User-friendly information for families with disabled children

A guide to good practice

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Contents

Acknowledgements

Summary

The importance of relevant and accessible information about services for families with disabled children has been highlighted in numerous studies and re-emphasised by Quality Protects. These studies have also shown that this need is frequently not met. This project explored the criteria by which parents judge the quality of information and their ideas of good practice in this area.

- Parents proposed similar criteria for good quality information, irrespective of their child's disability. These clustered around four themes: how information is presented, the content of information, the way it is delivered and how it is organised.

- Parents wanted to receive information, especially written information, on different levels. They wanted short, direct summary guides of local services as well as more in-depth, informative booklets. These should be clearly written with an easy-to-use index and employ colour and images to make them interesting.

- The content of the information should cover the roles of all the different agencies involved in providing services for families with disabled children. It should also consider key aspects of families' and their children's needs, from the child's birth through to adulthood.

- Parents continually emphasised that booklets, leaflets and videos are not enough by themselves; personal contact with, and guidance from, information givers was regarded as crucial. A person, a 'key worker', 'link person' or 'facilitator', was wanted who would guide families through the maze of information potentially available.

- Good practice is three-dimensional: families need to receive succinct directories of local services and support networks, alongside more in-depth and informative booklets, with support from locally based 'facilitators' or 'key workers'.

1 Background

Families' needs for information

The need for relevant and accessible information for families with disabled children has been highlighted in a number of research studies of families' views of their needs (for example, Quine and Pahl, 1989; Sloper and Turner, 1992; Beresford, 1994, 1995). Information has been shown to be one of the most valued aspects of families' contacts with services (Baine *et al.*, 1995; Clare and Pistrang, 1995), yet a number of studies have found that a substantial proportion of parents report that their needs for information remain unmet (Quine and Pahl, 1989; Sloper and Turner, 1992; Social Services Inspectorate, 1994; Beresford, 1995; Chamba *et al.*, 1999). Parents do not know where to go for information and often find out about services and benefits in an ad hoc way through contacts with other parents, for instance whilst waiting in clinics.

Families' needs for information cover a range of topics: information about their child's condition, services and financial benefits, and how they can best support their child's development. Such information comes within the remit of a number of different agencies, and therefore provision of information to families requires a coordinated multi-agency approach, which again has been found to be lacking (Sloper and Turner, 1991; Beresford, 1995). Moreover, people's needs for information vary between individuals and within individuals over time:

> *... information is situationally, temporally, and personally bound. What is information to one person may not be to another; what a person found informing at one time, he or she might not in another situation.* (Baker and Connor, 1994, p. 37)

This implies that information providers need to take a flexible approach and understand the needs of each individual family.

The importance of being well informed

Parents with disabled children have been shown to be vulnerable to high levels of stress (Quine and Pahl, 1991; Sloper and Turner, 1993; Wallander and Varni, 1998). Theories of stress and coping emphasise the importance of how individuals appraise their situation and the way in which the resources available to them influence both these appraisals and the strategies they can use to cope with the stressful situation (Lazarus and Folkman, 1984). Information and knowledge are important resources in people's efforts to manage the difficulties they encounter in their lives and to maintain a feeling of control. Information is necessary for family members to understand the changes in their lives relating to having a disabled child, construct their own interpretation of what this means for them, obtain support and find ways of coping with the demands they face. Research has shown that feeling well informed about a source of stress contributes to feeling a sense of control (for example, Weitz, 1991). In turn, feeling in control is related to more effective coping with stressful events (for example, Janis, 1983). Parents' sense of control, in relation to feeling that they are in control of events and can obtain appropriate help for their child and family, has been shown to be related to their levels of stress (Friedrich *et al.*, 1985; Frey *et al.*, 1989).

Lack of information clearly limits the resources available to people, and thus their options for finding strategies to cope with stressful situations. For instance, not knowing about support that is available from services, entitlements to benefits, or ways that have been shown to be successful in dealing with disabled children's behaviour or sleeping problems constrains the coping strategies open to parents.

How should information be provided?

Although there has been a considerable amount of research showing that parents have needs for information, what these needs cover and the extent to which they are met, there has been less

research on how parents would like to receive this information: their preferred means of information delivery and information formats. We know a considerable amount about how parents want to receive information about their child's diagnosis (for example, Sloper and Turner, 1993; Cunningham, 1994; Green and Murton, 1996), but less about how their continuing information needs should best be met.

Written information about local and national services, addresses of relevant organisations and key contacts can provide a resource on which parents can draw. Provision of such a 'Helping Booklet' in one area was shown to result in a reduction in the number of parents who felt they did not have enough information compared with a similar area where there was no such booklet (Quine and Pahl, 1989). The recognition that written information is an important resource in relation to health conditions, yet much of it is of poor quality, led to the setting up of the Centre for Health Information Quality in 1997 as part of the Patient Partnership Strategy in the NHS. The Centre is co-ordinated by the Help for Health Trust[1] and has defined three key criteria for information booklets or leaflets, they must be:

- easy to read
- based on evidence
- developed with individuals who have that condition.

Applying these criteria to the types of information required by families with disabled children points to the need for clearly and simply written information which avoids 'jargon', is up to date and accurate, and is informed by the involvement of parents in drawing up plans for the content and design of the information to ensure that relevant topics are covered and the format is accessible.

In some areas, for example work on medical conditions, other forms of information media, such as audio or video materials, are increasingly being used. As yet, there has been little evaluation of their role in information provision. Voluntary organisations concerned with medical conditions often provide telephone help

lines offering information and support. Research on the use of such help lines for adults with cancer suggests that they can be an effective way of obtaining relevant information which addresses an individual's concerns (Anderson *et al.*, 1992; Manfredi *et al.*, 1993). However, help lines are less developed for families with disabled children and we are not aware of any research that has evaluated their use for this population. Support groups are another source of information for some families. Other parents who have a child with a similar condition can provide very valuable information and parents often feel that only other parents can really understand their situation. However, systematic ways of ensuring that all families obtain the information relevant to their situation are needed, as obtaining information from other parents can often be a hit and miss process, and not all parents have easy access to a support group.

Whilst the provision of information that parents can use alone is clearly important, parents frequently express a need for personal support – someone who will make sure they get the appropriate information, help them to use it and act as a facilitator of access to further information as and when needed (Beresford *et al.*, 1996). The importance of the personal role in information provision was highlighted by the finding that information giving was rated as one of the most helpful aspects of the role of Portage workers (Clare and Pistrang, 1995). A person facilitating information provision can also help to ascertain what information the family needs at what time. Evidence suggests that information becomes most crucial at times of transition. These include diagnosis and starting and leaving school, but can also relate to changes in a child's condition (Baldwin and Carlisle, 1994).

Research on the process of information giving at and after diagnosis, and on parent–professional relationships provides a number of pointers to the important characteristics of information providers (for example, Sloper and Turner, 1993; Dunst *et al.*, 1994; Dale, 1996). They should: be sympathetic to and understand parents' concerns; have good listening skills and communication

skills; be honest and realistic, but not concentrate on the negative; respect parents' own expertise about their children; be responsive to families' own values and goals; work in partnership with parents; be direct and approachable and open to questions.

