

Still missing out?

Ending poverty and social
exclusion: messages to
government from families
with disabled children

Neera Sharma




Barnardo's
GIVING CHILDREN BACK THEIR FUTURE

‘ There have been no reforms that benefit the parent or the child in the long run, because what we’re given, is just as soon taken away ’

‘ I wish that the government would provide us all with one idiot-proof booklet, the easy guide to what you’re entitled to ’

‘ They do not provide for ethnic minorities. They do not know very much about my culture ’

‘ Recognise disability more and know it’s not the same as everything else ’



‘ As my daughter gets older and we seem to cope more, we seem to get less ’

‘ Listen to what people want, because there are lots of different disabilities ’

‘ Everything you want, you have to fight and beg for it ’

‘ I’m disillusioned with the way that we’re treated – everything is a battle and a struggle ’

‘ We need emergency services set up in each care centre that are adapted to the people who use them ’

‘ They should assess the child and not the parents ’

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Ending poverty and social exclusion: messages to government from families with disabled children

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What needs to be done? Summary recommendations

- All mainstream programmes and targeted initiatives should have a specific focus on disabled children and young people, with clear targets and indicators which are monitored as part of *Opportunities For All*.
- Government should establish a minimum income standard which includes targeted support to meet the extra, essential costs of caring for a disabled child.
- The benefits system should be reformed so that it is understandable and accessible, and encourages take-up.
- A government-funded national awareness campaign on disability benefits should be developed, to increase take-up through the provision of information which is clear and accessible in all formats and in different languages.
- Housing policy should be reviewed, so that all disabled children can grow up safe and warm in homes which are accessible and suitable for their needs.
- There needs to be economic analysis of the investment required to ensure that government programmes aimed at lifting children out of poverty also reach disabled children.

These recommendations to government are included in more detail in Chapter 4 below (page 32).

Barnardo's vision is that the lives of all children and young people should be free from poverty, abuse and discrimination.

Barnardo's purpose is to help the most vulnerable children and young people transform their lives and fulfil their potential.

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First published in 2002 by Barnardo's

Tanners Lane
Barkingside
Ilford
Essex IG6 1QG

Charity registration number 216250

A catalogue record for this book is available from the British Library

ISBN 0 902046 87 X

Further copies of this report are available from:

Barnardo's Childcare Publications, Barnardo's Trading Estate, Paycocke Road, Basildon, Essex SS14 3DR. Tel: 01268 520224. Fax: 01268 284804

Price: £5.00 each plus postage and packing

Acknowledgements

Barnardo's wishes to thank all the families from across the UK whose contributions were so vital to the production of this report.

This report was co-authored by Nick Jenkins, Julie Healy, Sam Jagusz, Nicola Smith, Jo Stephens and Edwina Strachan.

Many thanks to: Andrea de Berker, Rosanna Duncan, Asif Hussain, Liz Garrett, Lorraine Hart, Jan Morrison and Tony Newman from Barnardo's; and to the readers' group of Lorna Reith, Disability Alliance, Mark Priestley, Leeds University, Christine Lenehan, National Council for Disabled Children, Dr Byrony Beresford, Social Policy Research Unit, University of York, Michelle Perera, SCOPE.

Foreword

Still missing out? makes disturbing reading. Based on the experience of families across the UK, it illustrates the extent to which poverty continues to blight the lives of so many disabled children, young people and their families. The voices of these families also show how there are still many barriers within society that prevent disabled children from leading ordinary lives in their communities.

The government has pledged to end child poverty within a generation. However, there is little evidence from the case studies in this report that current initiatives are improving the lives of disabled children significantly. If the government is to achieve its mission to end child poverty, then more deliberate steps need to be taken, including increased resources for disabled children and their families.

Most poor families do not have a disabled child; but tragically, many families with a disabled child do live in poverty. That is why Barnardo's anti-poverty campaign has chosen to highlight the hidden struggle of these families. It is also why we challenge the government to take urgent and sustained action to ensure the inclusion of all our children within our society.

Roger Singleton CBE
Chief Executive
Barnardo's

Still missing out? The case studies

A companion volume to this report features the full case studies of the 17 families across the UK, which are extracted in the following pages.

Still missing out? The case studies (ISBN 0 902046 88 8, 48 pages) is also available from Barnardo's Trading (tel 01268 520224), price £5.

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Executive summary

INTRODUCTION

The government has pledged to end child poverty within a generation and has committed itself to tackling the causes of poverty and social exclusion by improving public services, including better childcare provision and by encouraging parents back to work.

