

6

Meeting the needs of disabled children

Services play a vital role in meeting the needs of disabled children and their families and in ensuring that they are not excluded from the opportunities that most non-disabled children and their families take for granted. A common theme from parents' and children's accounts is the desire for an ordinary and reasonable quality of life. Yet, research suggests that there is a long way to go before this is achieved. Social attitudes and limited and variable service provision continue to exclude disabled children from many opportunities, and to constrain the lives of their families.

objective 6: to ensure that children with specific social needs arising out of disability or a health condition are living in families or other appropriate settings in the community where their assessed needs are adequately met and reviewed.

sub-objective 6.1: to arrive at a complete picture of the numbers and circumstances of disabled children by ensuring that in each local authority the social services department, the education department and relevant health agencies share the information they hold.

sub-objective 6.2: to increase the number of children in receipt of family support services - including short term breaks and domiciliary services and the number of hours of service provided in order to enable disabled children and their families to lead as ordinary life as possible.

sub-objective 6.3: to increase the number of disabled children who use inclusive play and leisure services, including holiday play schemes, after school clubs and pre-school provision with appropriate support if necessary.

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 basis¹.

NUMBERS AND CIRCUMSTANCES OF DISABLED CHILDREN

The assessment of children's and families' needs and the development of services to meet those needs are vital steps towards well-being. Having a complete picture of the numbers and circumstances of disabled children is part of this process, yet there is no current, complete information in the UK to guide local areas. The most comprehensive data are contained in Gordon and colleagues' re-analysis of the OPCS (Office for Population Censuses and Surveys) Disability Survey. However, these data were collected in the mid 1980s and do not reflect changes in the prevalence or pattern of disability, for example increases in numbers of children with complex health needs and children diagnosed with autistic spectrum disorders. The analysis shows that most disabled children have more than one disability, with severely disabled children commonly having physical, sensory and learning disabilities. Therefore service planning which focuses on just one disability at a time or on the 'main' disability is problematic.

The Children in Need census data provide information on the numbers of disabled children receiving services from Social Services Departments.

¹Since this briefing was written, objectives for disabled children have been amended and expanded. However, the issues covered here are still included.

The 2000 data show that 12% of children receiving a service in the census week were disabled; 2.5 per 1,000 children receive a service and are disabled. Comparison with estimates from OPCS data of 32 per 1,000 children having one or more disabilities suggests that only 8% of disabled children receive a service from SSDs in a week. These findings emphasise the need to share data from all agencies in order to get a complete picture of the profile of disabled children and plan local services. Development of effective joint registers in some areas (e.g. Nottinghamshire, Kensington and Chelsea, Camden, Stockport) is facilitating planning.

Information about the circumstances of disabled children is important in informing needs-led (rather than service-led) provision, which takes a holistic approach to the whole family's needs. There is a considerable body of research on the needs of disabled children and their families. High levels of unmet need have been found in relation to a number of areas:

- information about services, the child's condition, and how parents can support the child's development
- breaks from care
- domiciliary support
- financial support
- housing, aids and equipment, and transport.

For children themselves, unmet needs are found in relation to:

- learning skills for future independence
- help with learning, communication and physical development
- opportunities to make friends and take part in social activities
- opportunities to make choices and develop independence
- access to someone to talk to about being disabled
- information about their condition and treatment, and about living with the condition and tackling disabling barriers.

High levels of unmet need are particularly common among poor families, families of children with very severe impairments, among minority ethnic families and among families with more than one disabled child.

The majority of parents with disabled children provide care well in excess of that of other parents. For example, a recent survey of families with children with profound and multiple disabilities found that 60 per cent of parents spent more than ten hours per day on basic physical care; one third of these were providing 24 hour care. The care demands on parents, combined with lack of child care assistance, affect parents' ability to work. Mothers with disabled children are much less likely to have paid employment than other mothers, and fathers' employment and earnings are also affected. Employment limitations and extra costs for families with disabled children mean that they are at greater risk of poverty than families with non-disabled children, and the poorest families are the least likely to receive services such as short term breaks and aids and equipment.

It should also be noted that disabled children are over-represented in the population of looked after children and more likely to be placed in residential settings. They are also more likely to experience abuse than non-disabled children and those with multiple impairments are particularly vulnerable.

