Quality services for disabled children

Wendy Mitchell and Patricia Sloper

Current health and social care policy seeks to develop and refine standards of service quality. However, the concept of 'quality in services' is rarely defined in terms of service users' and their families' experiences or preferences. This study explored the concept of quality in services as defined by disabled or chronically ill children and young people and their families and identified key quality service indicators. The main findings were:

- Disabled or chronically ill children and their parents valued different quality criteria.
- Children's notions of quality services included staff attitudes and approach, meeting and making friends, opportunities for making choices and age appropriate community based leisure activities.
- Parents tended to focus on broader organisational and whole family issues, including staff training and ability to listen, accessible information, services that meet their child's and the whole family's needs and agencies working together.
- In further discussions, parents and children identified a number of 'core indicators' of service quality that applied to all types of support services. Other quality indicators were felt to be relevant to specific types of support services.
- However, in the services they received, parents and children experienced some core indicators less frequently than others, despite these being high priority amongst current policies, such as Quality Protects. These indicators included listening to children, meeting the needs of people from different cultures, multi-agency working and social opportunities for children and parents.

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Background

Past research has demonstrated that families with disabled or chronically ill children have a wide range of support needs but these needs often remain unmet. At the same time, reports from parents, practitioners and researchers reveal that there are services that families really value.

The government recognises the importance of quality in services and is currently seeking to establish national standards and develop performance indicators for a range of services, including those for disabled or chronically ill children. Despite this, the concept of quality is often ill defined.

Project Objectives

The project was divided into two phases, the first phase sought to:

- Explore parents' and children's views of 'quality' in services.
- Define service quality indicators based on children's and parents' views.

Using these ideas and experiences of quality in services, the key objective of the second phase of the project was to:

Produce a web based directory of support services commended by disabled children and their families. The directory would contain examples of services valued by families throughout the UK.

Findings

Discussions with children and parents during the initial phase of the project revealed that they have clear ideas about quality in services based upon their own past experiences and future service expectations.

What is Quality in Services? – Children's Views

Children's assessments were firmly grounded in their experiences of the clubs and activities they attended.

- **Staff attitude and approach**
  Quality services are those where staff make you feel welcome and part of the service.
- **Meeting and making friends**
  Friends play an important role in children's lives. Quality services should respect and seek to nurture friendships.
- **Choice making**
  Opportunities to make real choices that are then acted upon were valued.
- **Community links**
  Services providing age appropriate club and community based activities, such as dancing, going bowling or out for meals, were highlighted.

What is Quality in Services? – Parents' Views

Parents' assessments of quality focused on wider information and organisational issues.

- **Staff approach and training**
  Quality services are those where staff respect and listen to parents and children and act upon their wishes. Parents valued staff whose training equips them with the skills to work competently and confidently with families.
- **Information**
  Information should be accessible and available in a range of formats using clear, jargon free language. It should also be provided regularly, ideally through one person, who acts as the family's 'key worker'.
- **Service organisation**
  How and when services are delivered was central. Parents highlighted the importance of services that are flexible and work with rather than against family lifestyles and routines. Multi-agency collaboration was viewed as important to ensure effective coordination and delivery of services.

Core Quality Indicators

Further discussions with children and parents produced two lists of characteristics of services that they particularly valued. These were seen as indicators of a good quality service. The children's list contained 19 and the parents list, 24 specific indicators. Some indicators were regarded as 'core indicators', fundamental to any service irrespective of its role or the support it provides *(see Figures 1 and*

Figure 1
Children's core indicators

- Staff understand about my illness or disability
- Staff know how to help and look after me
- Staff listen to me
- Staff ask me for my ideas and take notice of what I say
- I can ask the staff questions and they explain things to me
- Staff allow me to make choices.

Figure 2
Parents' core indicators

- Meeting the child and whole family's needs
- Listening to the child and family members
- Treating the child and all family members with respect
- Staff knowledge and training
- Welcoming and helpful staff
- Service respects family's culture

2). Indeed, many parents indicated that they would be reluctant to use services if they did not have these characteristics.

Specific Quality Indicators for Different Types of Services

In addition to these core service indicators, parents and children also emphasised that some other characteristics were important for specific types of services. Thus, in order to develop comprehensive and relevant service quality indicators both core and specific indicators need to be considered.

