

foundations

Supporting disabled children and their families

The Joseph Rowntree Foundation is funding a programme of research concerning disabled children and their families. This *Foundations* summarises the main findings from the first five years of the programme and identifies implications for policy and practice.

Human rights

- The human rights of disabled children (for example, their right to be consulted) are often not recognised in practice, particularly in the case of those who have high levels of support needs.

Co-ordinated support

- There is little evidence of inter-agency working and few examples of co-ordinated approaches to family support.
- Parents and carers of disabled children often have to deal with many different professionals and would appreciate a co-ordinated approach with one person acting as a 'keyworker'.

Flexible support

- Families with disabled children need and appreciate access to support which is flexible in terms of timing and type of help provided.

Information

- The availability of information, and the way in which it is given, is often crucial to the well-being of parents and carers.

Housing provision

- Having a disabled child can mean that a family has particular housing requirements. Whether these housing needs are met or not can make a major difference to the quality of children's and parents' lives. It can also influence what other support is required.

Short breaks

- Family-based short breaks ('shared care') have proved popular with both parents and children; waiting lists have increased over the last few years.
- Some families prefer residential-based short break services, particularly if their children have nursing care needs. Some disabled adolescents like spending time away from home in a communal setting with their peers.

Economic and social policy

- Central government's economic and social policy initiatives generally treat the families of disabled children as peripheral or invisible.
- Tackling the social and economic inequality faced by disabled children and their families requires resources; policy initiatives to date have not allowed for this.

Introduction

There are over 300,000 disabled children under the age of 16 in England and Wales. This is a prevalence rate of more than 30 per 1,000 children. Multiple impairment is common. A significant number of families have more than one disabled child: a health authority area covering 500,000 people is likely to have about 250 families where there are two or more children with significant impairments. Children with high levels of support needs, including those with nursing care needs, are increasing in number.

This *Foundations* draws on the findings of projects listed on the last page to set out some evidence about what circumstances create difficulties for disabled children and their families, some of the things that would help and some of the policy and practice implications of the research findings.

Disabling barriers

Poverty

Article 27 of the UN Convention on the Rights of the Child affirms "the right of every child to a standard of living adequate for the child's physical, mental, spiritual, moral and social well-being". There is considerable evidence that the standard of living of families with disabled children falls below that necessary to satisfy this right.

Parents of disabled children face three times the costs of parents of non-disabled children. It costs on average £125,000 to bring up a child with significant impairments (£7,355 per year) in comparison with an average of £37,394 (£2,100 per year) for a non-disabled child. The discrepancy is most marked for children under the age of 5.

The average additional weekly cost of bringing up a disabled child is £99.15. Even if families receive the maximum benefit entitlement for their disabled child, benefit levels would need to be increased by between £30 and £80 per week (depending on age and impairment) in order to meet minimum essential costs. Many families do not receive their full benefit entitlements, particularly black and ethnic minority families. Moreover, the benefits system does not take into account the cumulative costs of having more than one disabled child.

It's all the little things, the extra clothes, sheets, even food that you're buying every week and you don't realise what it costs or rather it would scare you if you sat and worked it out so you don't. ... And just when you think that you might be getting straight it all falls apart, she'll have a bad patch and maybe she'll need a new bed again or she's back in hospital and that costs and sometimes accidents just happen and she'll break something. The thing you have to realise is that everything like this is a disaster for us.

From **Paying to care: The cost of childhood disability**, Dobson and Middleton (1998, p. 13)

Diminished employment opportunities

Parents of disabled children are less likely to be able to meet these higher costs because of diminished employment opportunities. Combining paid work with looking after a disabled child is difficult because: employers fail to take parents' caring responsibilities into account; local support services are inadequate; schools and hospitals assume that parents don't work.

Diminished earning power means families are less able to pay for adaptations, equipment or child care, or get transport from one place to another. All this results in increasing vulnerability to social exclusion for the disabled child and their family.

Inadequate housing

About half of families with a disabled child are living in housing unsuitable for them and their child. Current policy does not adequately address the housing needs of disabled children. In particular, the means-test and the delays associated with the Disabled Facilities Grant system leave many families in very difficult circumstances.