However, despite changes to disability benefits and other services, many of Britain's 360,000 disabled children and young people and their families still live in poverty and are socially excluded from their communities.



Barnardo's has carried out detailed interviews with 17 families including disabled children to find out more about the issues facing them and what impact, if any, government policies have had on their lives.

THE PROBLEM

At present, a disproportionate number of families with disabled children are living in poverty, for the following reasons.

- Work – parents with disabled children are often unable to work because they cannot secure childcare suitable for their child's needs.
- Extra costs – on average it costs three times as much to raise a child with severe impairment than a non-disabled child. At present, benefits do not meet these needs.
- Benefits – many parents are confused about entitlements and find procedures overly complicated. As a result, uptake is limited and the poorest families are not accessing the benefits they need.
- Lone parents – there is a higher rate of lone parents among families with a disabled child, which places greater pressure upon the caring parent.
- Minority ethnic families are more likely to have low incomes and unsuitable housing. In many cases they are less able to access services.

Families with disabled children also face many other difficulties.

- Unsuitable housing is a key issue for all the families interviewed. Some cannot use wheelchairs indoors because of narrow doorways; others have to carry their children upstairs. Families have to wait years for adaptations.
- Transport – many families have unmet needs, as most public transport is inaccessible and cabs are expensive.
- Access to services – families are uncertain about the services available, many of which can only be obtained following persistent pressure.
- Education – while most parents appreciate school services, many families express concern about secondary education and the future.
- Transition to adulthood – families express particular concern about the future, as disabled young people face unemployment levels at double national rates and will not be as independent as other young people when they reach adulthood.
- Accessing community life – there are barriers preventing disabled children from accessing play schemes and other community facilities.

GOVERNMENT INITIATIVES AND THEIR IMPACT

The government has stated that the main route out of poverty for all children – including disabled children – is by increasing families' incomes. Preferably this should be achieved through paid employment.

New policies to benefit families with a disabled child include:

- developing a new childcare strategy to get parents back into paid employment through the new, more generous Childcare Credit and by creating more childcare places; a number of area-based initiatives have been developed to support the strategy
- developing area-based policies within the national childcare strategy, to include early excellence centres and neighbourhood nurseries, as well as the Sure Start programme
- increasing the child premium of Income Support
- extending the higher-rate mobility component of the Disability Living Allowance to 3- and 4-year-old disabled children
- bringing all available tax credits and Income Support premiums for children under the umbrella of the Child Tax Credit by 2003.

CONCLUSION

While there is no doubt that families have benefited from new policies, many families with a disabled child are still entrenched in poverty, isolated and excluded from their communities.

To address these issues, Barnardo's recommends:

- a government-funded national awareness campaign on disability benefits aimed at increasing take-up through the provision of information which is clear, accessible, in all formats and in different languages
- that all mainstream programmes and targeted initiatives have a specific focus on disabled children and young people, with clear targets
- that the government establishes a minimum income standard, which includes targeted support to help with the extra, essential costs of raising a disabled child.

Introduction



'Our historic aim will be for ours to be the first generation to end child poverty, and it will take a generation. It is a 20-year mission, but I believe it can be done.' (Speech by Prime Minister, Tony Blair, 18 March 1999)

The UK has one of the highest rates of child poverty in the world. Approximately 3.9 million children – one in three – live in poverty. In the mid-1990s, Britain had the third highest relative child poverty rate of 25 countries – only better than Russia and the United States.(1)

The Blair government has pledged to end child poverty within a generation and has committed itself to tackling the causes of poverty and social exclusion by improving public services, through

better childcare provision and by encouraging parents back to work. There is a UK-wide programme with England and the devolved administrations in Wales, Scotland and Northern Ireland, working to meet this objective.(2)

As a result, around 300,000 children have been lifted out of poverty (after housing costs) since 1998/99, although the government had estimated that its reforms would have lifted 1.2 million children out of poverty by 2002.(3)

However, these reforms have done very little to improve the lives of disabled children and their families. There are approximately 360,000 disabled children in the UK (roughly 3 per cent of the child population). Despite changes to disability benefits and other services, families with a disabled child are still much more likely to live in poverty.

