3% found talking to another parent helped a lot. 39.5% found it helped only a little or not at all.

64.1% of those who found it helpful felt it offered emotional support; 60.3% felt it helped them to learn about benefits and services; 23.5% found it useful to see another family living with the same or similar issues.

It is a common argument that the best people to support parents are other parents. Parents have instant empathy and, importantly for budget holders, they are cheap. However, the above data demonstrates that not all parents find it beneficial and respondents showed that talking to other parents is not enough and can, at times, do more harm than good.

Timing
One of the key areas highlighted by parents as a reason for it not being helpful to meet with other parents was timing. Parents talked of having to deal with their emotions themselves before talking with other parents: *"It* [meeting other parents] *was traumatic so early on"* (central England). *"Other parents can offer a safe environment to offload but it takes a while before an individual is ready for this. While denial/non-acceptance is still strong or the parent is emotionally vulnerable these parent-to-parent situations can be overwhelming"* (mid Wales).

Meeting other parents also takes time itself and some families simply didn't have the time: *"We would have liked more meetings with parents in similar situations but at first there wasn't time for this"* (eastern England).

Acknowledging the difference between parents
There is an assumption that if you put all parents together their children with special needs will bring them closer and they will find they have lots in common and are thus able to support each other. Parents of children with special needs are, however, as disparate a group as parents as a whole and the links can, at best, be tenuous: *"All parents have different outlooks and lives. Just because you have a child with special needs it does not mean that your child will be the same as the next one"* (south-west England).

Inevitably, differences of opinion arise and these can put parents off attending groups altogether: *"We were given the number of a support group. We decided not to use it as it was run by a parent who had adopted two children with our son's condition but she did not believe in offering her children any treatment and, as we believe the opposite, we did not* *believe it would help"* (central England). In a generic special needs group, these differences can be insurmountable: *"There are too many different complex needs to be met at this infrequently-run support group"* (eastern England).

It is also not unusual for parents to feel that talking to parents comes with its own disadvantages *"It encouraged me but at the same time it frightened me"* (north-west England). Other children can often represent a glimpse into a possible future for the parents of younger children, which can, in itself, be upsetting: *"Information was supplied by our local children's centre on a support group for parents but I didn't feel the need to contact them at that stage. My son was less than 6 months old then and I found reading the reports of children older than him very upsetting"* (north-east England).

This is particularly so with children with degenerative conditions, as one parent of a child with muscular dystrophy put very clearly: *"My son was 5½, hers was 11 years. My son was still walking, hers was in a wheelchair. I found it very upsetting and very frightening. It made me even more depressed"* (north-west England).

Parents attend support groups because they need support themselves. This can make some members refrain from stating their own needs: *"I also held back from other parents because I knew they had their own crises to deal with"* (London).

Exchanging information

Two-thirds of respondents said that they appreciated talking to other parents because they could share knowledge: *"Parents with children with similar needs often have practical advice and understanding, they can pass on information on everyday issues re equipment, useful organisations"* (south-west England).

It is, however, perhaps not wise to rely solely on other parents for practical advice as they will undoubtedly have information that relates only to their child's situation. Children with different needs and families with different situations may have a different range of benefits and services available to them. A parent's-eye view is useful for other parents - to find out how things are really experienced - but it may not be the most complete or up-to-date view.

Therapy

Being in a parent support group is a therapy in itself as one parent put it, she was *"able to return the support and benefits, thereby feeling more useful, less useless"* (north-west England). Helping other parents can be part of the process of regaining control and confidence. It also has undoubted social benefits for parents who might otherwise find it difficult to get out and about and make friends.

There is the temptation for parent-to-parent support to be provided as a cheaper alternative to other forms of support, however, it is important to be honest and up-front about the potential disadvantages. Support from parents is not an alternative to support from someone who is trained to do that work, it is an extra to be added on to a professional support system.

Other research on keyworking

Keyworking is not a new concept: the need for it was identified over twenty years ago in the Warnock report (Warnock 1978). Glendinning carried out one of the first experimental fieldwork-based studies with a piece of research which provided a number of families who had a child with a disability with a single worker who could act as a keyworker for the family. Her conclusion was that this type of service was effective and greatly valued by the families (Glendinning 1986). The message that families want a holistic, co-ordinated approach has been repeatedly given by research since then. (Beresford 1994a, Beresford 1994b, Sloper 1999). Baldwin and Carlisle (1994) give a comprehensive overview of research in their literature review and conclude that there is no evidence to show that a co-ordinated approach is being provided consistently by the support services.