Families with very disabled children, who are increasing in number, are particularly likely to have difficulties with their housing, as are families from black and minority ethnic communities. They also often experience a lack of information about their entitlements and a lack of understanding on the part of housing and other professionals.

Not enough resources – in terms of financial assistance and availability of technical advice – are made available to families of disabled children who face housing difficulties. This results in a poor quality of life for many

children and an undermining of their human rights to privacy, to play, and to involvement in family life.

Research on the housing circumstances of disabled children also illustrates their families' experiences of social exclusion and the importance of including these families in national and local initiatives to tackle social exclusion.

Mr and Mrs A lived in a four-bedroom house on an estate with a bad reputation on the edge of the city. They had six children, two of whom were severely disabled. One child had a serious heart problem and the other had cerebral palsy. Their 'people carrier', financed through the Motability scheme, was frequently vandalised but was too big to go into the local garage block. The family reported that their council had been very dismissive of them when they asked if their garage could be made larger. A specialised buggy had just been stolen from the shed. The garden was unusable – it had neither grass to play on nor a hard surface. The family had had graffiti daubed on their walls and one of the boys suffered sexual abuse from a neighbour. The house was in poor repair and very cramped.

From **Homes unfit for children**, Oldman and Beresford (1998, p. 15).

When health, social services, education and housing fail to work together

Children who have a range of health and support needs often receive many assessments and unco-ordinated services from different agencies. They are also particularly at risk of unequal access to health care and education. Access to both primary care and hospital services can vary from area to area. Schools have different policies concerning support to children who need medication or who use ventilators etc. Some children's human rights to good health care and to education are being contravened.

Exclusion of disabled children and young people from childcare, play and leisure services

Childcare services and play and leisure activities open to non-disabled children and young people frequently exclude disabled children and young people. The ordinary sources of having a 'break' are therefore closed to parents and they have to look to specialist provision which often means segregated provision – facilities and services which separate their children from their peers and the wider community.

We like to have fun, we like to go partying but this society won't make it possible for us.

Mumtaz Chanchwelia, in **The road to freedom**, Jawaan Aur Azaad (1994)

Responses to families' needs for support

The relationship between social services departments and families with disabled children is dominated by parents' requests for a break and the most common service provided is 'respite care'. Parents ask for services they know are available, and social workers focus on whether the child and family meet relevant eligibility criteria which tend to be related to level of impairment rather than to family and support needs.

There is a significant amount of unmet need amongst families with disabled children: even amongst those with very disabled children, most do not use existing respite care services. They may not know about such services, or they may feel existing services are inappropriate for their child. Children with very challenging behaviour and those with nursing care needs are often not catered for.

There are increasing numbers of children with continuing nursing care needs, whose parents may be in particular need of a break from looking after them but who may find that local short break services do not cater for their needs. Some of these families use children's hospices as a source of support: most children staying in hospices are not in fact terminally ill. Children Act regulations do not cover placements of disabled children in hospices.

Disabled children and young people are rarely consulted or involved in decisions about their care

It is rare for children to be consulted on their views, partly because many of them have communication impairments and social workers do not feel they have the necessary skills or experience to communicate with them.

The Children Act 1989 requires social services departments to "ascertain the wishes and feelings" of children who spend time away from their families in "respite care" services, and to carry out reviews and care plans. Nevertheless, disabled children whose parents use "respite care" services are often not recognised as "accommodated" and "looked after" in the terms of the Act; their "wishes and feelings" are seldom ascertained;

reviews and care plans are often not done. Many children are not visited at their shared care placement and most families using this type of service do not have their own social worker.

Black and minority ethnic families

Black and minority ethnic families are more likely to have unmet needs and less likely to have support from their extended family than white families. The way in which support services are provided can result in institutional discrimination against black, Asian and other minority communities: a failure to recognise cultural, linguistic or religious aspects of needs means that services are inappropriate.

Black and minority ethnic disabled children with significant impairments are less likely to receive Disability Living Allowance and less likely to be awarded the higher mobility or care component than white disabled children. The parents of black and minority ethnic disabled children are less likely to receive Invalid Care Allowance.