Information for children

The majority of work on the information needs of families with disabled children has concentrated on the needs and views of parents. There has been little work that has consulted directly with children themselves about their information needs. One exception is the recent work by Beresford and Sloper (1999), which looked at the information needs of chronically ill or disabled children and adolescents, aged ten to16. They found that the children's information needs encompassed both medical information about their condition and any treatment they required, and psychosocial information about how to manage daily living and the impact of their condition on the emotional, social, educational and future aspects of their life. Young people wanted to go to different people for different types of information. They often found communication with health professionals difficult, but wanted to be able to obtain medical information from them. Other favoured sources of information were parents, and books and leaflets. Preferred sources of psychosocial information were parents, friends and someone else with the same condition. However, the young people had few opportunities to meet peers with their condition. The role parents play in providing information was acknowledged by many of the young people, but it is clear that, if parents are to fulfil this role, they themselves require good information that they can understand and share with their children.

Young people's preferences about the characteristics of information providers were very similar to those noted above in relation to parents. In addition, they wanted professionals to talk directly to them, not just to their parents. Written information was wanted in different versions for different age groups; in accessible

language; with the use of visual forms, such as pictures, diagrams and cartoons. The study participants recommended that young people should be involved in the design and writing of information. The internet was seen as having the potential to be a good source of information, but was not widely accessible to the young people. Telephone help lines were not an information source that participants had used or wished to use. They did want to have opportunities to contact other young people with the same condition, particularly to get information around psychosocial needs, but actively disliked the idea of a 'support group'. They wanted the opportunity to meet others in an informal and social setting, and also felt that different ways of establishing contact with others should be available, for instance telephone, one-to-one meetings, writing or e-mail/internet and group meetings.

The policy context

Information provision is central to government policy in health and social care. Within health, there is increasing emphasis on patient involvement in decision making, both at the individual and the service development level (for example, Department of Health, 1996, 1997, 2000). Information about a condition, its treatment and management, and the available support services is needed for patients to share in decision making, and this is acknowledged in policy. However, there is little consideration of the special information needs of disabled or chronically ill children and their parents. The 'Patient Partnership' initiative (Department of Health, 1996) mentions children once, noting that they are one of the groups for whom finding ways to engage in effective partnership will be 'particularly challenging'. In the NHS Plan, children are mentioned only in relation to prevention of ill health, and the various plans set out to make sure that patients are informed and involved do not mention any special measures that may be needed to ensure that children and their parents can benefit. The problem of including both children and their parents in information provision

has received little attention in policy terms, and it is often unclear whether terms such as 'patient' are taken to refer to parents if the person receiving treatment is a child.

Policies focusing on carers apply more directly to parents with disabled children, for example, *Caring about Carers* (Department of Health, 1999a) states:

> *... our policies and procedures should ensure that both people in the caring relationship are valued. We must not subordinate the needs and wishes of one party to those of the other.*

However, when one party in the relationship is a child, established ways of working and cultural norms about the role of children may mean that dialogue with the parent is taken as a proxy for the child's views and involvement. This may exclude children from direct access to information and subordinate their views to those of the parent.

More consideration is given to the needs of children and their families in social care, for instance within the 1989 Children Act and Quality Protects (Department of Health, 1999b). The Children Act stresses the importance of seeking children's views on matters relating to their welfare, and its philosophy of consultation with children has implications for all agencies providing services to disabled children and their families. This is spelled out clearly in Quality Protects, where sub-objective 6.4 is: 'To ensure that parents and disabled children are provided with information about services from the statutory and voluntary sector on an inter-agency basis'. In order for this objective to be fulfilled, a clearer picture of how information is best provided to disabled children and their families is required. We need to know their views on a number of issues:

- the delivery of information – what are good ways of providing information about services?

- the content of information

- the best forms of information, e.g. written, audio-visual, face to face

- the style of information within each form

- the timing and accessibility of information – when is information needed? How can it be made accessible to families so that they can get it when they need it?

The study reported here was designed to investigate these issues from the point of view of parents with disabled children.

2 Collecting ideas and experiences

This project set out to explore the issue of information from the perspective of families with disabled or chronically ill children, particularly the types of information families would like to receive and how best to provide it. In order to gain the most comprehensive, yet in-depth perspective within the limited time span of the project, four diverse groups of parents/carers and a group of Family Fund Trust Visitors (practitioners with backgrounds in health and social care involved in the applications process when families seek a grant from the Trust) were consulted. The latter group provided an opportunity to broaden the scope of the project, both in terms of information providing, the intermediary role that Visitors play between families with disabled children and local service providers, and Visitors' broad knowledge of the different forms of information provision in their local areas.

In total, 27 parents and five Family Fund Trust Visitors were consulted. Because of limited time and resources, the project was only able to consult existing groups of parents currently working with the researchers rather than establishing new groups. Within these groups, it must be noted that minority ethnic families were not represented. However, the parents who were consulted cared for children with a diverse range of disabilities or chronic illnesses, for example, cerebral palsy, language disorders, congenital heart disease, complex medical, physical and learning disabilities and autistic spectrum disorders. Geographically, the parents' groups were located in Northern England and the Family Fund Trust Visitors came from Southern England. Each of the four parents' groups received services and information from different NHS trusts and local authorities encompassing unitary, county and city councils. Indeed, one parents' group straddled two diverse authorities. As all the parents had previously met within their individual groups, either as local support groups or as groups involved in another research project, this created a more informal and relaxed atmosphere, which in turn aided group discussions and debate.

Each group met twice over a period of three months (June, July and August 2000) at a venue of their own choice. These ranged from a community centre, a local hotel and a parental home, to a London conference facility for the Family Fund Trust Visitors. Group discussions were tape recorded and lasted between an hour and an hour-and-a-half. Tapes were transcribed and then all the transcripts were read by the two researchers. Content analysis of transcripts was used to identify criteria for good information provision and to inform the development of a model of good practice. After transcription, each group member was sent a comprehensive summary of their meeting.

First group meeting

At the first meeting, each group explored and discussed the key factors that they either used or looked for when judging the quality of information they received. In most cases, each group began to note a 'wish list'. Collating these ideas and 'wishes' together, it was clear that many parents shared similar information criteria, concerns and experiences irrespective of their child's disability. A list of quality criteria and considerations was developed by the researchers and passed onto each group; these were subsequently discussed at the start of the second group meeting.

In order to move beyond the abstract and enable parents to practically apply their criteria, the researchers began to collate a range of information currently produced for families with disabled children. At the start of the project, the aim had been to collect information perceived as 'good practice', as noted within Quality Protects Management Action Plans[1] (MAPS) prepared by local authorities. However, the MAPS submitted to the Department of Health provided fewer details of information services and sources of information for disabled children and their families than initially anticipated. Furthermore, no concrete examples of information provision were submitted as evidence within MAPS. This, in itself, is an interesting situation but beyond the scope of this project to explore.

