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## **Coping with a child with disabilities from the parents' perspective: the function of information**

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Accepted for publication 11 December 1998

### **Summary**

**Fifteen semistructured interviews were conducted with 20 parents ( $n = 5$  with both parents;  $n = 10$  with mother only) of disabled children who had a range of physical and learning difficulties, to explore what information they had received about their child's disabilities, from whom and whether they had found it useful. Information needs were also explored. The interviews were audiotaped and transcribed, then analysed for content. The reasons for needing the information was examined for themes. Personal communication was the most frequently cited medium of information. Parents most frequently reported professionals as their source of information, but parents and voluntary organizations were also mentioned. Information was found to assist the process of adjusting emotionally to their child's disabilities, to enable parents to access services and benefits, and to improve their management of their child's behaviour. Parents' comments indicated that information was usually useful, but occasionally of mixed benefit.**

**Keywords:** coping, information, learning disabilities, parents, physical disabilities

### **Introduction**

Parents of disabled children face the difficulty of balancing the normal tasks of parenting with treatment programmes, additional physical duties and the need to adjust emotionally to their child's difference from the parents' expectation. Information is acknowledged as a vital component in understanding the

Child: Care, Health  
and Development

VOLUME 25  
NUMBER 4

1999

PAGES 299–312

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practical implications of the disability and in facilitating adjustment to it (Philp & Duckworth 1982; Dale 1996).

A model of the process of transition towards acceptance and adjustment to a new situation was developed by Hopson (1986) which included seeking and using information as one of several 'coping skills' which enable people to respond constructively to transitions. Although this model was developed in relation to a range of life events such as bereavement, illness and changes in employment, it can be applied to parents as they seek to accept their child's disability or when that child approaches milestones of development which bring new situations. Parents need time, effort and mental energy to adjust to the transition (Dale 1996).

Information-seeking is described as one of many problem-solving strategies in the literature (Folkman & Lazarus 1988; Thompson *et al.* 1992). Pearlin and Schooler (1978) defined advice-seeking as a preparation for action to address the stressful situation and Parry (1990) stated that non-directive information is good for those coping with crises. Some people are termed 'information seekers' when they gather more information than professionals deem usual, but this may have the function of doing something when remedial action is not possible, and Beresford (1994a) concludes that information seeking has consistently been found to have a positive effect as a coping strategy.

With the above exception of information seekers, the literature does not make explicit the connection between information, the use made of it, and the psychological sequelae to that utilization. Learning from others' experience and ways of coping is considered a help in reducing feelings of isolation, and to encourage the parent to tackle the adjustment positively (Medvene 1992). Information would also equip the parents to engage in collaboration with treatment and management of the child, and Dale (1996) includes information-giving as a precursor to negotiated problem-solving. This would arguably raise self-esteem and feelings of control (Tones & Tilford 1994).

It is clear from the literature that personal communication is highly valued by parents (Beresford 1994b). One means of enhancing the flow of information conveyed personally has been through key workers. These have been reported as valued by parents (Glendinning 1986; Beresford 1994b; Vernon 1995; Dale 1996), because key workers are seen as approachable, and the information they provide is facilitative and tailored to the individual's need (Appleton *et al.* 1997). Beresford (1995) conducted a postal survey of parents of disabled children and found only 33% of the 1100 respondents had key workers. Portage teachers may unofficially take this role, at least with regards to information (Cameron 1997).

Ley (1989), Peterson *et al.* (1989) and Sandler *et al.* (1989) are amongst the authors that advocate that all the necessary information should be covered verbally first before the use of printed material as a back up. Written material is valued because it can be re-read as necessary and Quine and Pahl (1989) found that the provision of a booklet with local and national information reduced the number of parents of severely disabled children who felt they were given inadequate information from 47% to 18%. However, general printed information rather than a record of a consultation, is limited in that it fails to answer many of the parents' particular queries concerning their child (Philp & Duckworth 1982).