During 2000/01, two-thirds of households with one or more disabled children (66 per cent) were in the bottom two-fifths of income distribution. And 72 per cent of households with a disabled child and a disabled adult fell into the same category. In fact, the rates of poverty are probably even higher, as these government statistics do not take into account any additional costs that may be incurred due to illness or disability when estimating 'equivalised income'.(4)

Disabled children, young people and their families are poorer; they are often forced to live in unsuitable housing; they cannot get out and about; and they cannot access childcare that would enable them to go to work and break out of poverty. They cannot afford or access the activities and holidays that millions of other families take for granted.

As one mother said *'We are a disabled family. We don't just have a disabled child – it impacts on every single aspect of our lives.'*

While the government has introduced many initiatives encouraging parents back to work to help alleviate child poverty, the needs of families with a disabled child have been largely ignored. In fact, because the costs of caring for a disabled child can be much higher, many parents believe that it is more cost effective for the government to keep them at home as unpaid carers. *'We are not allowed to be part of the community. It's like we are from planet disabled and everyone else is from planet earth,'* said a lone mother with two children, one of whom is autistic.

'We are a disabled family. We don't just have a disabled child'

Being a parent brings many rewards and difficulties, but living in a family with a disabled child does create added challenges, many of which could be avoided if the government provided sufficient benefits, better access to information, care and support services.

This report is based upon detailed interviews with 17 families who have one or more disabled children. All the families receive support through Barnardo's projects. Through their experiences, the report shows how families with disabled children face a daily struggle with everything from accessing benefits to coping with unsuitable housing. These are commonplace concerns among families with disabled children – concerns that make paying bills, getting around and planning for the future a huge worry and stress.

'It's like we are from planet disabled and everyone else is from planet earth'

One parent said: *'People don't realise the mental stress of 24 hours a day for the rest of your life.'* Another added: *'At the end of the day, these ones like social workers or ministers, they go out and do a day's work and then go home and forget about it. But we can't, we can never forget about it.'*

In fact, the pressures can be so intolerable that family breakdown is not uncommon. This, in turn, can lead to greater poverty and greater pressures on the caring parent – problems that could have been avoided if help had initially been available and sufficient.

If the government is serious in its pledge to eradicate child poverty within a generation, then much more needs to be done. But at present, as the families interviewed for this report explain, families with a disabled child are still missing out.

I Disabled children and poverty: the facts



DISABLED CHILDREN AND POVERTY

- Of all families in the UK who care for disabled children, 55 per cent either are or have been living in poverty.(5)
- Disabled children are much more likely to be born into poorer families: children are three times more likely to have a disability if their father is an unskilled manual worker as opposed to a professional.(5)

WORK AND PARENTS OF DISABLED CHILDREN

- Parents of disabled children are much less likely to be in full-time work than parents of non-disabled children.(5)
- If in work, parents of disabled children are more likely to be in poorly paid and low-quality employment and are more likely to be in receipt of some form of state benefit.(6)
- Parents of disabled children often find it difficult to work overtime or to take time off to care for their child due to inflexible employment practices and a 'long hours' work culture.(7)
- Mothers of disabled children are far less likely to be in work: they are often viewed by professionals as 'a reserve army of nurses', which further obstructs them from finding employment.(8)
- The benefits system can make the transition from welfare to work difficult, as parents can lose entitlement if they earn more than their Invalid Care Allowance (ICA) limit.(9)

EXTRA COSTS

- It costs, on average, three times as much to raise a child with a severe impairment as a non-disabled child.(10) The main areas of additional expenditure are transport, toiletries, bedding, food, replacing damaged household items, special toys and equipment.
- The majority of the parents feel they do not have enough money to provide their child with basic necessities, despite the fact that they spend around twice as much as parents of non-disabled children.(10)
- Parents are often forced to go into debt to meet their disabled child's basic needs, while other non-disabled siblings simply go without.(10)

ADEQUACY OF BENEFITS

- Despite recent increases in benefits, research shows that the maximum benefit entitlements still fail to meet the needs of parents with a disabled child. The maximum benefit level would need to be increased by £27.77 per week to meet the required minimum standard.(10)

TAKE-UP OF BENEFITS

- Many parents are uncertain or misinformed about what benefits they are entitled to. When they are well-informed, they often find it very difficult to make successful claims.(10)
- Only between 40 and 60 per cent of families claim Disability Living Allowance (DLA). Socially disadvantaged families are least likely to apply.
- In 2000, only around half of all disabled children and young people in Britain claimed DLA.(11)
- Poorest families and those from minority ethnic groups are least likely to claim DLA.(12)
- Language and cultural barriers prevent many parents from minority ethnic groups from claiming support for their disabled children.(12)

LONE PARENTS

There is a higher incidence of lone parenthood in families with disabled children, which is likely to be the result of increased stress and lack of support.