Faced with a dearth of information, a broader trawl was undertaken, which included e-mailing the Parent Partnership network, via the Council for Disabled Children; the researchers telephoning local authorities and charities asking for copies of any relevant information; and representatives of the Department of Health e-mailing members of the Association of Directors of Social Services network on disabled children to ask for examples of good practice in information provision. The project ultimately received information from 34 different sources. However, the telephoning exercise proved an important experience for the researchers, as it confirmed many problems previously noted by parents in trying to find out who to contact to get hold of information: for example, frequently being internally directed from one local authority department to another and being left on hold for long periods of time. This is a frustrating and demoralising experience for anyone, but for many parents of disabled children it would mean important financial and time related costs, as they are likely to be busy, unpaid carers.

Second group meeting

The second set of meetings focused upon each group evaluating the information literature collected, using the agreed list of parental criteria as a guide. In particular, parents and Family Fund Trust Visitors were asked to comment upon how information was presented and its content. Each group could not practically view and comment upon all the literature, so a range of service directories, fact sheets, leaflets and videos, relevant to each group's disability interests, were taken to meetings. Despite evaluating a range of literature, it soon became apparent that certain presentational formats and content issues were regarded as signifiers of good practice by parents and Family Fund Trust Visitors alike. Finally, the criteria and evaluations of 'good practice' gleaned from many different informational sources were used to build a parentally guided model of good practice.

3 Criteria for good information provision

Presentation of information

Clarity

Information for families should be accessible, easy to read and non-threatening, avoiding medical and technical jargon. A clear and visually attractive presentation was also seen as positive, for example, good indexing with the use of headings, bold fonts and drawings.

Variety of formats

Parents valued having the option of a range of information formats available to them, such as written leaflets and booklets, verbal advice and guidance and, in the future, the internet. They welcomed a combination of formats, especially receiving verbal advice and guidance followed by written information, which could then be read at leisure:

> *You need them to tell you but when you go away quite often you've forgotten everything they've said, so if it's written down on a piece of paper as well, exactly what they've said to you, then you can go back and when you've got five minutes to spare you can read it and then you remember it.* (Parent)

Further information

Further information about how to get in touch with organisations should be clearly identifiable, with telephone numbers to aid quick and easy contact. Similarly, in order to aid accessibility, information should be available in everyday, non-threatening places rather than 'hidden away' in specialist clinics or medical centres:

We said we'd like to see information more in places like the post office, doctors' surgeries because some people find clinics intimidating to just walk in. We shouldn't really have to search out information, it should be readily available in places that you go into everyday. (Parent)

However, before one can even begin the information-seeking process, parents stressed the crucial role that diagnosing a child's condition plays. Parents who had experienced long delays in getting professionals to take their concerns about their child seriously, and consequently in gaining a diagnosis, had found that they did not know where or who to turn to, and so could not get any information about services that might help them until they had a diagnosis:

... for years you don't know what you're doing, you haven't had the right information, you're grasping at straws. There's two people here tonight who have come along, they didn't know whether to go to the ADD [Attention Deficit Disorder] *meeting or the autism meeting, they don't know what to do.* (Parent)

Content of information

General issues and areas

A key criterion noted by all was the importance of up-to-date and accurate information, keeping parents abreast of any service and/or support developments:

When you're talking about information, you really do need to make sure the information is up-to-date. (Parent)

Parents also felt that any information provided should recognise and accommodate the fact that different families have different information needs and requirements at varying stages of their child's and their own life course. Thus, information should be

targeted at key periods, such as diagnosis, starting school, puberty, the transition from child to adult services, post-school options and longer-term caring issues, especially as parents age. The important content areas noted were:

- financial issues, particularly entitlements to and how to claim state benefits

- general and more specific information surrounding a disability or condition

- different forms of childcare available and respite provision

- leisure activities and opportunities, including after-school/holiday schemes

- support groups, both nationally and locally

- knowing your rights and how to complain

- sources of support for the whole family, including siblings

- housing options and adaptations

- help in dealing with behavioural and emotional problems

- opportunities for young people when they leave children's services

- friendships, relationships and sexuality.

Delivery of information

Information for all families

Parents and visitors alike emphasised that all families, irrespective of class, ethnicity or their child's disability, should be offered information and support:

There shouldn't be any assumptions made about the ability of the family to cope or not to cope ... because everybody who is placed in the situation of suddenly having a disabled child needs help or needs some space to get back on their feet and face the problems. (Parent)

Personal contact and guidance

Throughout discussions, it was continually reiterated that leaflets and booklets were not enough by themselves; parents prioritised personal contact and guidance from information givers. More specifically, parents wanted a person, whether described as a 'key worker', a 'link person' or a 'facilitator', who would help families through the maze of information potentially available by providing clear and relevant information to each family. A recognition of the individual needs and situation of families was thus valued. These feelings were succinctly summarised by a parent of an autistic child:

... a lot of the information we need really does need to be delivered personally by a person because there's no one standard answer to autism. And the other thing is that a leaflet's great but you need to ask questions personal to your child and get feedback.

The importance of phased information was also noted, as families' concerns and interests change throughout the life-course. Diagnosis was felt to be a crucial time when information should be available, via personal contact but phased, as and when families want or require information to be provided:

Somebody sympathetic to approach you and say, 'I understand you might not want to talk about this now but get in touch with me or I'll give you a ring in a couple of weeks and talk about this'. (Parent)

Information giver qualities

In order to be a valued information provider, parents highlighted a number of personal skills and qualities. An approachable and understanding manner was first and foremost: parents wanted professionals to listen and respect their concerns, knowledge and experiences rather than dismiss them as overprotective or neurotic parents. Effective communication skills were also valued; information givers should be able to pitch the information given to families at an appropriate level. Those who presumed too much or too little created information barriers:

> *I find they're either one thing or the other. They either start off treating you as if you're a bit stupid and then, if you show you're not and you've got a bit of knowledge, they go right the other way and start using the complex medical terms as if you're a medical student ... They don't seem to have the middle way.* (Parent)

Appropriate training was felt to underpin good communication skills; indeed, some parents felt that there was a clear divide between those professionals who had 'been trained' or had considered different communication needs and requirements of disabled children and those who had not. The latter, they felt did not actively engage with disabled children:

> *I will say our GP is very good but he's had training with children ... so he knows how to relate.* (Parent)

Information givers should also have a comprehensive knowledge of local services.