There are many protocols for good practice for the breaking of news about a diagnosis, for example Dale (1996; App.3.1), and information needs at this time have been well reported (McCubbin *et al.* 1983; Humphrey *et al.* 1996). But it is not only immediately after diagnosis that information is required. Beresford (1994b) found that many parents felt information was hard to get, and that they had to know the right questions to ask, and Sloper and Turner (1992) found that 59% of parents with severely disabled children wanted more information at least 2 years after diagnosis.

The aims of this study were therefore to gain a better understanding of the role information plays in the coping process for this group as they face the challenges of bringing up their child; to identify sources of information, the purposes for which it is used and the parents' opinion of its usefulness; and to explore what information those with differing educational backgrounds found helpful.

## **Methods**

The parents of 80 severely disabled children between the ages of 4 and 8 years under one Paediatric Consultant were contacted by letter asking them if they would be willing to talk to the researcher in their own home. This age group was chosen with the intention that the child's diagnosis would have been made 2 or more years previously, and information needs around that time already met. There was a 65% response rate (52 returns), of which 37 agreed to be interviewed.

Eleven of these were randomly selected, but learning disabilities were better represented than physical disabilities, so five children with a physical disability were selected from the remaining positive responses to give a spread of disabilities. One family cancelled their interview date, another had two children with disabilities, so 15 interviews were conducted concerning 16

children whose characteristics are summarized in Table 1. One child was from an ethnic minority and all attended special schools.

Of the nine children with learning disabilities, six had autistic characteristics, and one also had some muscle weakness associated with a chromosome abnormality. Of the seven children with physical disabilities, three of the four with severe cerebral palsy had learning disabilities too, one child had a life-threatening condition not amenable to surgical correction, one had speech and comprehension difficulties, and one had complications arising from a faulty shunt. Some aspects of the children's disabilities are recorded in Table 2.

In-depth semistructured or 'focused' interviews (Cohen & Manion 1994; Morse & Field 1996) were conducted in the family home, normally lasting 45 min. A schedule was used so that the way parents made sense of their experience and the things they felt helped or hindered them in coping could be explored. The interview began with the parent describing their child's disabilities, then they were asked to describe any difficult periods. This approach was used to avoid focusing on information too early, so potentially missing areas that parents may not consider strictly as 'information'. The reasons for the difficult periods, and whether information had helped, were explored. Sources of information were mentioned spontaneously rather than systematically requested, and the only medium of information they were specifically asked about was written information.

Five interviews were with both parents, the remainder with the mother alone. The parents were asked about their education since the age of 16; three categories were used: those with none; those with university education; and the remainder had attended various courses.

**Table 1** Characteristics of the sample interviewed

Characteristic	<i>n</i>	Characteristic	<i>n</i>
<i>Environment</i>		<i>Resident parents</i>	
Rural	2	One	1
Urban	10	Both	14
Semi-rural	3		
<i>Education (parents)</i>		<i>Siblings</i>	
Basic	6	None	2
Further	7	One	8
University	6	More than one	5
<i>Parent interviewed</i>		<i>Type of disability</i>	
Both	5	Learning	9
Mother only	10	Physical	4
Father only	0	Both	3

\*One family had two disabled children

**Table 2** Aspects of the children's disabilities

	<b>Learning disabilities (n = 9)</b>	<b>Physical disabilities (n = 4)</b>	<b>Both (n = 3)</b>
The need for constant supervision cited	3	0	0
The need for greater supervision than expected for a child of that age cited	5	1	0
Epilepsy	2	0	2
Incontinence	3	2	3*
Communication difficulties	9	3	3

\*One child was continent when at home

The interviews were audiotaped and transcribed, and then coded according to whether the information was received or was an unmet need, with subcodes for the received information to identify its source and medium. This facilitates describing and quantizing the data (Miles & Huberman 1994). All comments about information were then analysed for the reasons information was needed, and these examined for themes. The transcripts were re-examined to interpret whether the parents had judged the information useful by looking at their comments on the outcomes. Those judged useful were divided according to level of parental education, categorized by medium (oral, written, from experience or via television/videos) and by whether the source was a professional or not.