As noted above, considerable information about the circumstances of disabled children and their families is available from research and this can be used to inform services at a local level. National information on numbers of disabled children is emerging from the Children in Need census data. A further source of information is the Family Fund Trust database. This is the largest database on disabled children in the UK. It contains information on more than 200,000 families and represents over half of all families with severely disabled children. Data are available broken down by local authority and can provide a comparison with the local authorities' own data. Current figures suggest that just under 70% of families applying to the Family Fund Trust are known to SSDs, but there is considerable variation between regions, from 53% to 78%. Families not represented on the database are those with higher incomes (FFT has an income cut off of around £20,000pa for eligibility) and those who do not know about the FFT – a group unlikely also to know about other services².

FAMILY SUPPORT

A reason for high levels of unmet need is lack of co-ordination between different agencies and professionals providing services for disabled children, so that no holistic view of the child and family is obtained. Parents report 'a constant battle' to find out about what services are available and the roles of different agencies, and to get professionals to understand their needs. Up to 80% of families report poorly co-ordinated services. Policy has emphasised the need for a single point of contact for the family: a 'key' or 'link' worker or care co-ordinator, yet research shows that fewer than a third of families have this, and when they do it is rarely a systematic part of service provision. However, families receiving this service report better relationships with services, fewer unmet needs, better morale, fewer feelings of isolation and burden, more information about services, higher satisfaction, and more parental involvement than families without this service.

Care co-ordination should ensure that families' needs for information, advice and help are identified and addressed. Particular areas covered should include financial support – help with claiming benefits; aids and equipment; housing adaptations; behaviour problems; and support for all family members' needs.

Establishing a multi-agency steering group to develop care co-ordination is the first step. Crucial elements in developing the service are:

- time for the group to develop working relationships
- the preparation of detailed action plans
- the commitment of managers
- a clear service model and key worker job description
- a service co-ordinator
- key worker training and supervision and protected time to do this, as well as carry out the key worker role
- identified channels of communication for key workers with all agencies, including those responsible for housing and benefits

²More information about the use of the database can be obtained from the Family Fund Trust, PO Box 50, York YO1 9ZX.

- clear ongoing communication with all stakeholders.

The service itself should include:

- pro-active regular key worker contact
- key workers working across agencies, acting as advocates for the family and working with families' strengths
- an holistic family-centred approach
- multi-agency care planning meetings.

An important aspect of family support is reducing stress. Parents with disabled children are at increased risk of stress compared to other parents and stress levels are strongly linked to child behaviour and sleeping problems. Training professionals to help parents deal with such problems is important. For example, Quine's report of a training programme for dealing with sleep problems shows positive results in reducing child problems and parents' distress.

A break from caring is one of parents' most frequently reported needs, but families also require support that enables them to do activities together as a whole family. Short-term breaks, domiciliary services, and accessible and appropriate play and leisure services are all part of this support.

SHORT-TERM BREAKS AND DOMICILIARY SERVICES

Parents who are satisfied with short-term breaks believe they are important in helping them to continue caring for their child at home, and they report lower stress levels and more social activities than non-users. Short-term breaks can also provide a positive experience for children by enabling friendships to be struck with other children and by encouraging social activities, new experiences and supportive relationships with carers. Highest levels of parental satisfaction have been reported following family-based short-term breaks, but some families and children prefer residential provision, particularly where nursing care is required, and some adolescents like spending time away from home with their peers.

However, a number of issues need to be addressed. First, the most common area of dissatisfaction is the amount of breaks available, especially at weekends and school holidays, and a lack of flexibility and choice. Second, only a minority of families uses short-term breaks. Factors affecting take-up include a lack of information, of culturally appropriate services and services supporting children with challenging behaviour or complex health needs. Over-subscription of services is also a problem. Prewett's survey of shared care services found that 90% had a waiting list, numbers on waiting lists equalled half the number of children receiving services, and around a third of users wait over a year. Shortages of carers, scheme staff to recruit carers, and funding all contributed to this situation.

About one in three families either do not know about or choose not to use short-term breaks. Several studies have shown that parents regard using such services as a sign of failure to cope with caring for their child; many worry about the effects of separation on the child.

Breaks from care should also be offered within the home. Sitting services are important in providing an opportunity for parents to go out together or

with their other children. Help with domestic tasks and/or the day-to-day care of the child is needed by around 40% of parents.