For example, alongside the above core criteria, when children discussed leisure and short break services they highlighted the importance of four specific indicators:

- Services providing me with opportunities to meet and make friends
- Having a variety of activities to choose from
- Opportunities to develop my independence
- Having a break from my family

In contrast, nursing care services required different specific indicators:

- Having a special person I trust
- Staff seeking to make my life easier

Parents similarly highlighted the importance of specific indicators for different types of services. For example, in services providing multi-agency co-ordination four additional indicators were prioritised:

- Professionals working together and communicating
- Accessible information
- Services that are reliable, i.e. there when you need them
- Service continuity

Short break services were felt to be more complex with four general indicators for all types of short breaks:

- Service flexibility
- Service reliability
- Service continuity
- Providing family members with a break

In addition to these, parents also felt that overnight short break services should have:

- Professionals working together and communicating
- Be easy to travel to
- Opportunities for children to meet and make friends
- Opportunities for children to mix with the local community

Ideal Models and Everyday Service Experiences

The above lists of core and specific quality indicators are what children and parents viewed as best practice in services. However, results from a survey of over 14,000 families with disabled children revealed that two core aspects of quality, listening to children and meeting the needs of people from different cultures, and two other aspects of quality, multi-agency working and social opportunities, were experienced less frequently than others. This suggests a gap between parents' and children's prioritisations of quality services and their everyday experiences.

The Web Based Service Directory

The quality indicators identified in discussions with children and parents formed the basis of the survey in the second phase of the project and the subsequent development of a UK wide directory of valued support services. The directory is available on the world wide web and contains the contact details of over 1,000 services, all of which have been commended by disabled children and their families. Around 200 of the services are described in greater depth. Services can be searched for by service type, geographical region or country, or a combination of both.

Implications

The findings demonstrate that disabled children and their parents prioritise different quality criteria. Furthermore, both parents and children want different things when using different types of services. Thus, as current policy initiatives, such as Quality Protects and the Children's National Service Framework, seek to establish and define more clearly quality standards for services, the models that parents and children have developed in this project provide a useful starting point. Indeed, the core indicators provide a set of standards that should be the foundation of any service. In addition, highlighting specific quality indicators for different types of services provides a means for practitioners to refine or assess their own individual service quality indicators.

The survey findings demonstrate differences between parents' and children's ideas of what they most value and the services that they receive. Indeed, the four aspects of quality areas found to be less likely experienced by families (listening to children, meeting the needs of people from different cultures, multi- agency working and social opportunities for children and parents) have been high priority issues for a number of years in both health and social care policies. Although recognised as important, these are areas that still require practical development.

The web based service directory also has significant implications for both families and practitioners. For families, the directory provides a quick and accessible source of regional, country and UK wide information about services that other families have found useful. The directory is also an information source for policy makers and professionals, enabling them to locate valued services and share elements of good practice. This may help to reduce time and effort spent 'reinventing the wheel' when local areas are looking to develop services.

Methods

The project (Sharing Value) was funded by the Community Fund and carried out in partnership with the Family Fund Trust (FFT) and Barnardos over a period of 30 months, commencing January 2000. Consultation groups of parents and disabled children were recruited to guide the project. Quality in services was discussed in-depth by four groups of parents and three groups of disabled children over a series of meetings. Parents were located in Yorkshire and the Midlands and 21 parents, in total, took part in the groups. The parents cared for children with a wide range of disabilities and chronic illnesses. The children's groups were located in Yorkshire and the North West. The children ranged in age from 11 to 17 years, with 27 children being involved in total.

Using the quality indicators developed by the groups in the first phase of the project, three postal questionnaires (one each for parents / carers, disabled children and siblings) were then devised and sent to a random UK wide sample of 14,538 families in the second phase. The sample of families was drawn from the FFT database. Parents / carers, disabled children and siblings were each asked to nominate 'valued' services that they use or have used in the recent past, and to indicate which of the quality indicators they experienced in these services. Nominated services were contacted and around 1,300 services agreed to participate and provided contact information for the directory. A sub-sample of 200 of these services were short-listed using parents' and children's quality characteristic priorities for each type of service. These were then visited and are described in greater depth in the directory.

Further information

Visit the Sharing Value Directory at http://www.sharingvalue.co.uk or contact the FFT for further information, e-mail info@familyfundtrust.org.uk.

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Mitchell, W. and Sloper, P. (2002) 'Quality services for disabled children', *Research Works*, 2002-02, Social Policy Research Unit, University of York: York.

Related publications

Mitchell, W. and Sloper, P. (2001) 'Quality in services for disabled children and their families: what can theory, policy and research on children's and parents' views tell us?' *Children and Society*, 15, 4, 237–252.

Mitchell, W. and Sloper, P. (forthcoming 2003) 'Quality indicators: disabled children's and parents' prioritisations and experiences of quality criteria when using different types of support services', *British Journal of Social Work*.

Lister, S., Mitchell, W., Sloper, P. and Roberts, K. (forthcoming 2003) 'Participation and partnerships in research: listening to the ideas and experiences of a parent-carer', *International Journal of Social Research Methodology: Theory and Practice*, 6.

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Social Policy Research Unit,
The University of York, Heslington,
York Y010 5DD, United Kingdom.
Telephone +44 (0)1904 433608
Fax +44 (0)1904 433618
Text +44 (0)1904 432626
E-mail SPRU@york.ac.uk