## Results

### Information sources

Of the range of media through which the parents reported obtaining information, personal communication was preferred to any other medium, and the written word was valued by more people as a back up to what had been said, rather than as a primary source of information, for example:

There was no substitute for real people, written information is nice to have as a comfort factor, but you really get your information from people, talking face to face with them.

*Parent with a child with learning disabilities*

Others mentioned the helpfulness of 'home books' carried by their child to and from school, in which teacher and parents write comments.

Little feedback was forthcoming about the content of printed information from the parents interviewed. One had found the pictorial representation of

autistic behaviours helpful, both personally and when explaining about their child's behaviour to others. The only other publications mentioned were books or newsletters with stories of other families with similar problems, and the locally produced booklet for families with children with special needs under 5 years old that is given to all who attend the local child development centre. Written records of assessments or reviews were also welcomed.

One child's parents felt that merely having leaflet racks available, although useful, may not be sufficient:

Mother: They've got . . . leaflets . . . [on the ward] and I thought, 'When you're stressed, you're not up to looking around.'

Father: Information is definitely slow, information has to be found.

*Parents of a child with an inoperable condition*

Parents also needed to consider advice given, and work out for themselves how to apply it within their family, for example:

But we do need guidance from people that know. Advice is given we mull it over. Sometimes a fresh pair of eyes can give us pointers. You might think an approach is rubbish, but if you sit down and think about it, you may think differently.

*Parent of a child with autistic behaviour*

Professionals were the most frequent source of information about the child's condition, management and services available, with several mentioned in every interview. Regular contact with, for instance, the Portage teacher, meant that parents had someone they could ask concerning who to approach for what:

You could talk to her about anything, and she was really good. She knew people who could help you if you were stuck, or would say 'well, you could try this, or that, or something else'.

*Parent of a child with learning disabilities*

Many parents made references to other parents as a useful adjunct to the official information concerning managing the child:

You see so many professionals, and they will tell you all the medical terms for everything, and you see the educational people, who give you all the jargon on what they want you to hear, but you need the parents who have experienced the shortfalls in the system, or the good and bad.

*Parent with two disabled children*

Another commonly cited source of information was voluntary organizations, which provided a range of advice, leaflets and services.

I contacted the Spastics Society, and in fact they were quite good . . . as well, a social worker came round, and told me about the benefits, I had no idea about, [my child] was 9 months old then.

*Parent of a child with cerebral palsy*

Having access to the necessary information helped parents to plan and feel more in control, with many mentioning this type of information use. A parent whose nephew also had learning disabilities had observed the benefits of respite care and realized that they might want this service when their child was older:

There might be a stage when respite will be needed. My sister, she's got respite.

Only one parent appeared to seek excessive information, and she would often pass information on to other parents.

### **The purposes for which information was needed**

Although not all parents had unmet information needs at the time of interview, they had all experienced needs in the past, or expressed them for the future. From the reasons for wanting information, three themes emerged: to enhance management of the child, to help the parents cope emotionally, and to be able to access benefits and services.

#### *To enhance management of the child*

Personal communication from school teachers, Portage teachers, health care professionals and other parents were the main sources of information parents used to gain advice. This could be for physical management, such as the parent who sought help when her child with cerebral palsy was having feeding problems:

They said, 'no more bottles, we want her to drink from a cup.' . . . Within a few weeks, she was drinking from a cup . . . That's when I realized, I need people with experience. People who know things about this.

Alternatively, it was to help with behaviour problems. In this context, a parent of a child with learning difficulties said:

I could ask my Portage teacher for help. Advice, 'what should I do about this? What should I do about that?' So she'd give me advice.

Another child's sleep problems had made his parents seek advice in desperation, and eventually a specialist community nurse's advice was obtained and successfully implemented.

Many parents expressed information needs that were connected with making proactive decisions about their child's management, denoting the expectation of having control over the process. One parent described the type of residential home she hoped her child might live in, but indicated she felt it would be difficult to find information. Another parent wanted more information before embarking on toilet training:

I need to know actually the practicalities, how to go about it with [my child]. To meet his emotional needs as well as the practical ones.