- Lone parents with disabled children are far less likely to be in full-time paid employment. Only one fifth of mothers with a disabled child work, compared with three in five mothers overall.(13)
- Services for disabled children are often based on the assumption that at least one parent does not work. This makes it more difficult for single parents to find secure and long-term paid employment.(14)
- Lone parents with a disabled child are more likely to have higher costs: they spend twice as much as two-parent families on school activities and one-and-half times as much on out-of-school activities.(15)

Lone parents are less likely to own a car and are more likely to live in low-quality housing.

MINORITY ETHNIC FAMILIES

Minority ethnic families with disabled children are likely to have significantly lower incomes than white families, although this varies between different minority ethnic groups.

- Minority ethnic families with a disabled child are more likely to live in poor-quality housing.
- They are more likely to have difficulties accessing the support they need due to institutional racism and stereotypes concerning minority ethnic family support networks.(16)

PARENTS CARING FOR MORE THAN ONE DISABLED CHILD

Approximately 10 per cent of families with disabled children care for more than one disabled child and the intensive demands this brings are rarely recognised.(17)

- Families with more than one disabled child are much less likely to be in paid employment, compared with parents caring for one or no disabled children.(18)
- Families can be denied the support they need, for example, in being allocated hospital appointments, because service providers do not appreciate the additional demands of two or more disabled children.(18)

2 Disabled children and poverty: the families

Social exclusion and poverty are terms that are often used interchangeably. Yet social exclusion is more than not having enough money to live on. It is what can happen to individuals and communities when they face a combination of linked problems such as unemployment, poor skills, low incomes, poor housing, high crime rates, bad health and family breakdown.⁽¹⁹⁾

Social exclusion is not an issue just for disabled children, but for the entire family, as the case studies in this report show.

Families are denied the opportunity to participate in everyday activities. Disabled children and their siblings are trapped in poverty and, as a result, are unable to develop themselves and to participate in the wider community. Parents face the same difficulties. In addition, the added responsibilities of bringing in money when unemployed, owing more money than you have coming in, and caring for a disabled child 24 hours a day, all cause great stress and loneliness.

Most parents hardly ever go out together, because of a lack of appropriate childcare. Even when childcare can be arranged, parents cannot afford to pay for both childcare and a night out. It can be similarly difficult to afford childcare for adult education classes. Such social isolation can result in parents, disabled children and their siblings losing confidence and a sense of their own worth. A few parents and young people speak of depression. Minority ethnic parents feel isolated from their own communities and cannot get out to social functions or attend places of worship, which means a potentially valuable support network is lost. Unsurprisingly, family breakdown and single parenthood is commonplace.

Disabled children and their families undoubtedly experience a totally unacceptable level of social exclusion and isolation. *'That's the poverty,'* said one mother.



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This chapter now looks in more detail at the perceptions of the families who participated in this study. The main factors that prevent them from living ordinary lives within their communities are as follows:

1. extra costs
2. income and employment
3. housing
4. transport
5. access to services
6. education
7. transition to adulthood
8. sibling rivalry
9. cultural issues
10. access to community life.

1. EXTRA COSTS

CASE STUDY Rachel and Paul live in London and have three children, two of whom are disabled. Courtney has severe disabilities and needs constant care and support. Her brother Jamie is autistic. They also have a 3-year-old sister, Tracey. The parents are receiving all entitlements and are happy with the amounts that they receive. Their main cost for Courtney is clothing because of her incontinence. Daily washing and buying new clothes regularly are expensive. Clothing is also costly because Jamie has a tendency to make holes in his clothes and shoes and rip them. He also causes damage to furniture and equipment.

Having a disabled child costs more money and can put severe pressure on the already over-stretched income of families. Many necessities, like 24-hour heating, would be considered a luxury for most households. But for families with a sick child, whose body temperature needs to be maintained, these requirements are essential. Energy bills are increased further when disabled children cannot use the toilet or feed themselves easily, as there is more washing and drying to be done.

Many disabled children take longer to become toilet-trained, if at all, and disposable nappies for older children and young people cost much more than those worn by babies. In addition, some disabled children – especially those with physical impairments – require new clothes more frequently because they tear or damage them. While others, with particular physical difficulties, require special-fitting clothes, like extra wide shoes that cost more.