'Stronger Links', the good practice guide produced by Shared Care Network, provides useful information about increasing uptake and reducing waiting lists. Interviews with carers providing breaks for 'hard to place' children suggest a number of strategies to increase the recruitment of family based carers:

- advertise at professional quality, with positive disability images
- highlight enjoyment and satisfaction for carers, and skills gained
- involve current carers and users in recruitment
- develop links with local communities – give talks at groups and events
- ensure groups such as single parents, young people and people from minority ethnic groups know they are welcome
- use appropriate images and community languages
- employ staff from minority ethnic backgrounds
- target people with relevant disability experience.

Confidence levels among families need to be raised if the number of children receiving services is to increase – parents and children deserve better information about what they are being offered. Attention should be given to the way short-term breaks are introduced to them, to making sure breaks provide children with positive and inclusive experiences, to developing high standards of care appropriate to the child's needs, to providing flexibility and choice in the type of service (by offering home and community based breaks as well as family-based and residential breaks), and to improving consultation with children about their preferences and experiences.

The *Carers and Disabled Children Act, 2000* provides carers with the right to receive an assessment of their own needs, including the need for help in the home. Families differ in the type of support they would like to receive and the use of direct payments to purchase support in the home or other forms of breaks could be of considerable help to some families. Research indicates that few carers feel that they have had an assessment of their own needs or are aware of their right to ask for one. It is important that assessments are clearly offered to carers.

PLAY AND LEISURE SERVICES

Disabled children do not participate in sport and leisure activities as much as non-disabled children. Older children in particular report difficulties accessing social and leisure facilities. The lack of inclusive activities leads to boredom and loneliness and means that disabled children spend more time at home and more time watching television than non-disabled children. On the other hand, the services viewed most positively by disabled children are those which promote friendships, and offer opportunities to go out into the community, join in with leisure activities, and develop skills in an entertaining setting.

what helps

Children and parents identify several barriers to participation in inclusive play and leisure activities. They include: unsuitability or lack of local facilities, lack of accessible transport, high cost and lack of money, the attitudes of staff and members of the public, and the lack of personal support. Unsuitable housing also excludes children from everyday play and leisure activities within the home. Parents suggest that if mainstream services were more accessible and they had better housing they would have less need for short-term care.

Achieving participation in inclusive play and leisure services requires a multi-agency approach, involving leisure, education, social services, transport and housing. Inclusion is something that has to be actively supported. Simply ensuring that disabled children are able to attend the same facilities as non-disabled children does not mean that they will join in activities together. A number of factors appear to be important in promoting inclusion:

- staff knowledge and training
- adequate resources and staffing to assist children during activities
- suitable environments, such as soft play facilities, which are barrier free and minimise the effects of differences in children's abilities.

Examples of successful practice are identified in The Children's Society's evaluation of work on inclusion. The *Student Scheme: PACT Yorkshire* involves student volunteers from local universities linking with families and providing assistance such as helping a young person access local leisure facilities. *SPACE (Suffolk Partnership Achieving Choice and Experience)* enables disabled young people to socialise with non-disabled peers by supporting access to local community and leisure facilities. Key factors in such schemes are:

- involvement of disabled children and young people in service planning
- a focus on ordinary activities, such as going out with friends, enjoying family outings
- the presence of disabled children in community environments, which can itself changes social attitudes.

INFORMATION

Much research highlights the needs of parents for information about services, about their child's condition, and about how they can support their child's development. Children also speak of the need for information about their condition and treatment, about how to live with the condition and how to overcome disabling barriers. In many cases these needs have not been met.

Parents propose a three dimensional model of good practice:

- short directories of local services and support networks, which are regularly updated
- more in-depth and informative booklets covering local and national services
- support from locally based facilitators or key workers to guide parents through the information.

what helps

Information should be written clearly in an attractive format with an easy-to-use index and, as well as everyday advice, should include: multi-agency information covering both specialist and community wide services; planning for the future and an explanation of the roles of different professionals and agencies. Parents' involvement in the design of information helps to ensure that it is attractive and accessible.

