

# Information needs of disabled young people



RESEARCH FINDINGS FROM THE  
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At the centre of health service policy are the notions of a well-informed public and working partnership with patients. Both require meeting the information needs of people. But what of children and adolescents? Little mention is made of them in policy or guidance documents. The project set out to identify the information needs of chronically ill and physically disabled young people. The key findings were:

- the information needs of young people with chronic conditions extend beyond medical information to knowing how to manage daily living and the 'extraordinary' stresses that having a chronic condition can bring: the psycho-social information needs.
- different information needs require different information sources. Health professionals, parents, others with the same condition and written information are important information sources.
- considerable difficulties exist in using health professionals as an information source.
- it is not possible to use age to predict when a young person may need a particular piece of information.
- most project participants did not have opportunities to use other young people with the same condition as an information source. Yet, this was seen as a critical source of psycho-social information.

## Background

Previous research on patient knowledge and education takes a highly medicalised approach, focusing on knowledge about a condition and how that relates to medical outcomes. Similarly most work on patients' information needs is restricted to medical information. Yet we know that having chronic illness impacts on all areas of an individual's life and this will generate a wide range of information needs. Children and adolescents are a particularly neglected group in terms of our understanding of their information needs and how to meet them.

Provision of information to patients is a key feature of health service policy, alongside a commitment to promote working partnerships between health professionals and patients. There is also an increasing emphasis in legislation on consulting with children and empowering them to be directly involved in decision making.

### Project objectives

In the project we set out to:

- identify the information needs of chronically ill and physically disabled children and adolescents
- develop recommendations for good practice in the provision of information.

## Findings

### Types of information need

The information needs of chronically ill young people can be categorised into medical information needs (see Figure 1) or psycho-social information needs.

The young people in the study wanted information that enabled them to make sense of their situation. For example, knowledge

**Figure 1**

#### Medical information needs

- the condition
- general human biology
- treatments
- tests and investigations
- managing an exacerbation
- lifestyle factors
- current research
- health service and other sources of statutory support

**Figure 2**

#### Psycho-social issues generating information needs

- dealing with negative emotions
- living with physical symptoms
- living with unanswered questions
- dealing with parents
- dealing with peers
- managing at school
- managing other social situations
- living with restrictions on lifestyle
- maintaining a positive attitude
- planning for the future

of human biology is important in providing a necessary context to understanding the actual condition. It is also important to know how the results of any tests and investigations compare with other people with the same condition. All the young people reported unmet medical information needs. The less informed had very basic questions about their condition, while the well-informed participants had more detailed and specific questions.

The second category of information needs related to the role that information can play in enabling a young person to deal with the situations and emotions that result from having a chronic medical condition. We have called these psycho-social information needs (see Figure 2).

Coping effectively with these issues or situations draws on information as a 'coping resource' in two main ways. First, information about the condition, and about health and other support services, is necessary. Second, knowledge about appropriate or effective ways of coping is needed. For example, a young person can draw on the problem-solving skills and the experiences and strategies used by others with the same condition in deciding how to cope with a source

of stress. Meeting psycho-social information needs is as important as addressing medical information needs.

### What to know and when

Considerable individual differences exist in what young people want to know, and when they want to know it. How young people cope influences information needs in two ways. First, individuals differ in how much they need to seek information when dealing with a new or stressful situation. Secondly, avoiding information can be a way of coping with the adverse implications of the condition. For example, some young people with life-threatening conditions did not want to know about their prognosis and health at the end stages of their condition.

Changes in the condition or its treatment, as well as exposure to events or new information relevant to the condition, also generate information needs. These sorts of events are not always predictable or controllable. This means that it is not possible to use age or life cycle stage as indicators of when to provide information.

**Figure 3****Key preferred sources of information**

<b>Medical information needs</b>	<b>Psycho-social information needs</b>
Hospital doctor	
Parents	Parents
Book/leaflet	Someone else with the condition
Other health professional	Friends

**Sources of information**

The preferred sources of information varied according to the type of information need (see Figure 3).

**Using health professionals as a source of information**

Many young people reported difficulties using health professionals, especially their hospital doctor, as an information source.

*'It seems a lot of persuading to get the doctors to tell you everything.'*

Some described how information was withheld from them, or how they were excluded from consultations involving themselves, their parents and their doctor. Difficulties establishing a rapport with their doctor, a tendency to concentrate on medical matters in consultations, the shortness of clinic appointments, and the presence of parents all hindered the development of effective communication between young people and their doctors. The communication skills and confidence of young people themselves could compound these difficulties.