Nearly all the families interviewed need to keep frequent hospital and other appointments. All the families consider a car a necessity, but sadly not all can afford one and have to rely on mini-cabs and taxis to get around, which is very costly. Public transport is out of the question for some, where wheelchair access

is not available on buses and trains. One family with two disabled children pointed out that appointments for hospital, school, etc have to be made individually – doubling the cost.

Around the home, there are other expenses too. Special adaptations to make homes safe – like stairgates, fireguards and locks on windows and doors – all cost money. Some families also spoke of the need to replace furniture and household equipment, if their child damages or breaks them.

A few of the families interviewed also require a special diet for their disabled child that is more expensive. Buying equipment and toys which are durable and adapted to the needs of a disabled child is also more expensive.

In addition, the extra costs of caring for a disabled child can impact on other children in the family. Two of the families interviewed for this study are in debt because they have bought clothing from catalogues for their other children.

2. INCOME AND EMPLOYMENT

CASE STUDY Chris's daughter Joanne has complex learning difficulties, epilepsy and cerebral palsy and needs 24-hour personal care. Chris used to work as an accountant but left her well-paid job shortly after Joanne contracted meningitis at 13 months to care for her full-time. She gets £26.50 Income Support and has to budget very carefully. Because of her accountancy background, Chris is able to work out most of the information relating to benefits, but she says, *'It's like piecing together a jigsaw. The benefits and disability people do not and never have worked in conjunction with each other. If they did, it would make our lives a lot easier.'*

Chris also works as an escort on Joanne's school bus. This was suggested to her by the local authority after she complained that nobody on the bus was able to administer rectal diazepam, which Joanne needs if she has a severe epileptic seizure. Chris earns £30 a week for this, £10 of which is deducted because she exceeds her earning threshold for Invalid Care Allowance.

Despite the fact that families with a disabled child have increased living costs, their incomes are lower. This is because they cannot go out to work and have to live on benefits. All the families interviewed who are not in employment express a strong desire to work and want more help to enable them to go back to employment.

The following factors prevent parents from working and being able to improve their standard of living.

- **24-hour care** Caring for a disabled child is a full-time job, 24 hours a day, seven days a week. Many parents have to get up in the night to turn their

'I don't want to be seen as a charity case. I prefer to earn my own living and claim nothing'

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child; or change the bedding; or respond to cries: all of which can lead to exhaustion. In this situation, work is not a feasible option. Such intensive caring places a great deal of physical and emotional stress on the parents.

“ I expected them to say “we’ll help you to work” but instead they said, “we’ll help you not to work” ”

- **Community-based play and leisure facilities** While many families use after-school facilities to support employment, this option is rarely available for families with a disabled child. Most services for disabled children focus on providing care for short breaks, rather than after-school care supporting parents’ employment.
- **Day care** Specialist day care for disabled children is difficult to find and many services for children under 8 fail to provide for disabled children at all. Often it is simple barriers, like the requirement that children are toilet-trained before they can attend nursery, that prevent parents from securing a nursery place. Some childminders and day-nursery staff do have the necessary skills but they often charge much higher fees and the Childcare Tax Credit does not take this into account.⁽²⁰⁾ Most childminders though, are not trained or even willing to take on children with special needs. One mother spoke of trying to arrange separate childcare for her children, as her disabled son requires one-to-one support. This would have meant that she had to visit at least two childminders each day, before and after work. Specialist childcare also costs more. Because of this, many of the parents do not believe that organising and paying for childcare for both disabled children and their non-disabled siblings is a feasible option. This is especially so if the childcare is to be good-quality, locally accessible and affordable.
- **Inflexible working hours** Because parents have to keep numerous hospital and other appointments, many feel that it would be difficult to make a commitment to an employer, as they have to keep taking time off work. Additionally, many disabled children are more vulnerable to illness.
- **Work has to pay** Because childcare costs are so expensive, many parents do not believe it is worth their while financially to go out to work
- **Training needs** Some of the parents interviewed feel that they would need some training before they could return to work and that childcare would need to be available while they trained. One parent had accessed funding to do a part-time computing course but lack of suitable childcare meant that she could not start the course.
- **Parents’ own health** Full-time caring can result in parents not having the time or childcare to look after their own health needs. One mother needed an operation but could not go into hospital because there was no one who could care for her child.