A number of sources of information are required to meet children's information needs. Children identify parents themselves as an important information resource, and so ensuring that parents have access to information is crucial for children as well. Other sources include health professionals, teachers, friends, other disabled children, written information and the internet. Children identify a number of key requirements:

- professionals who will take time to listen to them – not just to their parents
- the importance of using appropriate communication aids to enable all children to communicate
- age appropriate information in accessible formats to suit the child's needs
- opportunities to contact other disabled children.

what helps

CONSULTING CHILDREN AND FAMILIES

Finally, finding out how families regard their needs is a valuable part of local service development in relation to all Quality Protects objectives. The 'Listening to Families' project in Hull and East Riding provides a good example of this. Families' views of local services, such as multi-agency support, transport, breaks from caring, and play and leisure, are regularly obtained through questionnaires, and information is collated for appropriate agencies. Positive examples of consultation with disabled children are demonstrated in The Children's Society's 'Ask Us' project, involving consultation with over 200 disabled children about their experiences and needs, Triangle's consultation with disabled children using a residential respite service, and Morris's work with disabled children in Newham. A number of resources are available to aid consultation: for example, Triangle's 'Two Way Street' training video on communication with disabled children, The Children's Society's 'I'll Go First' toolkit for planning and review, and Morris's work on involving children with communication impairments ('Don't Leave Us Out').

KEY RESEARCH

Beresford, B. (1995) *Expert Opinions: a national survey of parents caring for a severely disabled child*. Bristol: Policy Press.

Beresford, B., Sloper, P., Baldwin, S. and Newman, T. (1996) *What Works in Services for Families with a Disabled Child?* Barkingside: Barnardos.

Chamba, R., Ahmad, W., Hirst, M., Lawton, D. and Beresford, B. (1999) *On the Edge: minority ethnic families caring for a severely disabled child*. Bristol: Policy Press.

Dale, N. (1996) *Working with Families of Children with Special Needs: Partnership and Practice*. London: Routledge.

Gordon, D., Parker, R. and Loughran, F. with Heslop, P. (2000) *Disabled Children In Britain: A Re-analysis of the OPCS Disability Surveys*. London: The Stationery Office.

Morris, J. (1998) *Accessing Human Rights: Disabled children and the Children Act*. Barkingside: Barnardos.

Quine, L. (1993) *Working with parents: the management of sleep problems in children with learning disabilities*. In Kiernan, C. (ed) *Research to Practice? Implications of research on the challenging behaviour of people with learning disability*. Clevedon: BILD Publications.

Prewett, B. (2000) *Committed to Caring: The views of short break carers for children who are 'hard to place'*. York: York Publishing Services.

Sloper, P. (1999) *Models of service support for parents of disabled children: What do we know? What do we need to know?* *Child: Care, Health and Development*, 18: 259-282.

USEFUL RESOURCES

Beresford, B. and Oldman, C. (2000) *Making Homes Fit for Children: Working together to promote change in the lives of disabled children*. Bristol: Policy Press.

Council for Disabled Children (2000) *Second Analysis of the Quality Protects Management Action Plans: Services for disabled children and their families*. London: National Children's Bureau.

Family Fund Trust (2001) *After 16 - what's new?* York: The Family Fund Trust, PO Box 50, York YO1 9ZX. www.after16.org.uk

Jones, V. et al (2000) *Stronger Links: A guide to good practice for children's family-based short-term care services*. Bristol: Policy Press.

Mitchell, W. and Sloper, P. (2000) *User Friendly Information to Families with Disabled Children: A Guide to Good Practice*. York: York Publishing Services.

Mukherjee, S., Sloper, P., Beresford, B. and Lund, P. (2000) *A Resource Pack: developing a key worker service for families with a disabled child*. University of York: Social Policy Research Unit, (available from Information Office, Social Policy Research Unit).

NSPCC (2001) *Two Way Street: Training video and handbook about communicating with disabled children and young people*. NSPCC National Training Centre, 3 Gilmour Close, Beaumont Leys, Leicester LS4 1EZ.

Quine, L. (1997) *Solving Children's Sleep Problems: A Step by Step Guide for Parents*. Huntington: Becket Karlson.

The Children's Society (2001) *Ask Us CD-ROM*. The Children's Society, Publishing Department, Edward Rudolph House, Margery Street, London WC1X 0JL.

Triangle (1999) *Tomorrow I Go: What you told us about Dorset Road: Young people's views about a residential respite care service*. Triangle, Unit 310, 91 Western Road, Brighton BN1 2NW.

Researched and written by Tricia Sloper, Professor of Children's Healthcare, Social Policy Research Unit, University of York. Tricia is grateful to Margaret O'Brien, Project Co-ordinator, Listening to Families Service, Hull and East Riding Community NHS Trust and to Bryony Beresford, Research Fellow at SPRU for their comments on earlier drafts. This Briefing has been independently and anonymously reviewed by an academic and a practitioner with special interest in disabled children.

For a fully referenced version of this Briefing visit the **research in practice** website: www.rip.org.uk/mainmenu.html?publications/qpb