Parents indicated that nearly all information given concerning the management of their child was helpful, but some comments indicated mixed benefit, for example one parent who considered professionals' advice 'A lot of interference'. There was also one instance of a judgemental statement from a professional, 'They told us we should teach him more, he didn't know enough. But, you can't because he just couldn't [learn].'

Inability to formulate the questions did not mean information was not wanted, as one parent of a child with communication and behavioural difficulties expressed:

I think if somebody could have perhaps have come to the house, and been with you in the day-to-day dealings with a child like that, to help to learn how to cope. Because you just have to fumble your way through. And you don't always do what's best.

*Parent of child with learning difficulties*

But when information was timely and appropriate, parents felt satisfied, 'Things have fallen into place we consider we've been lucky in what has happened.'

*To help parents cope emotionally*

Information about the condition came mainly from health care professionals, and several interviewees indicated that such information helped them to accept the child's difficulties and adjust expectations. One parent said having the diagnosis of autism meant, 'You can understand it's *him* rather than you've failed to do something properly'. Some parents had found that written information had assisted acceptance of their child's problems, for example one parent reported reading an article about autistic behaviours:

As I was reading it he was lining all his cars up on the floor, repetitive, . . . he always liked things done in a certain way. Yes, he is autistic.

Written records of reviews were also mentioned:

Mother: Portage do reports . . .

Father: They do 6 months, what his target was, how he's doing.

Mother: It's extremely helpful.

The above helped with acceptance that the child's progress was different from normal developmental patterns, but information about the condition itself, to aid the understanding of reasons for their child's disabilities, was also wanted:

When they said he had oral dyspraxia, we could go into it, and find out exactly what it was, and how we could deal with it, and that's when we tutored our families.

This quotation also illustrates that a diagnosis can help parents when explaining to their own families, which in this case lessened the family's judgemental attitude concerning the parents' handling of the child.

Conversely, when no diagnosis was possible, honesty about this was valued:

[The paediatrician] said like 70%, they can put a name to what they've got, and 30% they never can, they never know. I don't know how true that is, but there are some people that just never know why children do certain things, or can't do certain things.

*Parent of a child with learning disabilities*

Information about likely progress was wanted, particularly when prognosis was poor, to help parents prepare themselves for the future:

[We were given] a book, that was fantastic. It started from birth, the finding out, then it went through the operating theatre, little drawings of who everybody is, and then it went to bereavement, and how you felt, how the families would feel, how your parents would feel.

*Parents of a child with an inoperable condition*

The majority of parents who mentioned joining a specialist voluntary organization indicated that knowing others in a similar situation was helpful. But it could work in the reverse direction, because seeing older children with a similar condition caused some anxieties:

Mother: What makes it worse is that we have an autistic relation as well.

Father: In some way, because you can see what my sister's been through.

You think, 'we've got that to go through.'

*To access benefits and services*

Parents all expressed a need to know what services, benefits and facilities were available, to enable them to choose what was most appropriate for their child, for example a school:

It is more difficult to get that information when you have a child with special needs. So I would have liked more information regarding the schooling side.

*Parent concerning her child with autistic behaviour*

Information concerning services and benefits were predominantly useful, but there were instances of mixed benefit, usually because the services or benefits were not known about soon enough, or not readily available nor as comprehensive as had been hoped:

'Cos we did get a book of all the schools, and there didn't seem to be many [special] senior schools.

*Parent of a child with learning difficulties*

Another parent who had difficulty in getting in to a centre was not offered transport until the child had almost finished attending.

### **Information and level of education**

The information that parents indicated was useful was examined according to the level of parental education and the medium of delivery. Those with higher education did not appear to mention oral information as frequently as the other two groups, and expressed the desire to find information for themselves. For example a parent was reading a book about autism:

Try and understand his behaviour . . . maybe work out how *he* sees the world. He might be locked away, inside, but the book might describe how he feels this.