Organisation of information provision

Continuity

In light of families' prioritisation of the 'human element' within information giving, it comes as no surprise that parents valued continuity of personnel and an opportunity to build a relationship with their information provider:

> *If you had one person you knew ... you might feel more confident.* (Parent)

Ideally, this information provider would get to know a family and their circumstances, which in turn would enable them to seek and target relevant information, as and when needed in a more relaxed and personal manner:

> *I think they would have to kind of come to you first, and to know your situation and the sort of things that would be useful to you and to tell you about them without you having to say.* (Parent)

Multi-disciplinary information

Parents wished to receive a comprehensive and holistic information service, cutting across professional boundaries and areas of support, i.e. a multi-disciplinary information service:

> *If they* [different professionals] *are not passing on information one to the other in an efficient manner what's the point? What is the point!* (Parent)

In order to receive such a service, they recognised the need for, and importance of, professionals working collaboratively together to share information. However, the many negative experiences that were discussed highlight this as an area still in need of improvement:

They have to communicate in some fields, but they only communicate along the areas that they need to communicate on and, if you want anything over and above that, you need to facilitate it yourself. (Parent)

4 A model of good practice for information provision

Information advisers

Our discussions with parents made it clear that written information is not enough by itself. Indeed, the assumption that, as long as numerous leaflets and booklets are produced, families will be able to inform themselves was dismissed as both simplistic and potentially dangerous:

> *... if you go into any office – health, education or social work – you wouldn't think there was any problem with information because there's thousands of leaflets ... and yet people still say they don't get enough information. So to me that's the starting point of the problem. It's not simply that people aren't getting the information, it's why are they not getting it when they want it, or in the form that they can absorb it, or in a way that they can act on it? ... So it's not enough for services to simply chuck the leaflets across and say 'there you are, there's the information' because it doesn't work.* (Parent)

At the heart of any future information-giving service, parents emphasised the central role a personal information adviser could and should play. Despite attaching a range of names and ideas to the concept of such an adviser, a number of underlying themes were frequently reiterated. These focused upon 'the human element': more specifically, parents knowing how and where to contact an information giver, ideally, a designated person attached to each family, who would provide information, advice and guidance, as and when needed. For many families, the idea of having the reassurance of a known person was high on their 'wish list'. One parent summarised these ideas extremely succinctly:

Parent: *There needs to be a facilitating process.*

Researcher: *Do you have any ideas about that?*

> Parent: *Well, I think a facilitating process needs some human input there, that's fairly obvious. Once again, you're in a very delicate area ... so it needs to be one person as far as possible who, I was going to say, could be parachuted into the family – right from the beginning to be introduced to the family and to get to know the family, to have time to sit with them and absorb the culture of that family. And then they are in the best position then to make some kind of decision on what way the information should be given to that family, how much information. It would be some kind of key worker or facilitator.*

Parents envisaged a range of professionals and practitioners, such as community nurses, health visitors and social workers acting as information givers, given their community-based role. However, some parents felt that using social workers may be problematic as many people still negatively associate them with child abuse and social stigma more generally. In order to avoid stigmatisation, parents suggested that clear boundaries should be drawn between workers' everyday role and social workers performing an information-giving role. In effect, they should be known as information advisers, workers or facilitators rather than as social workers, as a parent explains:

> *I think if you're going to have some sort of key worker or something to provide information you shouldn't call it a social worker because they* [families] *might think it's like a stigma, that they'd failed if they had to call on a social worker.*

Thus, whilst recognising and highlighting specific examples of good practice amongst the literature reviewed, parents continued to emphasise that written and audio-visual information must be viewed in conjunction with a personal information adviser. Models of good practice should not view them as either/or but rather as interwoven and complementary.

The importance of providing information on different levels and using a range of media was further emphasised during the second

group discussions. Parents wanted to receive both short, direct information and in-depth accounts and explanations of services. Indeed, parents recognised the potential benefits and different supportive roles that both types of information could provide as families cared for disabled children at different stages of their lives. Thus, many parents recognised the value of having an in-depth booklet, clearly describing a wide range of services and support: an informative guide, acting as a key reference point for parents to dip in and out of, as and when needed:

> *This book* [Brighton and Hove, *Through the Maze*, see the Appendix for details] *is not designed to be read from cover to cover, all in one go. It is more like a reference book to dip into when particular questions arise ... I would have loved to have received a book like this when I was first starting out; especially one devoted to my local area. In fact, it would be great to see our area bring out a similar book, as even the more experienced parent needs a refresher now and again ... Overall, I thought it was a good book to keep on the shelf.* (Parent)

In addition, many parents felt that short booklets providing essential information about local services and support in a summarised form were useful. In effect, these shorter booklets were viewed in a similar manner to telephone directories; quick, direct and easy to use. Recognising the important, albeit different, role that these two types of information can play, developing a model of 'good practice' ideally becomes a three-dimensional process, with families simultaneously receiving a succinct directory or summary of services and support, alongside a more informative and in-depth booklet. This written information would be complemented in turn by locally based advisers providing support and guidance to families. The following model describes some of the key characteristics, especially presentational formats and contents issues, that parents and Family Fund Trust Visitors valued and would like to see within any information produced for families with disabled children.

Presenting information

The following presentational features were generally viewed as standards of good practice and thus apply to any written information sent to parents, whether in the form of a summary directory or a more in-depth booklet.

Most parents preferred to receive bound information as opposed to a loose collection of sheets or leaflets, which they felt could be easily lost, were often difficult to sift through and presented information as 'bitty' rather than comprehensive:

> *If you get everything in one book and you've got it on the bookshelf and you can refer to it at home. It's all the information or a step to further information in one book.* (Parent)

However, Family Fund Trust Visitors and a small minority of parents felt that a collection of fact sheets held the practical and financial advantage of being more easily and cheaply updated compared to a bound booklet, as information was forever changing.

Eye-catching and interesting

Attractive front covers were viewed as a simple but frequently forgotten consideration. Colourful and interesting designs drew parents towards a guide, as one parent noted:

> *… visually, it's very accepting or welcoming if you like.*

In contrast, those that were black and white were seen as 'bland' and uninteresting. Similarly, when parents looked inside a guide, they liked to see information clearly presented, using a range of different formats, such as bold type, headings, symbols and cartoons. Once again, this was felt to be welcoming rather than threatening, as it broke information down into manageable, clearly differentiated chunks rather than appearing as a sea of dense and uninteresting text, as one parent explains:

Parent: *I quite liked that one* [Family Fund, *After 16 – What's New?*, see the Appendix for details]*. I liked the pictures in it, they're quite good.*

Researcher: *It's colourful, isn't it.*

Parent: *Yes and it has bold writing too, so you can pick things out. 'Cos I mean, they've* [points to page] *got an insignia with money, so that's obviously about money, so you know, if that's what you're looking for.*

Referencing made easy

Parents stressed that they did not have the time or energy to hunt for information:

… it's just time because you don't have time to search through these books and if you're going to spend more than five minutes looking for something you think, 'ohh' [sighs]*. You just chuck it and think, 'I'll come to that when I've got more time', then you just don't have more time. So the quicker you can find it, the better for the person who's using it.* (Parent)

Thus, they looked for booklets and directories that were more than a 'conglomeration of undigested information', preferring well presented and referenced guides. Clear contents pages and indexes were regarded as invaluable, as they gradually eased the reader into what can be a potentially frightening mass of information. As one parent noted with relief:

... straight away you can see what you've got in the book, it's not overwhelming.

EXAMPLES OF GOOD PRACTICE

A Guide to Services for Young Disabled People in Cheshire, Vale Royal Disability Services[1]

Parents found the cover illustrated below effective because it was bright and cheerful. They particularly liked the fact that the words 'services for young disabled people' stood out and thus encouraged them to pick up the directory and flick through it.