There is a small body of research that looks at the idea of a keyworker from the perspective of 'what would have been helpful?' The parents involved in the research carried out by Cottrell and Summers had described to them a model of keyworking:

> *One member of the hospital team co-ordinates the other professionals involved. The keyworker would ideally know about all those trying to provide help for the family and organise events to avoid duplication of effort or mixed messages. Parents would go to the keyworker for advice or information which the key worker would either supply or arrange for others to provide. It is not expected that the keyworker would know all the answers, rather they would explain the system to the family and help the family find answers for themselves (Cottrell and Summers 1990, pp216-217).*

All the parents in the group thought that this would be an effective way of providing support. Other research has come to similar conclusions: Stallard and Lenton's research suggests that the establishment of a keyworker with specific counselling skills would be a way of ensuring that the needs of the parents are met. The parents in their research talked of the impact of coming to terms with their child's difficulties and emphasised the fact that their feelings of guilt, anger and loss were not being acknowledged or addressed, even though they were receiving help and support from professionals who were focusing on the needs of their child. It was felt that having one worker to address their needs would have offered them the support they needed (Stallard and Lenton 1992).

A series of workshops for parents held in the north of England recently identified the need parents had for a co-ordinated service. These workshops formed part of the initiative involving parents in Scope's *Right from the Start* campaign, promoting good practice in diagnosis delivery. The clear message from these workshops was that regardless of how 'right' or 'wrong' things were from the start, parents wanted one person to whom they could relate when they began their journey through the maze of services for their disabled child. This person, parents identified, would be a keyworker (Right from the Start 1999).

Other research has evaluated a keyworker model where it has been put into practice. Glendinning's research has been cited earlier and Buchan et al (1987) describe a project that provided regular ongoing support and counselling for families with a child with complex disabilities. The research found not only did families value the service they received, there was also evidence that the children benefited from the attention paid to the needs of the parents:

> *There have been several examples of families whose children have had behaviour problems that no longer present difficulties. Dramatic improvements in language development have occurred. There also appears evidence of other changes occurring in families such as the ability to contribute to their child's full assessment procedure, and to cope more efficiently with other difficulties such as financial problems (Buchan et al 1987 p86).*

An independent survey of the keyworker system provided by One Hundred Hours (West 1994, pp26-27) made the following conclusions:

i. the service is flexible in its approach basing its work on the needs of the child and the family
ii. One Hundred Hours is a major source of information regarding any other services that may be of use to the families
iii. the keyworker can act as a link between the families and the myriad other professionals with whom they may come into contact
iv. the keyworker is able to provide emotional support to the parents at a time when one of their greatest needs is someone who has time to listen to them

A further user survey of the One Hundred Hours model (Spencer 1999) identified specifically those elements of the keyworker service parents valued. Parents talked of the keyworker bridging the gap that they experience on first leaving hospital. They appreciated the keyworker's positive approach, and the fact that it was a non-medical, independent service. They found the fact that the service was provided in the family home supportive and practical and valued the way the keyworker attempted to understand them and really listened to them as a whole family. The role carried out by the keyworker in linking all the services together was also highly valued.

McConachie (1999) stresses the importance, not only of providing effective support services to families, but also evaluating how far they are meeting the needs of families. She exhorts the One Hundred Hours model and the way in which it is a parent-led service.

> *The voluntary organisation One Hundred Hours has demonstrated a model of early support to families of children with multiple disabilities and health needs, making a limited contract with a family within which they control how much of what kinds of services they would like to use and receive, a model which statutory services would do well to emulate* (McConachie 1999 p106)

The crucial elements of a keyworker model have also been investigated in the literature. Dale (1996) and Davis (1993) describe the elements of an effective helping relationship in detail, and it is these elements upon which the One Hundred Hours model is based. Davis identifies the key factors as working closely, having common aims, parents and professionals recognising that they have complementary expertise. He stresses that there must be mutual respect, communication and negotiation between all parties and that the relationship needs to be one based on honesty and flexibility.

A recent piece of research looks at not only the elements of an effective keyworker system but the way that this model can be implemented (Mukerjee et al 1999 and Sloper et al 1999). Mukerjee et al describe two pilot keyworker systems that were initiated by research, define each of the models and evaluate them. The research identifies six major elements of a keyworker model:

pro-active regular contact
a supportive, open relationship
a family-centred approach
working across agencies
working with families' strengths and ways of coping
working for the family as opposed to working for an agency

These were the aspects of the service that parents valued and found distinctive compared to the other forms of support they received from statutory agencies (Mukerjee et al 1999 p58).

Sloper's research (Sloper et al 1999), recognising that the research has largely failed to be translated into practice, brings us a step closer to a solution by investigating the problems and opportunities experienced through developing and implementing a working keyworker system in two pilot areas.

The evidence of the research conducted over the last two decades is overwhelming. Parents are not, with a few notable exceptions, getting the service they need or want. The research has shown that keyworking would (and in the examples given, can) provide the support that parents are demanding. *Parents' support need*s, together with the rest of the body of research now needs to be put into practice.