CASE STUDY Linda, a district nurse, takes home around £150 per week after taxes: specialist day care for her daughter Jennifer is £40 a day. Working Families Tax Credit and Childcare Tax Credit do not meet the costs of specialist childcare. During the holidays and days when Jennifer is ill, Linda barely breaks even. She is worried too because she may soon be required to work shifts and cannot afford the extra childcare costs.

Linda feels that she has had no help from the government in returning to work and is frustrated by expectations that she does not work. *'It is an automatic thing, people assume that you are on benefits because you've got a disabled child'*. The expectation that Linda does not work has made it very difficult to take her daughter to hospital appointments that fall within her working hours. In one instance, this meant waiting six months for a re-scheduled appointment.

All the parents who work said that they did not do so for financial reasons, as they felt they would probably be better off not working. *'I can see why people say: "what is the point in going to work?";' said one parent. 'You stress yourself out and it costs me to work but I have to, to keep myself occupied.'*

3. HOUSING

CASE STUDY Of Ali and Tasneem's three children, both Nasser (7) and Zainab (3) have learning and behavioural difficulties and are registered disabled. The family home is short on space for the children's toys and equipment, and Ali and Tasneem are constantly supervising Nasser and Zainab because they cannot carry out all the necessary adaptations to make the house safe. The back garden is not grassed, so Nasser and Zainab get hurt when they fall onto the stones and pebbles. Tasneem and Ali are saving up so that they can get a front gate as they live in the constant fear of Nasser running out into the road *'There's got to be constant supervision... He just drops the scooter and runs. He won't know if there's a car or anything... I don't know when or if social work are going to do some adaptations.'* Tasneem also needs locks on the kitchen and the bathroom, and high cupboard space. The family has never been offered any help with the financial costs of adapting their house.

Housing is a key issue for 14 of the 17 families in this report. In another recent study, three out of five families stated that their home was unsuitable for their disabled child's needs. A disproportionate number of disabled children and their families live in poor-quality or unsuitable housing and minority ethnic families are even more likely to live in unsuitable accommodation. The most common complaints are lack of space and general safety issues.(21)

Only one quarter of families with a disabled child are able to afford to make adaptations to their home. Most of these families are home-owners.(22)

2

However, families caring for disabled children are more likely to live in council housing and, because of their specific needs, only a very limited choice of properties are suitable. Getting the local authority to put in adaptations or rehouse them is an uphill struggle. Many families have to pay at least some of the costs themselves, as the Disabled Facilities Grant is means-tested.(23)

As a result, most families caring for severely disabled children in Britain have unmet housing needs. Waiting for adaptations causes families a great deal of anxiety and stress, as they are forced to bring up their child in an unsafe environment and supervise them constantly.(24)

Of the families interviewed, many spend a lot of time chasing local authorities or housing associations about their adaptations and they are not always sure which department or official to contact. One mother believes that adaptations to her house are taking a long time because she does not have a social worker advocating on her behalf.

Once grants are obtained though, parents cannot rest. Further work is required as new adaptations have to be made over the years to meet the needs of a growing child. Getting these replacements is also a battle.

Living on a low income means that families who are buying their own home cannot afford adaptations and are often unsure whether they were eligible for help. One family lost any eligibility for a grant when they moved house.

Many of the families stress very strongly that a bungalow would provide the ideal accommodation, but the practice of most local authorities is to allocate these to older people. Furthermore, the majority of bungalows are too small for families with disabled children, so they would need to be extended or built to specification.

Living in unsuitable accommodation causes major problems for families. Parents speak of having to carry wheelchair-using children around the house because doors are not wide enough, which can lead to health problems, especially back problems. In one family, the father has to carry his 18-year-old daughter to and from the school bus because the entrance to the house is not big enough for her wheelchair.

Lack of space is also an important issue for many of the families. Some disabled children require a lot of specialist equipment, but housing policies do not make allowance for this, so many of the families live in cramped conditions.

Furthermore, families are allocated council housing according to the ages and numbers of family members and do not take other criteria, like disability, into consideration. So disabled children can end up having to share a bedroom with their non-disabled siblings, which can cause great disruption if they wake up

frequently in the night needing attention. One parent has to move out of her home when the short-break carer or her ex-partner come to look after her son due to the lack of space.

Lack of communication between different council departments can have disastrous effects. One family had to turn down the offer of a council bungalow after a long wait, because they could not get the local authority to install a ramp.

Families who have a child with behavioural difficulties constantly have to replace essential household items but one-off grants and other payments do not take this into account. This causes severe financial hardship for the families interviewed.