After 16 – What's New? Choices and Challenges for Young Disabled People, The Family Fund Trust

This book is written for young people and their families as they approach the transition from child to adult services and, more generally, move towards adulthood and greater independence. Overall, it was felt to be bright, welcoming and thus a positive read. Each page contained a variety of presentational formats. Parents particularly welcomed the use of:

· a large colourful cartoon introducing each chapter's content

· summarised points within easily identifiable coloured boxes

· coloured headings and key words

· smaller cartoons portraying young people asking questions and raising concerns in a light-hearted manner.

In addition, parents and Family Fund Trust Visitors welcomed colour-coded directories, as they provided a visual and thus more memorable way for parents to focus on relevant information:

This one's [Redbridge, *Sports and Leisure Directory*, see Appendix for details] *lovely and user-friendly, isn't it? Terribly simple. They've done it so that even if you've only got two minutes you can quickly find it.* (Visitor)

Yes, you instantly know after you've used it once or twice that you can skip the pink and blue and the green is relevant to you or whatever. (Visitor)

Again, the colours, how it's broken up into colours. (Parent)

EXAMPLES OF GOOD PRACTICE

Many of the guides made good use of contents pages and indexes. However, parents felt that two of the guides went beyond this, as they also provided a colour-coded form of referencing.

Sports and Leisure Directory for Disabled People in Redbridge, London Borough of Redbridge

In this guide, the activities are grouped into days of the week and then each day is represented by a different colour; for example, all activities on a Wednesday are printed on yellow paper. Activities that do not take place on a specific day are collected together and similarly colour coded.

After 16 – What's New? Choices and Challenges for Young Disabled People, The Family Fund Trust

With the aid of colour banding and a contents page linking each chapter to a specific colour (for example, 'Money matters' with blue), *After 16* similarly enables young people and parents to see at a glance the chapter they require.

Chatty manner and reassuring tone

Whether written or spoken, clear 'jargon-free' information was continually prioritised within group discussions:

Yeah, I think sometimes this is a problem, okay we are adults but I think when you're really dealing with a situation your brain

can't deal with the adult language half the time. You really do want plain, simple, basic language. (Parent)

Unnecessarily complex, technical or, as one Visitor noted, 'highfaluting' language was felt to be both confusing and potentially isolating for families. Similarly, how information was presented was also viewed as significant. Parents generally looked for an informal, chatty manner and reassuring tone, that is, one which made them feel more comfortable and confident about seeking support, sending out the message 'that it is okay to ask for help'.

It was in Through the Maze [Brighton and Hove] *that I noted there was a whole page devoted, in very simple easily understood language on how to claim DLA* [Disability Living Allowance] *... the way it was broken down and encouraging a parent, which is often very necessary because it's so daunting.* (Visitor)

EXAMPLE OF GOOD PRACTICE

Through the Maze: an Information Handbook for Parents of Children with Special Needs, Brighton and Hove

Presenting a guide in a chatty and reassuring, yet informative, manner is not an easy task, however, the authors of *Through the Maze* (network of parents of children with special needs and a parent link project) have successfully achieved this, with the aid of:

- everyday language, avoiding unnecessarily complex medical terms and professional jargon

- an informal and relaxed style of writing, for example, using common abbreviations, such as we're, we've, don't and colloquial chapter titles, for example, 'Finding out what's wrong', 'Someone to talk to' and 'Survival strategies'

- avoiding a patronising manner or judgemental tone

- an introduction which reassures parents that they do not have to read the guide all at once; it is a reference book to be used as and when necessary.

Further information

As parents viewed both informative guides and summary directories as an introduction to, or a first step towards, help and support, details of further information were regarded as imperative. An address, telephone number and where possible the name of a person to contact should be included. Practically, it may not always be possible to give an up-to-date contact name within directories. However, it is easier within smaller, localised directories or newsletters. Providing families with a named person was felt to be extremely advantageous, as it made initial calls less formal and it enabled parents to ask directly for a relevant person rather than being passed round a number of departments or placed on hold, whilst the correct person is found.

> *... having a name and not just a phone number, and I think that helps a parent when tentatively they say, 'Is that Anne?' after they've phoned and you have somebody say, 'Yes'. A name helps enormously.* (Visitor)

A small number of parents suggested that including internet addresses and associated relevant sites would be useful. However, only one or two parents had internet access at home or had ever used the internet as a source of information.

EXAMPLE OF GOOD PRACTICE

Manchester's Multi-agency Partnership for Disabled Children and Young People – Directory of Services

This directory provides a comprehensive range of contact details. Each service or organisation is accompanied by its:

- postal address
- telephone number
- the name of a contact person
- e-mail or website address where available.

Content of information

Throughout group discussions, it was clear that parents and Visitors alike wanted and expected information guides to cover a broad and comprehensive range of subject issues and areas (see Chapter 3 for a list of these areas). Indeed, the question of 'depth' was much discussed. As parents explained their need for an informative booklet, it was apparent that many wanted and looked for a guide that was more than a list of names and addresses. However, the degree of depth that was favoured varied enormously and appeared to be dependent on factors such as parental time, expectations, personal confidence and years spent caring. In light of this diversity, one must recognise the inherent difficulties of trying to provide information for a variety of families that is considered to be 'in-depth' but still manageable. In many ways, it is easier to consider what was felt to be *unacceptable*. For example, one information file clearly stood out because of its size, bulky nature and businesslike presentation; unsurprisingly, it was frequently regarded as unmanageable and thus passed over. Indeed, there was consensus that the file contained too much 'undigested' information and became both confusing and intimidating for parents, one mother's initial reaction was 'terrifying on first glance'. Developing an in-depth but manageable guide remains a complex and challenging task. However, the criteria and features discussed below provide an initial template, which would be valued by many parents.

Before describing these, it is important to reiterate that parents also wanted shorter, more succinct information. Although parents did not want this information in such depth, a broad and comprehensive range of subject areas was still expected and seen as important. Thus, many of the contents issues discussed below remain relevant. In addition, group discussions revealed that shorter directories raised a number of specific content issues, which are discussed later in this chapter.

Holistic support

Services
The value of wide-ranging, multi-disciplinary and multi-agency information was recognised and prioritised by parents and Visitors alike. Collating information from areas, such as health, social services, welfare benefits, education, housing, leisure and the voluntary sector, was regarded as a key starting point. Directories covering discrete service and support areas were viewed as too narrow and could also lead to increased confusion as parents had to sift through a range of guides in order to gain a comprehensive overview. In addition, parents found it useful for guides to include national and local contact details. Similarly, any holistic picture of support and services should include information on non-specialist, community-wide inclusive services, especially leisure activities, such as Cubs, Brownies and youth clubs, as well as detailed information on the specialised services available.

EXAMPLE OF GOOD PRACTICE

Finding your Way – a Guide to Services in Somerset for Children with Special Needs, Somerset County Council

This directory provides a comprehensive list of, and information on, social and leisure activities in Somerset. Information on non-specialist, community-based activities is also noted, for example:

- Beavers, Cubs and Scouts for boys

- Rainbows, Brownies, Guides and Rangers for girls

- fishing clubs

- the Duke of Edinburgh's Award.