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Summary and conclusions

The need for support
The news that a child has complex needs is traumatic and life-changing for parents. Parents cited the consequences of not having support as including depression, 'cracking up', not sleeping, marital breakdown.

The support needs identified were categorised into the following six key areas:

1. Emotional support
Parents cited a range of extreme and negative emotions in response to their child's diagnosis and their subsequent relationship with services. Long-term depression, alcoholism and marital breakdown were all given as consequences of a lack of emotional support.

The answer, respondents said, was quite simply someone to talk to - someone who would understand, who could listen and who had counselling skills.

2. Information about the child's condition
The consequences of not having information about the child's condition were cited as frustration, distress, uncertainty and an inability to understand what was happening (which means that they cannot then play a full part in decisions about their child's care).

Parents suggested a single information source available immediately on diagnosis (or suspicion of problems). The information needs to be given at the pace suited to the parents and in a way that they can readily understand. Information also needs to be given by someone who has the time to sit and talk through the information and address any concerns.

3. Information about services
Parents talked of the desire to be sure that their children were receiving the right care at the right time. This is a very strong driving force frustrated by the incomprehensibility of the maze of services available to someone new to the world of disability. Without support to find the right services, parents talked of their own frustration, periods of time in which their child was receiving no services at all, wasted opportunities simply because parents did not know those opportunities existed.

Respondents suggested a worker who would know the family and services available and could let the family know what was appropriate so that the family could decide what to use.

4. Accessing what is needed
Respondents talked of having to 'fight' and 'battle' for the services they wanted and needed for themselves or their child. They talked of this adding to the strain of their family's situation and having to reach crisis-point before they got what they needed.

The suggestions for improving this focused on having one worker who is knowledgeable and respected by the professionals and thus can ensure that the family gets what it needs.

5. Co-ordination of services
The lack of multi-agency co-ordination was experienced in several different ways- an unmanageable array of appointments, poor flow of information (causing the parents to repeat their story constantly) and a confusion of aims.

Respondents suggested having one person who takes on co-ordination. Good practice was highlighted as the different agencies being linked together.

6. The whole picture

Respondents expressed their frustration that no-one working with their family has the whole picture - the child's condition, treatment and progress and the wider family situation and welfare. The consequences of this were cited as including inappropriate care given, poor support for the family, concern that essential elements of care or treatment are missed and unrealistic demands made of the family.

The suggestion for change was clear - one person who took the time to get to know the family situation as well as the child.

Recommendations

1. Elements of an effective service.

Respondents made the following recommendations as to how care for the child and support for them as parents should be given:

1. Parents should be enabled to play an active and valued role in discussion and decisions about their child's care and treatment
2. Parents need to be able to control what services they want and when they need it
3. Partners and other key family members need to be included in support provision
4. Parents need access to knowledgeable helpers
5. Support for the family and services for the child need to be made available without the parents having to ask
6. Parents deserve effective feedback mechanisms relating to the services they receive.
7. Parents demand to be treated with the respect they deserve as the people who care for and know their own children
8. Support provision and services for the child need to have realistic and effective accessibility, including outside office hours
9. Parents deserve honesty in matters relating to their child
10. Parents need seamless services - without gaps in which they or their child are left simply waiting for services to start
11. Parents need to be able to rely on supportive services and have supportive individuals replaced should they leave
12. Where it is possible, parents want home visits
13. Parents need positive alternatives to the problem-focused medical approach

2. The keyworker

It is clear that the response to the needs of the parents is a keyworker approach - one individual worker who could provide the family with any or all of the following:

emotional support
information - about the child's condition, benefits and services
access to services
co-ordination of appointments, services and therapy programmes

It is clear that to achieve these elements appropriately and effectively, the keyworker would need to ensure that they the whole picture of the child and his or her family.

To achieve effective co-ordination of services, the keyworker would need to be supported by a degree of multi-agency working.

Through their examples of requested or good practice, respondents highlighted following characteristics as being necessary in the ‘helping’ role:

counselling skills
time to listen
understanding of what the family might be experiencing
non-judgemental
positive outlook
ability to explain things in a way parents can understand
... and at a pace appropriate to the family
a wide range of knowledge - covering all aspects of service provision
ability to enable the family to take decisions.
available to offer support immediately after disclosure
respected by all service providers
caring about the family

It is worth remembering that the SOFTY Survey did not set out to look explicitly at the keyworker model of support - we set out to look at parents’ support needs in general terms. The respondents, however, in the way they defined the support that they needed have collectively given us a very clear message that the keyworker model developed by One Hundred Hours has relevance throughout the UK.

But it is, of course, not enough to ask parents, find the answer and report on it. The SOFTY Survey joins other existing research which looks at the needs of parents and the consequences of there being no support. The next step is now unavoidable - the necessary support needs to be provided. Yes, this will mean structural changes. Yes, there are undoubtedly budgetary implications. Yes, there will have to be genuine joined-up working to provide families with the seamless services they need.