*'He's more interested in what's happening inside me than what I'm going to ask.'*

*'Some doctors think that mum or dad is more important than me, and they have to talk to them instead of me. But it's no good talking to them. I'm the one with the cough.'*

**Figure 4****When we see our doctor we want....**

- choice about who else is present
- continuity of contact with one doctor
- our doctors to be interested in us and not just the condition
- to be asked questions
- our doctors to talk to us, not our parents
- the opportunity to ask questions
- the language used to be understandable
- to be treated with respect
- to be made to feel comfortable and not rushed
- to have the choice about whether we see a male or female doctor.

The young people in the study identified the key features of an ideal appointment with their hospital doctor (see Figure 4).

**Written information**

Books or leaflets are important but limited sources of information. Unlike a conversation, they cannot be tailored to the circumstances which have generated an information need. Pictures or diagrams, and statistical information about prognosis and outcomes are the most useful aspects of written information. The participants' key recommendations about written information are summarised in Figure 5. There was no agreement whether 'bad news' should be included in leaflets.

**The role of parents**

Whether parents act as information providers is influenced by a number of factors including: age of the young person at diagnosis, duration

**Figure 5****Recommendations about written information**

- Young people should be involved in writing and design
- Facts, advice and 'real-life' histories all need to be included
- Different versions should be available for different age groups
- The language should be understandable, and information presented in an accessible way
- There should be a separate section detailing sources of further information and support.

of the condition, parental involvement in day to day care, and perceived levels of parental knowledge. Some parents face an enormously difficult task of knowing 'when' and 'what' to tell their child.

**Other young people with the condition**

Other young people with the same condition are a unique source of medical and psycho-social information. Yet many people do not have the opportunities for such contact. Different ways of establishing contact with another young person need to be available. For example, group meetings, one-to-one meetings, telephone, written, e-mail or internet contact. The phrase 'support groups' was actively disliked by most participants.

*'... it means you're not coping well. A support group is what you go to if you're not coping.'*

Our study respondents wanted the opportunity to meet with others in an informal and social setting where their condition was not the focus, but where there was an opportunity to make friends and share experiences.

## Other sources of information

Telephone help lines were not an information source that participants had used or would envisage using in the future. They were seen as stigmatising and would only be used in a crisis where no other support was available.

*'...makes you sound if you're not stable or something. That you've got no friends.'*

The internet has the potential to be a useful source of medical and psycho-social information but is not, as yet, widely accessible to young people.

## Implications

### Practice

Health professionals need to adopt a holistic approach to understanding and responding to the information needs of young people with a chronic medical condition. This includes the wide range of psycho-social issues that a young person may face as a consequence of his or her condition.

Given the changing information needs of young people, relevant written information should be offered on a regular, as opposed to one-off basis, as should details of web sites, help lines and voluntary organisations. Contact between young people of similar ages and with the same condition should be encouraged and facilitated.

### Further information

Copies of the final report *The Information Needs of Chronically Ill or Physically Disabled Children and Adolescents*, by Bryony Beresford and Tricia Sloper are available from the SPRU Information Office (contact Lindsey Myers, Information Officer, on 01904 433608 or email [lam7@york.ac.uk](mailto:lam7@york.ac.uk)).

Promoting effective communication between young people and health professionals needs to be priority. This should include improving the communication skills of health professionals, their attitudes to communication, and their beliefs and presumptions about young people.

### Policy

Medical and psychosocial information needs must be met in order to promote and support the physical and mental well-being of young people with chronic medical conditions. This is not recognised within health service policy, nor does the 1989 Children Act make provision for supporting children with chronic health conditions. There appears to be a 'policy gap' in terms of defining responsibility for meeting the wider psycho-social support and information needs of young people with chronic health conditions.

The independent rights of young people to information should be reasserted within health care policy, and their legal rights to information clarified. The role of parents as information providers and gatekeepers needs to be addressed.

The findings from this project reflect a wider issue within the health service about the extent to which the rights, and the value ascribed to the opinions, of children and adolescents are respected.

Policies directed specifically at addressing the needs of children and adolescents would serve to promote a change in culture.

## Methods

Forming part of the NHS Executive's Research and Development Programme on Mother and Child Health, the project was carried out over 28 months from late 1997.

Sixty three young people took part. They fell into two age bands: 10-12 and 14-16 years. The conditions represented in the project (juvenile chronic arthritis, cystic fibrosis, diabetes, epilepsy and Duchenne muscular dystrophy) were chosen to reflect most of the medical and psycho-social issues likely to be experienced by a young person with any chronic medical condition. The young people with each condition were recruited from a single site. Four hospitals, in different areas of the United Kingdom, were involved in recruitment. Just under half the young people responded to the invitation to take part in the project.

Participants were interviewed at home before attending two group meetings with other young people of a similar age and with the same condition. Participants unable to attend a group meeting were either re-interviewed or completed questionnaires and other materials by post.



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