Indeed, parents are encouraged to consider inclusive activities, as the guide explains how disabled children's needs are met and provides the name of a contact for further information.

Different life stages
Parents valued guides and directories that recognised the importance of different stages of children's lives (such as starting school, moving from child to adult services, puberty and leaving

home) and the impact that these can have upon children and their families. Planning for the future was felt to be a crucial, if not always easy, issue to discuss. In order to begin to plan, parents wanted guides to highlight important areas of changing support, future options and also to provide contact addresses for further information and guidance:

> *... who will look after your child if you die? That's everyone's worry ... we understand and accept the bairns but someone else isn't going to.* (Parent)

> *I like the* Guide to Services in Cornwall [Cornwall Social Services, see Appendix for further details] *as well ... It actually covers a few things that I haven't noticed in some of the others, like bereavement and it also covers over-16s, what next? I've had a read of it and it does tell you quite a lot about what's available, about independent living, a lot of the other ones just seem to be based at the younger end really.* (Parent)

EXAMPLES OF GOOD PRACTICE

The importance of young people's transition towards adulthood and yet the anxiety that this period can and does cause many families was clearly recognised within three of the guides viewed:

Through the Maze: an Information Handbook for Parents of Children with Special Needs, Brighton and Hove

Through the Maze devotes a chapter to 'Looking ahead'. Here, a diverse range of issues and areas of potential concern are discussed:

- relationships and sexuality
- changes in care and support
- further education
- benefits
- wills and trusts.

Although recognising that one chapter cannot hope to include or explain all services, the directory encourages parents to start thinking about the future as early as possible.

continued

Finding Your Way – a Guide to Services in Somerset for Children with Special Needs, Somerset County Council and Guide to Services in Cornwall for Children with Special Needs, Cornwall County Council

These two directories similarly provide a chapter for parents considering 'Services for the over-16s'. Both explore some of the different services and sources of support that disabled young people may wish to contact, in terms of:

• employment and training

• day care or residential units

• becoming more independent.

Post-16 finance, education and leisure issues are incorporated into general chapters; however, this makes searching for them potentially more difficult and time consuming.

The whole family

Alongside support and services for disabled children, parents and Visitors also stressed the need for information regarding sources of support for the whole family, both parents and siblings:

I have to stand up and give a clap to Somerset [*Finding Your Way*] *which was very good factually and I found for the first time ever DADDS* [Dads and Disabled Daughters and Sons] *in it ... they often get lost in the milieu, the dads coping with disabilities.* (Visitor)

EXAMPLE OF GOOD PRACTICE

Finding Your Way – a Guide to Services in Somerset for Children with Special Needs, Somerset County Council

In addition to parental support and advice (not forgetting fathers of disabled children), this guide recognises the importance of, and need for, sources of support for siblings and other relatives. Parents are reassured that any concerns they may have, such as not being able to spend enough time with their other children, are shared by many families. More specifically, the guide provides helpful advice and information for siblings and also a range of contact details for local and national support groups or schemes.

Some parents felt that this should be extended beyond the nuclear family, appreciating that other members, such as grandparents, may require information and support.

Explanations and definitions

Guides providing general background information, especially explanations and definitions of services, professionals' roles and acronyms used, were viewed as extremely useful as it was felt that all too often knowledge of this information was taken for granted or presumed. Having a guide or directory in which you can quickly and easily look up definitions was warmly welcomed as reassuring and a potential confidence booster, especially if parents were seeking a new source of support or service:

> *I liked this one* [Cheshire, *A Guide to Services for Young Disabled People in Cheshire*] *because it says 'children's services' and it tells you very briefly and straightforwardly what children's services exist and then you can go on from that. If someone's talked about children's services – what does that mean? You can just read in this each basic bit ... It's a real good starting point – 'oh, so that's what that means' – if you see it written down or it's mentioned in a meeting or whatever.* (Visitor)

A number of parents also suggested that it would be useful to have brief descriptions of the most common disabilities, accompanied by details of where and how to get more information. For example, an autistic support group felt that booklets and guides should include the main signs of autism, as autism is a disability frequently ignored or stereotyped.

> **EXAMPLES OF GOOD PRACTICE**
>
> **Through the Maze: an Information Handbook for Parents of Children with Special Needs, Brighton and Hove**
>
> **Finding Your Way – a Guide to Services in Somerset for Children with Special Needs, Somerset County Council**
>
> **Guide to Services in Cornwall for Children with Special Needs, Cornwall County Council**
>
> Within these guides, parental knowledge of local and national services, practices and professionals is neither presumed nor dismissed as unnecessary. These handbooks clearly and consistently introduce and summarise any policy, service/organisation or professional's role, as and when it is discussed. The depth provided appears to be just enough to inform rather than overburden parents with details. For example, when discussing education, the guides provide an easy to find 'who's who?' section and glossary of commonly used acronyms or jargon, as well as a step-by-step guide to the different stages of the *Code of Practice for the Identification and Assessment of Special Educational Needs* (Department for Education, 1994).

Everyday advice and experiences

Including parents' everyday comments and experiences of caring for a disabled child and its impact upon family life was also valued. More specifically, discussions revealed that such comments helped to make guides and directories appear less formal and dense, and more personal and interesting for families to read. Indeed, in the guides explored, many parents found areas of concern, situations or emotions that they could easily relate to:

> *I particularly liked the parents' comments, which made it feel more personal and the introduction helped to make the reader understand that others who have experienced what they might be going through wrote this book; it didn't preach.* (Parent)

> *... using parental comments, which I thought was really nice.* (Visitor)

In addition, parents also valued guides which included everyday tips and snippets of advice, for example, how to approach services,

organise personal correspondence with, or paperwork from, services.

EXAMPLES OF GOOD PRACTICE

Through the Maze: an Information Handbook for Parents of Children with Special Needs, Brighton and Hove

This guide is clearly written by parents for parents; in fact, the introduction highlights this:

We are all parents of children with special needs ... [we are] *happy to share our experiences for this handbook in the hope that other parents won't have to struggle as we did ... Most of us have probably been through some of the things that you are going through now. At times it might seem like finding your way through a maze. You may feel that you're not getting all the information you need or being understood by the people around you. This handbook is here to help you.* (1997, p. 2)

Throughout the guide, information is accompanied by parental quotes and real-life experiences. In addition, the 'Survival strategies' chapter contains practical advice and tips for parents, when:

- meeting professionals
- looking after a disabled child
- looking after the whole family
- looking after and making time for oneself.

Welcome to Birmingham Children's Hospital NHS Trust – Information for Parents, Children and Families, The Birmingham Children's Hospital

Although limited to services and support relating to Birmingham Children's Hospital, this booklet provides a wealth of advice and practical tips, ranging from transport routes to 'preparing your child for hospital' and 'what to bring for your child's admission'. For families whose children have never been to hospital before, such everyday advice and guidance can be both calming and reassuring.