The bare facts of the matter are that we need parents to be OK in the caring role. In financial terms, it's a great deal cheaper if children are cared for at home and it is also cheaper if those children and their families thrive. Early intervention to enable parents to do the best job possible is cheap in comparison with the alternatives. Parents are strong and resourceful. They strive to keep their children alive and to help them develop. We need to support them in this endeavour.

The plea from one respondent is well worth bearing in mind:

"I found it painful completing this questionnaire ... Please do something with the responses you receive otherwise as parents, we will have gone through pain with no gain!" (north-east England)

APPENDIX 1

Notes on the SOFTY Survey

About the survey
Between August 1998 and January 2000, postal questionnaires were distributed to the parents of children with disabilities throughout the UK. The questionnaires were seen via support groups, through article in One Hundred Hours newsletter, Opportunity, through the newsletters of other organisations and through local newspapers. Questionnaires were sent to every CDC in the country for workers to pass on to families in their care and to approximately 300 other health, education and social services workers.

Approximately 5000 questionnaires were distributed in this way and, although we received approximately 1,000 completed questionnaires, we have used only 455 in this survey having excluded questionnaires from families who had received most of their care abroad, those who had received support from One Hundred Hours and those who had first had formal acknowledgement of their child's disabilities before 1990. The response rate achieved was thus a little under 10%.

Notes on the presentation of results
Although many parents were keen to use the questionnaire as an opportunity to congratulate or berate specific individuals or organisations for the treatment they gave families, we have avoided naming these. This is a deliberate decision because we see the role of this report to promote constructive dialogue and not to single out individuals and organisations for particular praise or criticism.

Definitions
We did not define ‘complex needs’ but allowed parents to make their own decisions about whether the questionnaire related to them. Appendix 2 shows the range of disabilities which were ultimately featured in the survey. The survey also included responses from both foster parents and adoptive parents.

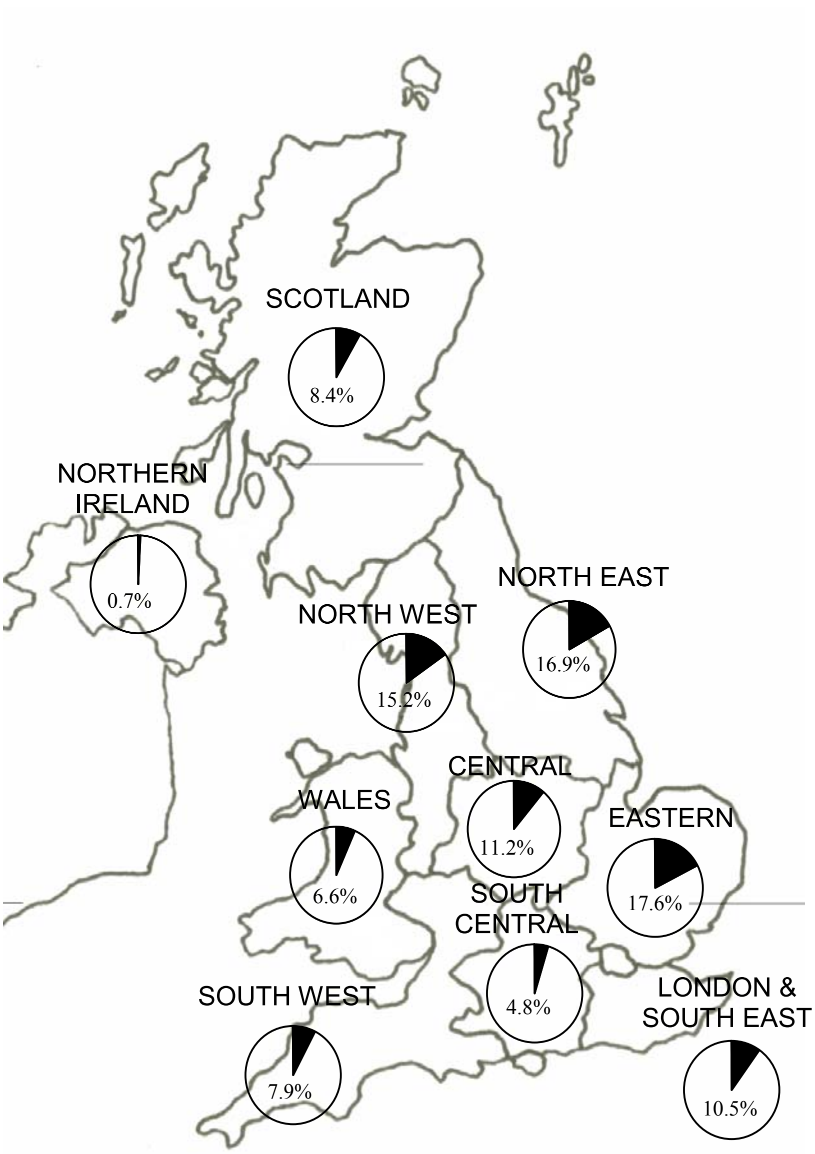
Having a child with disabilities
This report focuses on the negative aspects of bringing up a child with disabilities - aspects that are greatly exacerbated by a lack of support for the families concerned. This is certainly not to say that having a child with disabilities is a terrible thing and that parents did not want their children or found no joy in their lives. As some respondents were keen to point out that despite the problems *"our baby is an absolute joy to have and everyone loves him to bits"* (north-east England).