4. TRANSPORT

CASE STUDY – Geordie (13) is registered disabled with a non-specific condition. Some doctors believe that Geordie may be autistic. He also has learning difficulties, little speech and epilepsy. Geordie’s mum, Anna has had a car through the Motability scheme for three years. When her brother died, he left the family some money and Anna put that toward buying the car. She took out a loan to pay the balance and is paying it off with the allowance she gets for Geordie. Before they had a car, they travelled around by bus. ‘It was terrible,’ recalls Rose. ‘Geordie would sometimes wet himself or would be very noisy.’ Rose was put off going anywhere unless she had to.

Disabled children need to get around. As well as going to school and joining in activities with their friends, disabled children have to make regular visits to the hospital to see doctors, physiotherapists and other support services, especially in the early stages of diagnosis. Unsurprisingly, all the families interviewed in research published by the Audit Commission believe that a private car is essential.(25) One parent travels 20 miles each day to get her son to a playgroup. One survey has suggested that only half of parents with a disabled child have access to private transport, with lone parents being the least likely to own or have access to their own car.(26)

When families with a disabled child are forced to rely on public transport or taxis, the results can be highly unsatisfactory. Public transport services for disabled people are often fragmented and complex, and many buses and trains are too old to comply with the 1995 Disability Discrimination Act. Furthermore, many disabled children experience hostility or embarrassment from other travellers and transport staff.(27)

Taxis are not suitable for many families as they can be very expensive and the cost is not always reimbursed. Also there are not many wheelchair-accessible taxis in use and some families have reported negative experiences with their drivers.(28)

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Three of the families interviewed have a car through the Motability scheme; one is leasing a car; four use public transport or taxis; and the others have private cars. Having a car through the Motability scheme can be a lifeline but is not always without problems. One parent spent four years trying to get a suitably adapted vehicle from Motability: this included the frustration of getting consent letters from doctors, MPs and local councillors. When the car finally arrived it was too small to take the wheelchair and other specialist equipment.

Families who have a private car often cannot afford to have it adapted to make it safe and prevent their child from opening the doors or windows while the car is moving. Also there is no financial help available for expensive car seats or booster seats.

5. ACCESS TO SERVICES

CASE STUDY Simon (16) has Asperger syndrome, a form of autism. He lives with his mother, father and younger sister Rosalind. Simon's mother, Jane feels that the family has received very little support from the health service, social services and other government bodies. Simon was not diagnosed as autistic until he was 10, despite the fact that his mum suspected he was autistic much younger. *'I kept telling everyone I met, "I think he is autistic", and they kept going on and on that he wasn't',* sighs Jane. Simon used to have short-term breaks from his family but these ended in March 2001 when he was no longer considered a priority by social services. *'They didn't tell me they were stopping the service,'* explains Jane. *'It was the short-break care worker herself.'* Since then Simon's family has become very disillusioned with social services and is reluctant to rely on them for support.

'They didn't tell me they were stopping the service'

Disabled children can have particular problems accessing health services. Many disabled children have continuing health care needs: a key issue for such children is the delivery of community health services within the child's home, school, nursery or short-break setting.

Families are also especially distressed about the lack of support from social services and, in particular, the lack of allocated social workers, which means having to tell your story to a different person each time: *'Everything takes forever. You're better off doing things yourself as best you can,'* said one mother. Another family has been waiting for family-based short breaks for eight years.

Many also said that they find it difficult to get in touch with social workers. *'They're few and far between,'* said one mother. Another parent questioned the role of social workers. *'I always thought that a social worker was there to help you, and tell you what you should do and where you should go. But there's no contact like that.'*

One mother had constant problems accessing services for her autistic son and kept being told that: *'he wasn't disabled enough'*. She familiarised herself with the Children Act and the Community Care Act and wrote to one of the directors at her local health authority. It was then that she started to get all the services, such as short-term breaks, to which she was entitled and had been denied for over 18 months. *'And it actually says in the Children Act, you mustn't undermine the parents... give them help... but that doesn't happen.'*

Short breaks are a lifeline for many of the families: these are the only rest they get from around-the-clock caring. However, some of the families would benefit from more hours of care being available. They also commented that, at times, care services are not replaced when staff leave, and the general high turnover in staff results in discontinuity that is very unsettling for the children.