Shorter directories

Local news and support

Within shorter, more summarised directories, group discussions highlighted the importance of providing information about local

support services and networks in an easily accessible manner, that is, in the sort of directory you can keep by the telephone and quickly thumb through. Amongst the literature examined, information was presented in different formats, such as directories and newsletters. The latter were welcomed by both Family Fund Trust Visitors and a number of parents, as they were regularly distributed and thus helped to keep families informed of local news, events and meetings:

Researcher: *Do you have a newsletter or anything like that?*

Parent: *Yes, newsletters.*

Researcher: *Do you find those useful?*

Parent: *Yes, well you wouldn't get to know what's going on in the service, would you ... It just basically gets down to the point and tells us what's going on.*

If I'd been the parent of a disabled child, I'd be looking forward to that coming because it's got so much information about local things that are going on, play schemes in the summer, what they cost, all sorts of things really. (Visitor)

The Visitors also felt that newsletters accompanying more in-depth directories might help to foster continuous contact and feelings of support for families:

... making you feel you're part of an organisation really or a group of parents all coming together to share problems and things. (Visitor)

Keeping up-to-date

Practically, it was noted that smaller directories and newsletters could be more easily and cheaply updated as information changed, compared to larger, more in-depth guides, thus providing families with up-to-date information and contact details:

These newsletters, [Brighton and Hove, *Out of a Maze ... The News*] *are where you can put the new stuff in, on a regular basis.* (Visitor)

It was also felt that shorter directories may encourage, and make it easier for, parents to dip in and out of them on a regular basis, checking to see if there are any additional services or support that can be of use to them:

I've used it [Scarborough and Ryedale Carers Resource, *Caring for your Child with Special Needs*] *two or three times ... and I do still keep picking it up every now and again to see if there's anything else in.* (Parent)

EXAMPLES OF GOOD PRACTICE

Out of a Maze ... The News, Brighton and Hove

Out of a Maze ... The News accompanies and complements the in-depth handbook *Through the Maze*. This newsletter is produced periodically throughout the year and combines a mix of general advice with local news/ events and details of further information in a very informal and reassuring manner. For example, past editions have contained:

- benefit advice and updates, especially if changes have recently occurred, for example, in the March 2000 newsletter 'Money matters ... for disabled young people at sixteen and at school' were discussed

- information on local leisure/activity schemes, meetings or support group activities

- short articles or summaries of talks about everyday disability-related issues, for example, in the November 1999 edition, 'friendships, relationships and sexuality' were discussed

- parents' personal ideas, experiences and suggestions.

Caring for your Child with Special Needs, Scarborough and Ryedale Carers Resource

This booklet is very much in the style of a small telephone directory and, as such, is quick and easy to use. Colour headings and bold type enable the reader to view, at a glance, the most important details on each page. Despite its small size, the booklet presents a comprehensive overview of services and sources of support within the local area, combining succinct information and service definitions with clear details of further information.

Audio-visual information

Amongst the information collected, it is interesting to note that only three services or organisations included a video. Group discussions highlighted that videos were approached with mixed feelings. Some felt that videos were a good way to grab parents' attention, as they could present information beyond the written word quickly and forcefully and also enabled parents to listen to information at their own pace, rewinding the tape as and when needed. They were also viewed as a potential source of discussion and debate, especially at support group meetings, as one parent noted:

> *It* [Kensington and Chelsea, *Children First*] *would make a good talking point for parent support groups; if shown at a meeting the following discussion would be interesting and informative.*

However, videos were also approached with caution, as past experiences, especially amongst Family Fund Trust Visitors, had been disappointing and expectations had not been met. Watching the videos, both parents and Family Fund Trust Visitors highlighted a number of presentational and content issues, which they felt should be considered for informative support videos.

Presenting information

Presenters
Videos using parents as presenters, or at least describing their own search for support and experiences of services, were valued. Many parents did not feel they could really empathise with actors, indeed, some considered them rather patronising:

> *Perhaps a presenter who had a child with SEN and was willing to share that fact might have been more acceptable to parents.* (Parent)

Diversity

Within generic videos, parents recognised that in practice not all disabilities could be discussed, but diversity could be emphasised if families with a range of needs and circumstances were highlighted.

Length

Relatively short videos were preferred. One of the videos was over 20 minutes long; after 15 minutes, both parents and the Visitors felt they had lost concentration and interest.

Content of information

Depth

Although parents did not want overly long videos, they also did not want videos that simply glossed over, generalised or reduced information to a 'bland', simplistic level:

> *I'm not sure about the effectiveness of it* [Department for Education and Employment, *One in 5: A Parents' Guide to Special Educational Needs*] *really ... it's aimed at everybody in the country so they make compromises, which makes it very bland really.* (Parent)

Realism

Similarly, videos should also present a realistic picture of services and support networks rather than theoretical or ideal scenarios. Whilst watching two of the three videos, there was a general consensus that the situations and outcomes presented were unrealistic and did not match parents' everyday experiences. This immediately reduced the validity of the videos for parents. In addition, it was also felt that it could raise parents' hopes and expectations, which in reality would not always be met:

> *It was 'once upon a time', fairyland, not at all realistic.* (Parent)

It [Department for Education and Employment, *One in 5: A Parents' Guide to Special Educational Needs*] *does make it sound very smooth and straightforward, which isn't the experience of most professionals and parents.* (Visitor)

In light of this, videos should also address 'what to do if things go wrong or your child's needs are ignored', for example, rights of appeal and how to proceed with these:

The cynic in me wanted to see more on: 'What rights do you have if you feel that your concerns about your child's difficulties are being ignored?' (Parent)

> **EXAMPLE OF GOOD PRACTICE**
>
> **Children First: Services for Children with Disability, The Royal Borough of Kensington and Chelsea**
>
> This was well received by parents as it managed to combine interest, depth, diversity and reassurance within a relatively short video. More specifically, it highlighted a range of services and sources of support, such as social, educational, health and leisure services available in Kensington and Chelsea. Parents welcomed the fact that professionals' descriptions of available services and support networks were also discussed and explored through families' everyday experiences. Indeed, the video was felt to be of general value to many parents, as it explored the needs of disabled children and their families across a range of age groups and different impairments.

Conclusion

This project has demonstrated that parents, irrespective of their child's disability, proposed similar criteria for judging good quality information and were thus able to draw up shared 'wish lists' of how information should be presented, its content, the way it is delivered and how it is organised. Because of the limited time span of the project, information could not practically be collected from all authorities and organisations, only a sample; similarly, a relatively small number of parents were consulted. Indeed, the sample was not able to consider the ideas and experiences of minority ethnic parents/carers. The researchers recognise that this is an extremely

important but potentially diverse subject and thus feel it is an area that requires further research.

However, the samples of parents consulted and information examined were generally broad and diverse, encompassing a range of experiences of different disabilities and/or conditions and service provisions. As parents drew upon past experiences and their 'good' quality criteria to evaluate the sample of current information, it was apparent that they prioritised personal support and guidance as well as accessible information, whether short and direct or more in-depth. Hence, written or audio-visual information should be viewed in conjunction with personal interaction rather than as an either/or choice. In light of this, future models of good information-giving practice should be premised on three separate but interwoven elements: parents should receive in-depth booklets, describing a range of services and support, alongside shorter guides providing essential local information, whilst being supported by locally based 'key workers' or 'facilitators'. Diagrammatically, these key elements, which can be adapted to meet the needs of a wide variety of client groups, are summarised in Figure 1.