Diagnosis
The survey contains many stories about diagnosis - some good, many bad and some describing tremendous and needless heartache. The problems of giving diagnosis in a sensitive and appropriate manner have been covered in great detail by other organisations and much work is being carried out to support parents at this time. To avoid duplicating these efforts, we have chosen not to include information about the time of diagnosis in this report.

Practical help
A common cry was for greater practical support for the families - support such as respite care, better housing, financial help etc. These are vast areas are not covered in this report as our current priorities are in wider issues of support and these areas warrant more research and attention than we could currently afford them.

APPENDIX 2

About the respondents



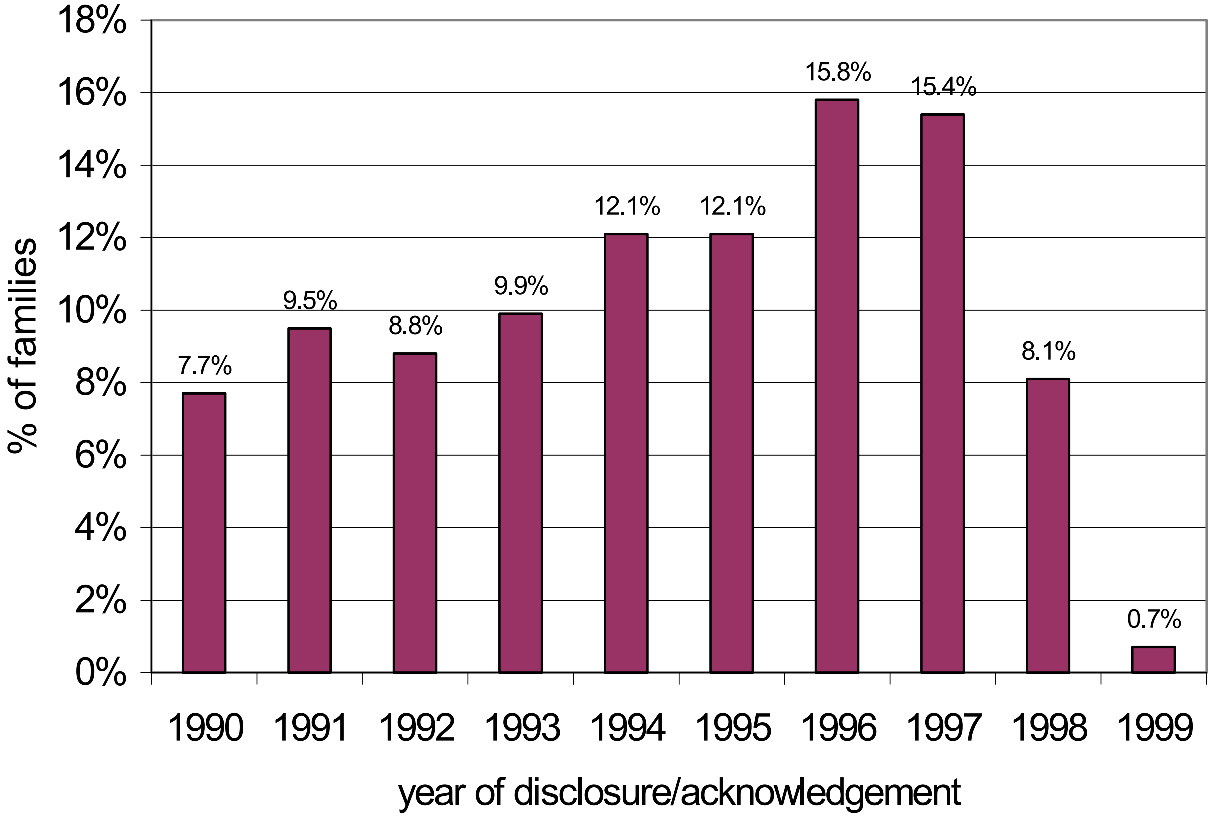
The respondents cited an average of three disabilities or special needs each.