### **Discussion**

The parents in this study reported personal communication of information most frequently, and wanted it to enhance their management of their child, to help them cope emotionally or to enable them to access services. The methodology used in this study enabled interviewees to mention information that was important to them rather than comprehensively cover all information that they had received. The data were therefore possibly biased towards the

highly pertinent and the counter-productive, but reflect the parents' agenda and needs. The findings are not directly generalizable to all parents of disabled children, but should be used to assist understanding in cases to which these data are judged applicable.

The interview with the parent from an ethnic minority was less fruitful than the others; the researcher's difficulty in encouraging freer communication may have been influenced by cultural differences, and such differences may be one reason for the lower information received by minority groups (Shah 1992).

### **Information sources**

The positive comments about the content of the locally produced information booklet in this study support Quine and Pahl (1989) who found that the provision of a booklet with local information increased parents' satisfaction with the level of information they had. Individualized written records of medical reviews were also appreciated. This does not mean that other printed matter is of little use, but it should be borne in mind that generalized publications have their limitations. If a pertinent leaflet is available, the findings of this study suggest that, for maximum impact, a professional should select and give it to the parent, and also indicate what are the most important sections within it, so the parents have the motivation to make an effort to absorb at least those sections. If such an approach was adopted as routine practice, those with low literacy skills would greatly benefit.

### **Purposes for which information was needed**

Information-seeking is defined as a positive coping strategy by Folkman and Lazarus (1988) and Pearlin and Schooler (1978), but the mechanism to explain why this should be so is less well defined. From this study it would appear that information has several functions. Firstly, it contributed to the process of acceptance, not only immediately after diagnosis which was mentioned by some parents, but also later, for instance through books that described other parents' experiences of children with similar conditions which helped the parents realize the implications for their family, and when written confirmation of assessments enabled the parent to absorb the child's current ability and progress. Secondly, information enabled them to manage their child's behaviour and judge what would maximize their child's potential. Linked to this, information provided parents the opportunity to plan for the

future, which returned to them some control over their family life. Thirdly, it enabled them to access services and benefits that eased their task of raising their child, so reducing stress and physical duties of caring to more manageable proportions. If one deduces from these data that the act of information-seeking is an indication of readiness to tackle these areas, then its role in adaptive coping can be appreciated.

The responsibility that professionals bear with regard to information-giving is demonstrated not only with positive outcomes, but also the incidence of some mixed benefits. Additionally, when parents do not actively seek information it may be because they do not know how to ask, or where to start. All parents need to know the implications of the child's disability for their family, and how they can fit what is being recommended as best for their child into family life. The obligation lies with health professionals to convey that information in a way the parent can understand, and the positive comments of the interviewees in this study concerning personal contact further support the concept of a key worker as an effective means of ensuring meaningful information exchange. Those whose first language is not English, none of whom this study included, would particularly benefit from facilitation of communication in this way.

### **Information and the level of education**

In this study, what was not said was revealing; not only that those with higher education mentioned personal communication slightly less than the other interviewees, but also very little written information was mentioned across the whole sample, and what was cited mainly followed a direct question by the researcher.

To summarize, professionals are the most common source of information for parents with disabled children. Personal communication was the most frequently cited medium for information delivery, but the results suggest those with higher education may be slightly less reliant on information given orally. Information-seeking was found to have several functions: it enabled parents to access services, it enhanced parents' management of the child, especially with regard to behaviour, and it assisted in coping emotionally. Information was needed on an ongoing basis to furnish the parents with sufficient knowledge of the child's condition so they could plan meaningfully and hence feel in control of their family's life. Personal contacts, and timely and appropriate information were valued by the parents. One way in which information could be made readily available is through key workers.

## Acknowledgements

Dr V Shrubbs, Consultant Paediatrician, Southampton Community Health Services NHS Trust, through whom the parents were recruited.

This study was undertaken as part of a Master's degree. My thanks to K Weare and V Box, Lecturers in Health Education/Health Promotion, University of Southampton who were my tutors.

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