Figure 1: How families with disabled children want information provided
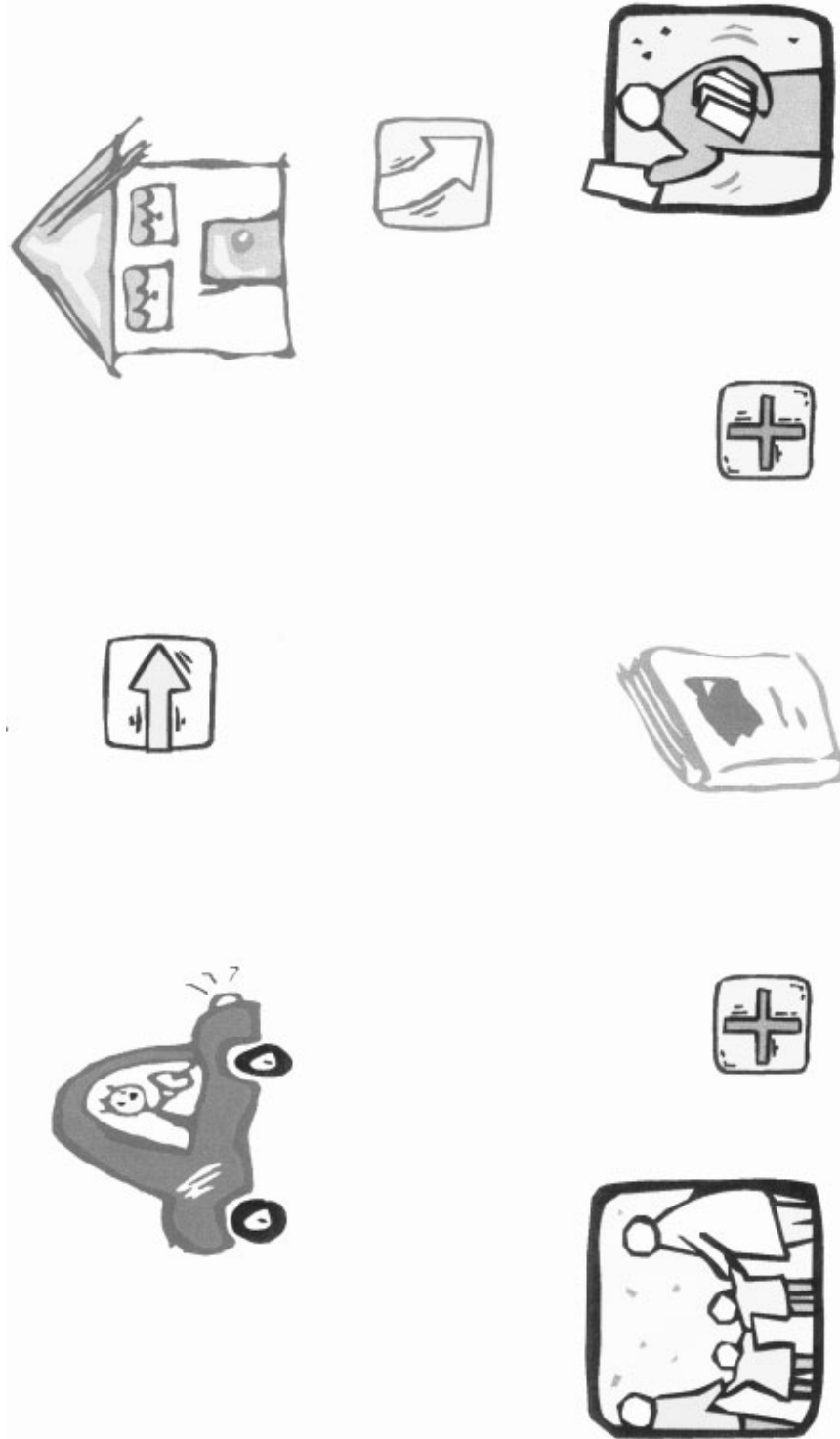
Notes

Chapter 1

1   Centre for Health Information Quality, The Help for Health Trust, Highcroft, Romsey Road, Winchester, Hampshire SO22 5DH. Tel. 01962 872245 [http://www.hfht.org/chiq/]

Chapter 2

1   MAPS – all English local authorities were required in January 2000 to document their progress in implementing Quality Protects and their plans for the forthcoming year.

Chapter 4

1   Contact names and addresses of all the 'best examples' within the report are given in the Appendix.

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Appendix: Contact names and addresses of 'best examples' within the report

Information guides and directories

A Guide to Services for Young Disabled People in Cheshire. Vale Royal Disability Services, The Council House, Church Road, Northwich, Cheshire CW9 5PD. Tel. 01606 350611

After 16 – What's New? Choices and Challenges for Young Disabled People. The Family Fund Trust, PO Box 50, York YO1 9ZX. Tel. 01904 621115 [http://www.after16.org.uk]

Caring for your Child with Special Needs. Scarborough and Ryedale Carers Resource, Outgang Road, Pickering, North Yorkshire YO18 7EL. Tel 01751 473727

Finding Your Way – a Guide to Services in Somerset for Children with Special Needs. SIGNPOSTS Information Service, Freepost TU 504, Social Services Department, Somerset County Council, County Hall, Taunton, Somerset TA1 4BR. Tel. Freephone 0800 317220

Guide to Services in Cornwall for Children with Special Needs. Cornwall Social Services, Health Information Matters Helpline. Tel. Freephone 0800 665544

Manchester's Multi-agency Partnership for Disabled Children and Young People – Directory of Services. Gillian Baldwin, Freepost MR4319, 102 Manchester Road, Chorlton-cum-Hardy, Manchester M21 6DD. Tel. 0161 8818116/8810911

Sports and Leisure Directory for Disabled People in Redbridge (London Borough of Redbridge). Louise Grafton-Mitchell, Leisure Services, Lynton House, 255–259 High Road, Ilford, Essex IG1 1NY. Tel. 020 8478 3020

Through the Maze: an Information Handbook for Parents of Children with Special Needs (Brighton and Hove edition) and *Out of a Maze ... The News*. AMAZE, 4th Floor, Community Base, 113-117 Queens Road, Brighton, East Sussex BN1 3XG. Tel. 01273 772289 [e-mail: amaze@freenet.co.uk]

Welcome to Birmingham Children's Hospital NHS Trust – Information for Parents, Children and Families. Jo Pritchard, Child and Family Information Centre, Birmingham Children's Hospital, Steelhouse Lane, Birmingham B4 6NH. Tel. 0121 338505

Video

Children First: Services for Children with Disability Produced by 'Full of Life', Mark Joseph, Canalside Activity Centre, Canal Close, London W10 5AY. Tel. 020 8968 1478 (video funded by The Royal Borough of Kensington and Chelsea)