The most common were:

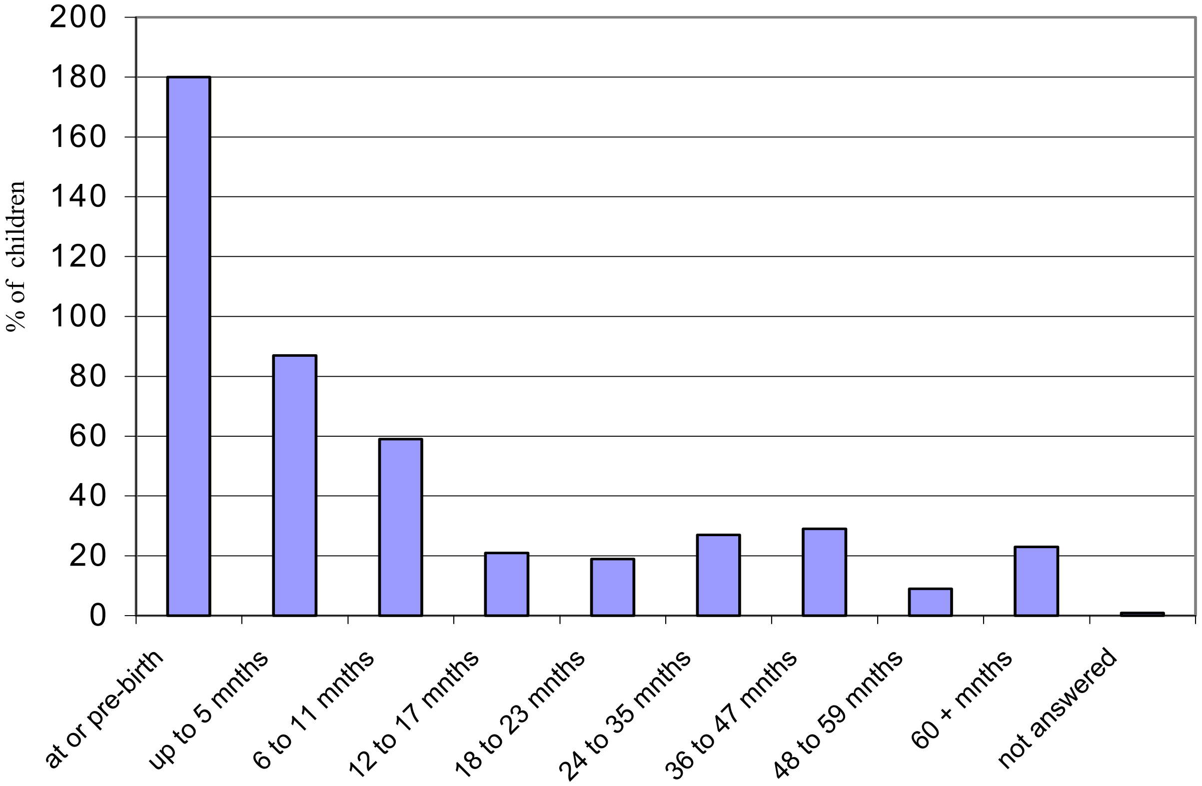
Learning disabilities	(46.6%)
General development delay	(40.4%)
Feeding problems	(25.1%)
Sleeping problems	(10.1%)
Cerebral palsy	(17.8%)
Blind or visually impaired	(16.9%)
Downs syndrome	(14.9%)
Autism	(12.1%)
Breathing problems	(11.6%)

10.3% had no known diagnosis.

The year in which there was acknowledgement or disclosure of the respondents' children's disabilities.



The age of the children at the time of this disclosure



APPENDIX 3

Comparison of responses across disabilities

Q: Was your trauma, as parents, acknowledged in the first days and weeks?

