

Information to families with disabled children

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, conducted by researchers from the University of York, explored the criteria by which parents judge the quality of information and their ideas of good practice in this area.

- f** 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.
- f** 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, using colour and images to make them interesting.
- f** Parents wanted information to cover the roles of all the different agencies involved in providing services for families with disabled children. Information needed to consider key aspects of families' and their children's needs, from the child's birth through to adulthood.
- f** Parents continually emphasised that booklets, leaflets and videos are not enough by themselves, personal contact with and guidance from information givers were regarded as crucial. A person – a 'keyworker', 'link person' or 'facilitator' – was wanted who would guide families through the maze of information potentially available.
- f** The researchers conclude that 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 'keyworkers'.

Background

Research exploring the needs of families with disabled children has demonstrated the importance they attach to relevant and accessible information. Indeed, it is one of the most valued aspects of families' contact with services. It is also an important resource as families seek to manage their lives and maintain a sense of control. Lack of information clearly limits families' options, especially when seeking strategies to cope with stressful situations.

However, previous studies have found that information needs frequently remain unmet. Parents often do not know where to go for information, finding out about services and benefits in an *ad hoc* way through contacts with other parents.

Although there has been considerable research highlighting that parents have information needs, the topics these needs cover and the extent to which they are met, there has been significantly less research on how parents would like to receive this information.

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 an individual and service development level. However, there is little consideration of the special information needs of disabled or chronically ill children and their parents. 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. The importance of accessible information is spelled out very clearly in Quality Protects sub-objective 6.4:

"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:

- 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 when they need it?

This study set out to investigate these issues from the perspective of parents with disabled children.

Criteria for good information provision

Focus group discussions highlighted that parents shared similar information criteria and concerns.

These clustered around four themes: information presentation, content, delivery and organisation.

Presentation of information

Clarity - parents stressed that information should be easy to read and non-threatening, avoiding medical and technical jargon.

Variety of formats - parents valued having a range of information formats available to them, such as written leaflets/booklets, verbal advice and, in the future, the Internet.

Further information - parents wanted details on how to get more information and how to get in touch with organisations to be clearly identifiable, with telephone numbers to aid quick and easy contact.

Content of information

General considerations - up-to-date and accurate information is essential. Parents also wanted information to recognise that different families have different information needs at varying stages of their child's and their own life. Information should be targeted at key periods, such as:

- diagnosis;
- starting school and changing schools;
- puberty;
- transition from child to adult services;
- post-school options;
- longer-term care issues.

Areas - parents wanted information about:

- benefit entitlements;
- a disability or condition;
- different forms of childcare available and respite provision;
- leisure activities;
- support groups;
- knowing your rights and how to complain;
- support for the whole family;
- help in dealing with behavioural and emotional problems;
- housing options and adaptations;
- opportunities when young people leave children's services;
- friendships, relationships and sexuality.

Delivery of information

Personal contact - parents wanted a special person who would help and guide their family through the mass of information potentially available.

Personal qualities - this person would need to have an approachable and understanding manner, effective communication skills, and respect for parents' concerns and expertise.

Organisation issues

Continuity - rather than many different information advisors, parents wanted continuity and time to build a relationship.

Multi-disciplinary - parents emphasised the need for and importance of professionals working collaboratively across service areas to share information.

Models of good practice

'Keyworkers' or 'facilitators'

Parents continually emphasised that booklets, leaflets and videos are not enough by themselves. The assumption that as long as written information is produced, families will be able to inform themselves was dismissed as simplistic:

"... 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 ... 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)

Parents highlighted the need for a 'keyworker' or 'facilitator' providing personal support and guidance to families:

"I think a facilitating process needs some human input there, that's fairly obvious ... 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 keyworker or facilitator." (Parent)

Professionals and practitioners - such as community nurses, health visitors and social workers - were seen as potential information-givers, because of their community-based role. However, the continuing perception of social workers being involved with child abuse work and the associated social stigma was recognised as somewhat problematic.