What helps?

Listening to disabled children and young people

Anyone, whatever their level of communication impairment, can express their views on what is happening to them. Disabled children's human rights are more likely to be protected and promoted when all those in contact with them address the barriers to listening to what children have to say (however they communicate this).

Providing information and advice

Parents find that getting a diagnosis for their child is important: having a 'label' gives access to, and credibility with, health, social services and education professionals. Parents often find that the most helpful sources of information and advice come from others with similar experiences. Getting information about what they and their children are entitled to, as early as possible, is very important.

Positive attitudes and a co-ordinated approach

Parents appreciate professionals who value their children and recognise the expertise they have as parents. Most parents want one point of contact for access to services and a co-ordinated approach is

especially important for families with more than one disabled child, and for those whose children have continuing health care needs. Parents are more concerned about personal qualities and skills than about the professional background of keyworkers.

Flexible support services which are tailored to individual children's and families' needs

Parents want support which is flexible enough to respond to their particular families' needs, and which is both available in an emergency and can also be planned in advance. Children and young people want support which enables them to do the kinds of things their peers do: this can vary from going swimming with their siblings to spending time away from home with their friends. The most popular services are often those developed by parents themselves, and by local disability organisations.

One of the most popular services amongst parents in the county was a scheme which allocated 80 hours of support workers' time throughout the year for parents to use when and how they chose. The hours can be used for help in the home, or going out, and can also be used for looking after non-disabled children within the family as well as the disabled child(ren).

From **Still Missing? Vol. 2 Disabled Children and the Children Act**, Morris (1998, p. 20).

Having more money

Families of disabled children need to get all the social security benefits they are entitled to, as early as possible. Good quality welfare rights advice is vital, particularly for people from minority ethnic groups who are less likely to get their entitlements. Enabling parents to have paid employment is also important and research has identified the factors which make this more likely. These include: appropriate childcare; flexible working hours and 'family friendly' work cultures; education and health professionals taking account of parents' employment when making appointments.

Measuring the actions of all statutory and voluntary agencies against the human rights of disabled children

Organisational and professional practice sometimes lose sight of children's human rights. Keeping these rights in mind can act as a valuable check. Disabled children have the same rights to freedom of expression, to play, leisure and cultural activities, to privacy, a family life, safety, health care and education as other children.

Policy and practice implications

On the basis of research undertaken, it is clear that central and local government need to give active consideration to the following issues:

Poverty and social exclusion

- Ensure that national and local policies and initiatives aimed at tackling social exclusion recognise the needs of families with disabled children
- Ensure that families with disabled children have ready and continuing access to good welfare rights advice and advocacy
- Tackle the direct and institutional racism experienced by black and minority ethnic families in terms of their access to services and to their benefits entitlements

Employment

- Review income maintenance policies and policies aimed at increasing employment opportunities in the light of the experiences of parents of disabled children
- Encourage employers to develop policies and practices which recognise the caring role that some employees have
- Develop local strategies to support parents who work: ensure that health, education and family services take into account parents' working hours

Facilitating appropriate support

- Review the Children Act to ensure that disabled children's needs and those of their families are better reflected in current regulation and guidance
- Develop local keyworker services so that families have one point of contact to a co-ordinated system of support
- Involve parents and young disabled people in the development of services. Respond positively to initiatives by local self-help and disability groups
- Extend the Independent Living Fund and direct payments to disabled children, to enable families to purchase support individually tailored to their children's needs

- Ensure that local resources are used in a way which enables a flexible response to each family's needs and, in particular, that services respond in a culturally appropriate way
- Recognise that flexible support services are not just the remit of social services: link in with education, leisure and youth services

Housing

- Review current legislation and local policies on housing development, allocations and adaptations with the aim of addressing the housing needs of disabled children and their families more effectively

Short break services

- Short break services need to be properly resourced. Link carers should be paid and trained for the work they do. This is particularly important in view of the increasing number of children with complex needs and/or 'challenging behaviour'

Setting standards and monitoring performance

- The standards and outcome measures increasingly used to assess service performance need to be grounded in research evidence on the experiences and wishes of disabled children and their families
- Measures used must also be sufficiently flexible to acknowledge minority experiences and preferences: for example, while most disabled children may prefer family-based short-term care, some, particularly adolescents, may prefer communal forms of short breaks. This gives them the opportunity to be with their peers and do the kinds of things all teenagers like to do

How to get further information

This *Foundations* is based on the following reports of research projects supported by the Joseph Rowntree Foundation. The details of any *Findings* (four-page summaries) relating to the research projects are given in brackets.