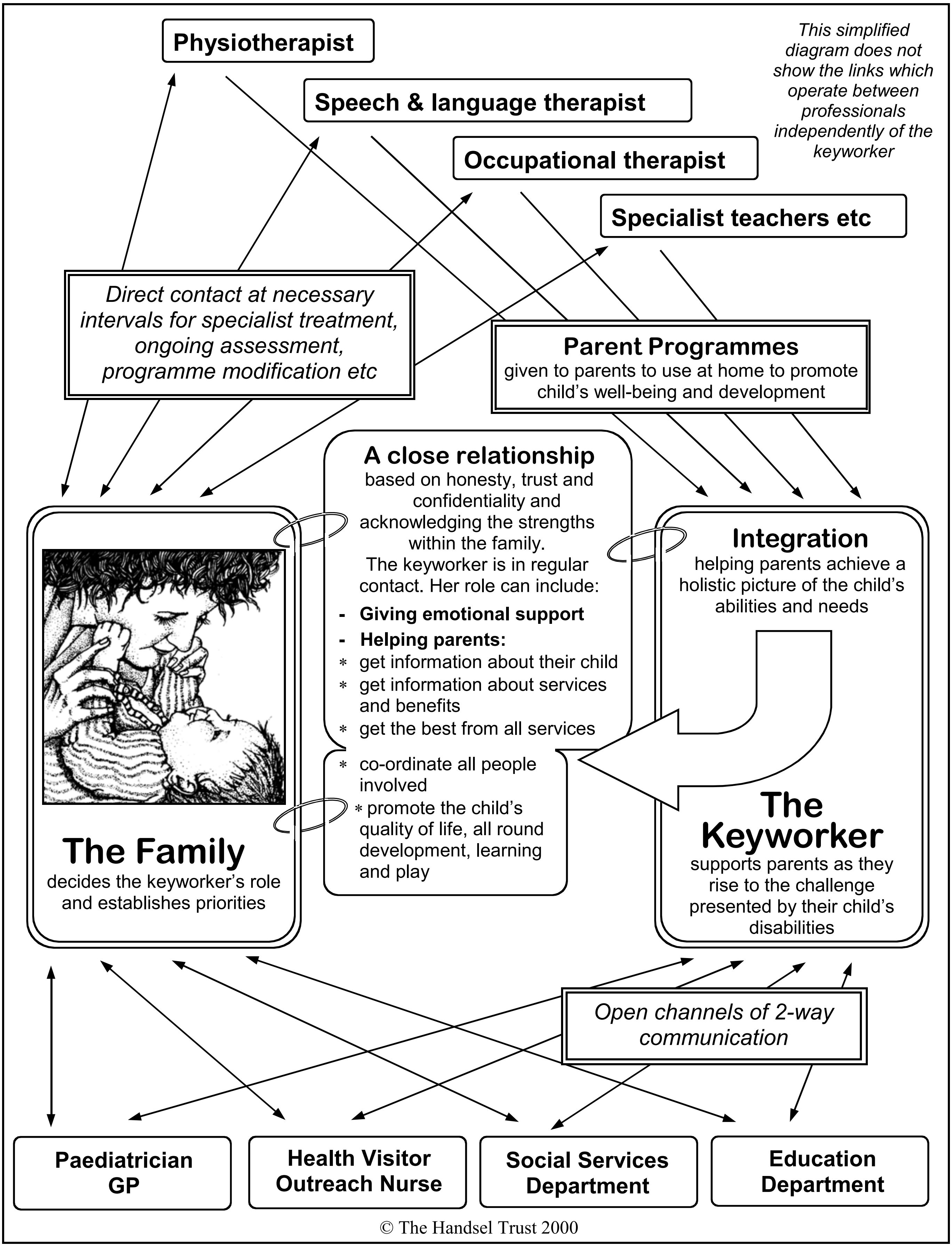
		Respondents with children who have ...				
	All respondents	**… Downs syndrome**	**… another genetic syndrome**	**… cerebral palsy**	**… no diagnosis**	**… autism**
Not at all	30.3%	10.3%	29.9%	29.6%	43.5%	47.3%
Not as much as I/we needed	18.5%	19.1%	20.8%	18.5%	15.2%	12.7%
Yes, but not early enough	5.5%	2.9%	3.5%	7.4%	6.5%	10.9%
By some professionals but not all	27.7%	41.2%	32.6%	25.9%	19.6%	16.4%
Yes, this was done well	16.0%	26.5%	11.8%	17.3%	10.9%	10.9%
Not answered	*2.0%*	*0*	*1.4%*	*1.2%*	*4.3%*	*1.8%*

Q: If your needs as parents were acknowledged, was there any attempt to meet them?

		Respondents with children who have ...				
	All respondents	**… Downs syndrome**	**… another genetic syndrome**	**… cerebral palsy**	**… no diagnosis**	**… autism**
Not at all	4.4%	1.5%	3.5%	4.9%	8.7%	7.3%
Not as much as I/	16.9%	16.2%	20.1%	16.0%	10.9%	14.5%
Yes, but not early	16.9%	5.9%	4.2%	7.4%	8.7%	9.1%
By some professiona	11.6%	10.3%	13.9%	18.5%	8.7%	3.6%
Yes, this was done	6.6%	33.4%	16.7%	9.9%	10.9%	10.9%
Not answered	*43.5%*	*33.8%*	*41.7%*	*43.2%*	*52.2%*	*54.5%*

APPENDIX 4

The One Hundred Hours keyworker model



Physiotherapist

Speech & language therapist

Occupational therapist

Specialist teachers etc

This simplified diagram does not show the links which operate between professionals independently of the keyworker

Direct contact at necessary intervals for specialist treatment, ongoing assessment, programme modification etc

Parent Programmes
given to parents to use at home to promote child's well-being and development

A close relationship
based on honesty, trust and confidentiality and acknowledging the strengths within the family.
The keyworker is in regular contact. Her role can include:

- **Giving emotional support**
- **Helping parents:**
  - ∗ get information about their child
  - ∗ get information about services and benefits
  - ∗ get the best from all services
  - ∗ co-ordinate all people involved
  - ∗ promote the child's quality of life, all round development, learning and play

Integration
helping parents achieve a holistic picture of the child's abilities and needs

The Family
decides the keyworker's role and establishes priorities

The Keyworker
supports parents as they rise to the challenge presented by their child's disabilities

Open channels of 2-way communication

Paediatrician GP

Health Visitor Outreach Nurse

Social Services Department

Education Department

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APPENDIX 5

The role of the keyworker in the One Hundred Hours model

The main task is to work with an agreed number of families:

- giving **emotional support** to parents and other key family members
  counselling skills are used but the keyworker is not providing formal counselling, the major element of this support is 'active listening'
- helping the parents get **answers to their questions** about the child's condition
- helping the parents get **information** about all relevant services and benefits
- helping the family get **all relevant services**
- helping the family to **promote the child's well-being**, play and development
- helping parents **co-ordinate the professionals** and agencies involved so that
  - appointments are rationalised
  - professionals know what each other is doing
  - parents are not over-loaded with things to do
  - duplication and contradictory advice is avoided
  - services provide collectively for the whole child and family
- helping parents **integrate all interventions** so that
  - they have a holistic picture of the child's abilities and needs
  - there is a whole approach which embraces all developmental activities, learning programmes and goals
- promoting parents as **equal partners** in all services to their child

The service is needs-led so what the family takes from the above list will change as their needs change. The keyworker is not an independent operator; to perform the above tasks she might need, with the prior permission of the parents, to liase with all relevant people from statutory and voluntary agencies. In all work, the family's right to privacy is treated as paramount.

The keyworker role with each family has four main stages:

1. **Introductory phase** - getting to know the child and family, valuing the child and focusing on his abilities, valuing the parents, acknowledging what they have been through and acknowledging their love and care for the child, working to establish mutual friendship and trust
2. Making **regular visits** over an agreed period of time
3. Negotiating and operating a **'winding down phase'**
4. Negotiating and operating a **'keeping in touch' phase**

Relevant records are kept as follows:

- **The Family File**: this is the repository of all notes, letters, reports, significant telephone conversations, etc. The file is held in strict confidence by the keyworker and is made available to the parents on request and at regular periods. The keyworker's supervisor has access to the family files
- **A log of each visit** detailing date, time, place, duration, who was present, any items/books loaned or collected, any action promised - kept by the keyworker
- There might be a **'Whole-Picture Book'** recording the child's progress on agreed areas of development and this stays in the family home
- There might be **a video record** of the child's progress and this stays in the family home

APPENDIX 6

The keyworker & the helping relationship

> *"The process of helping families hinges on the quality of the relationship established between the parents and the helper. It is argued that an ideal relationship would be based on the principles of a partnership model (as opposed to an expert model)."*
> Hilton Davis 1993, in 'counselling parents of children with chronic illness or disability'

In the One Hundred Hours model, the helping relationship between the keyworker and the parents and other family members is characterised by the following elements -

Begins as soon as possible after the disability is discovered or suspected
Does not have to wait for a confirmed diagnosis
Parents choose whether they want the service and when they want it
Support is offered during an evolving diagnosis
An immediate response to a request for help - within a day or two
Parents determine how they want the keyworker to help
The care the parents have given already is acknowledged
Relationship based on trust, honesty and real confidentiality
The child is valued, as are siblings
Parents are respected and their strengths are acknowledged
Parents are treated as equal partners in their child's care
The child is viewed as a child - not as a patient
The child is discussed in positive and honest terms
Visits take place in the family home
Visits arranged for days and times to suit the family
Visits can be evenings (and sometimes weekends) to meet a working partner
Visits can continue when the child is in hospital
The family's home environment is respected
Parents are informed what the keyworker can offer
Parents can pause, modify or end the service without explanation
The keyworker does not pretend to know best
Parents can be asked how they would like to use an individual session
The focus of the work can shift back and to between the parents and the child
Parents are asked periodically if the sessions are helpful - formally and informally
Parents' problems and anxieties are acknowledged in full
Visits are not rushed - two hours allocated though the visit might be shorter
A visit can be extended if need arises
Visits can include any key family members
The service winds down gradually and ceases by mutual consent
The keyworker can continue to visit if the child is dying
The keyworker can continue to visit after the child has died
Parents can re-establish contact when a need arises

"If someone had asked me how I felt instead of concentrating solely on my daughter's problems, I believe it would have released the stress that built up and led to severe depression six to seven months later.

My husband and I felt as if it were us against the world"

(a respondent in the UK SOFTY Survey)

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