Three dimensions

Using the above criteria, the groups evaluated a range of information produced for families with disabled children. It was clear that they valued short, direct information as well as more in-depth information. Collating parents' ideas and wishes together, a model of good practice emerged with three separate but interwoven aspects. Ideally, parents would receive in-depth booklets, describing a range of services and support, alongside shorter guides providing essential local information, whilst being supported by locally based 'keyworkers' or 'facilitators'.

Developing a model of good practice

The following model describes some of the key characteristics, especially presentational formats and contents issues, that the groups valued and would like to see within any information produced for families with disabled children.

Presenting information

Eye-catching and interesting - colourful and interesting designs, especially front covers, drawing parents into guides:

"Visually, it's very accepting or welcoming if you like." (Parent)

Bold type, headings, cartoons and symbols were also felt to add interest.

Referencing made easy - clear contents pages and indexes were viewed as necessary. Colour-coded directories were also welcomed, as they enabled parents to find relevant information quickly and easily.

Chatty manner and reassuring tone - parents looked for guides which made them feel more comfortable and confident about seeking support, sending out a message "that it is okay to ask for help":

"It was in 'Through the Maze' [Brighton and Hove] that I noticed 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." (Practitioner)

Further information - an address, telephone number and where possible, contact person's name, should be included. Contact names help to make initial calls less formal and ensure direct contact rather than being passed round a number of departments or placed on hold.

Content of information

Within more informative guides, depth and breadth were important. In shorter guides, although parents did not want such depth, they still expected coverage of a comprehensive range of areas.

Holistic support - guides should provide multi-disciplinary and multi-agency information, including non-specialist, community-wide services and support, as well as specialist services. Similarly, the need for information about sources of support for the whole family, including siblings was prioritised.

Future planning - planning for the future was felt to be a crucial, if not always easy, issue to discuss. In order to begin to plan, parents welcomed guides that highlighted important areas of changing support during their child's and their own lives.

"I like the 'Guide to Services in Cornwall' 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)

Explanations and definitions - providing background information, especially explanations and definitions of services, professionals' roles and acronyms was useful because all too often this sort of knowledge was taken for granted.

"If someone's talked about children's services - what does that mean? You can just read in this ['A Guide to Services for Young Disabled People in Cheshire'] 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." (Parent)

Everyday advice - including everyday tips and snippets of advice was welcomed as it made guides more than a list of names and addresses. Similarly, parents' comments and experiences made guides less formal and dense and more personal and interesting for families to read.

"I particularly like the parents' comments, which made it feel more personal..." (Parent)

Shorter directories

Within shorter directories the groups looked for summarised information about local services, support networks and events/news. Different types were examined; the favourite was in the form of a newsletter accompanying a more in-depth guide, which could be regularly distributed and easily updated.

Audio-visual information

People viewed videos with mixed feelings. Some felt they were a good way to grab parents' attention and present information quickly and forcefully, whereas others felt they frequently did not meet expectations, generalising information to a 'bland', simplistic level. Successful videos were viewed as those which actively involved a range of families and drew upon their everyday experiences in order to present a realistic picture of services and support.

Conclusions

Despite geographical and disability-related differences, the groups shared similar criteria for judging good quality information and had clear ideas how to develop models of good practice. In light of this, the researchers recommend that information provision should be three-dimensional and personally interactive: with families receiving in-depth and informative booklets alongside shorter, more succinct directories/newsletters of local services, whilst being supported by locally based 'keyworkers' or 'facilitators'.

About the study

The project ran for five months, from May to September 2000. Four groups of parents (27 in total) caring for children with a range of disabilities or chronic illnesses and one group of five practitioners, with backgrounds in both health and social care, were consulted. These practitioners worked for the Family Fund Trust. Parents were located in Northern England and received services from different health trusts and different types of local authorities - unitary, county and city councils. The practitioners were based in Southern England. Two meetings were held for each group, the first discussed criteria parents used to judge information quality. Then using these criteria, the groups evaluated a range of information for families with disabled children in their second meetings.

How to get further information

The full report, **User-friendly information for families with disabled children: A guide to good practice** by Wendy Mitchell and Patricia Sloper, will be published for the Foundation in December 2000 by YPS (ISBN 1 902633 79 2, price £6.00).