Beresford, B (1995) **Expert opinions: A national survey of parents caring for a severely disabled child**, The Policy Press/*Community Care* (ISBN 1 86134 004 4, £10.50), (Social Care Research *Findings* 76)

*Cavet, J (1998) **"People don't understand": Children, young people and their families living with a hidden disability**, National Children's Bureau (ISBN 1 900990 24 5, £9.95), (*Findings* 228)

*Chamba, R et al (1999) **On the edge: Minority ethnic families caring for a severely disabled child**, The Policy Press (ISBN 1 86134 134 2, £12.95), (*Findings* 539)

*Dobson, B and Middleton, S (1998) **Paying to care: The cost of childhood disability**, YPS (ISBN 1 899987 75 4, £11.95), (*Findings* 748)

Greene, M (1998) **Over to us: A report of an advocacy project working with young disabled people living in residential institutions**, Greater Manchester Coalition of Disabled People

Jawaan Aur Azaad (1994) **The road to freedom**, Race Equality Unit

*Kagan, C, Lewis, S, and Heaton, P (1998) **Caring to work: Accounts of working parents of disabled children**, Family Policy Studies Centre (ISBN 1 901455 09 2, £9.95), (*Findings* 538)

*Knight, A (1998) **Valued or forgotten? Disabled children and independent visitors**, National Children's Bureau (ISBN 1 900990 23 7, £9.95), (*Findings* 138)

*Lawton, D (1998) **Complex numbers: Families with more than one disabled child**, Social Policy Research Unit (ISBN 1 871713 92 7, £5), (*Findings* 218)

Morris, J (1998) **Still Missing? Vol. 1: The experiences of disabled children and young people living away from their families** (0 9525749 4 2, £7); **Vol. 2: Disabled children and the Children Act**, The Who Cares? Trust (ISBN 0 95225749 5 0, £8), (*Findings* 378)

*Morris, J (1998) **Don't leave us out: Involving disabled children and young people with communication impairments**, YPS (ISBN 1 899987 80 0, £6.50)

*Mukherjee, S, Beresford, B, and Sloper, P (1999) **Unlocking key working: An analysis and evaluation of key worker services for families with disabled children**, The Policy Press/*Community Care* (ISBN 1 86134 208 X, £13.95), (*Findings* D39)

Noyes, J (1999) **Voices and choices: Young people who use assisted ventilation – their health and social care, and education**, The Stationery Office (ISBN 0 11 322279 3, £12.50), (*Findings* 969)

*Oldman, C and Beresford, B (1998) **Homes unfit for children: Housing, disabled children and their families**, The Policy Press/*Community Care* (ISBN 1 86134 116 4, £13.95), (*Findings* 018)

*Prewett, B (1999) **Short-term break, long-term benefit: Family-based short-term care for disabled children and adults**, University of Sheffield/*Community Care* (ISBN 0 907484 37 9, £11.95), (*Findings* 979)

*Robinson, C and Jackson, P (1999) **Children's hospices: A lifeline for families?**, National Children's Bureau (ISBN 1 900990 26 1, £11.95), (*Findings* 669)

*Sloper, P, Mukherjee, S, Beresford, B, Lightfoot, J, and Norris, P (1999) **Real change not rhetoric: putting research into practice in multi-agency services**, The Policy Press (ISBN 1 86134 208 X, £13.95)

*Tozer, R (1999) **At the double: Supporting families with two or more severely disabled children**, National Children's Bureau (ISBN 1 900990 53 9, £10.95), (*Findings* N99)

*Ward, L (1997) **Seen and heard: Involving disabled children and young people in research and development projects**, YPS (ISBN 1 899987 48 7, £6.50)

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