Rules on eligibility can result in families losing out financially *'We weren't allowed free nappies until Claire was a certain age, but she was on steroids and weighed five and a half stone. We were having to get Pampers extra large, which were too wee,'* explains her mum. *'So every change time, you were peeling Claire's skin. We had to do that for seven months before they would give us the nappies. It was going to be something like £70 or £80 and we just couldn't afford it.'*

Families find the constant assessment for services a frustrating and excluding experience. *'Why should my daughter have to be assessed for an after-school club? Her sister wasn't,'* said one mother. *'All of these things do get on top and you start to become ostracised from the rest of the community.'*

Most families are in touch with a number of services, particularly social services, health and education. Families' experiences of the extent to which services are co-ordinated differ. Two parents with very young disabled children feel that their respective situations have improved due to good communication between the different professionals. But one parent feels that, apart from six-monthly reviews, the different services do not speak to one another. Co-ordination between services appears to be easier when there is a professional worker or advocate responsible for this role.

A lack of communication and poor co-ordination of services appears to be worst when children are being diagnosed, especially autistic children. In one case it took three years for a diagnosis, and in another case no firm diagnosis was given. The families did not receive any services while the diagnosis was going on. Parents also find that professionals do not understand the needs of autistic children. For example, one parent found it a battle to get a wheelchair because her son did not have a physical impairment.

Three of the parents with autistic children have struggled to get fencing put up around the house, and adequate locks in the house, for the children's safety.

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6. EDUCATION

CASE STUDY Jennifer (11) and her older brother Liam live with their mother. Jennifer was born with a chromosome disorder and she has physical and learning difficulties. She is classed as being terminally ill. At present, Jennifer attends one of the local primary schools that has a special needs unit. The school has introduced a new moving and handling policy, so Jennifer will no longer be able to attend. There are no other primary schools in the area that can cater for Jennifer's needs, so her new school will almost certainly be outside the county they live in. *'She's been going there since she was six,' says Linda. 'It's just a shame really. I don't know what will happen to her when she goes to a new school.'*

Most parents are happy with their child's school, especially when transport is available. Where schools offer after-school and holiday clubs, the parents find these invaluable, especially those who cannot afford summer holidays. One parent had to stop using the after-school club when the costs went up.

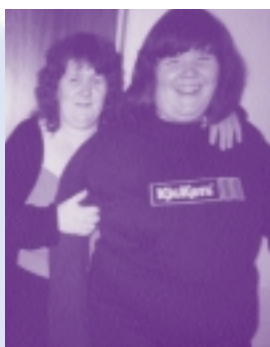
Good communication between the school and home is essential. One of the parents with a child at a special needs nursery said: *'They tell me what's been going on and it's brilliant.'*

'There will be nothing for Lauren to do when she leaves at 18, so what's she going to do'

While parents are mostly happy with school, the parents of children at secondary school are anxious about what will happen to their children when they leave and would like planning for this to start early. One mother summed up the feelings of many when she said: *'I am happy with the school my son attends, but my real fear is for when he is older. Where will he go then? His needs will not have changed, but there will be no support. I'm starting to panic now.'*

In addition, catchment areas for special schools are very wide and many local education authorities transport their children out of the area on the grounds that their needs cannot be met locally.

7. TRANSITION TO ADULTHOOD



CASE STUDY Cathy is a single mum with three disabled daughters. Susannah (18) has moderate learning difficulties and attends college. Lucy (17) has a behaviour problem and finds it difficult to get around since she had a recent operation on her hip. Lauren (13) has cerebral palsy and epilepsy and needs one-to-one support all the time. Cathy is very concerned about the future for Lucy and Lauren. She feels that more facilities and choices need to be available to them. *'That's the big gap. There's not enough for them to do when they leave full time education,'* said Cathy. *'There will be nothing for Lauren to do when she leaves at 18, so what's she going to do?'*

The transition from childhood to adulthood is a difficult time for all teenagers, but for disabled young adults it can be particularly fraught both in terms of accessing appropriate adult services and in dealing with their fears and anxieties at a key life stage. While disabled young people are moving into adulthood, many are not moving toward independence. One father explained how he was saddened when his daughter reached her 18th birthday recently: he would have liked to celebrate her move into adulthood, but could not because she still needs the family to care for her.

Parents have very real fears about the future and how their child will be cared for when they are no longer able to do so themselves.

One of the main concerns for disabled young people and their parents is the lack of employment opportunities. Disabled young adults are half as likely to be in paid work as other young people. As a result, they face long-term unemployment and will have incomes substantially below those of young people in general. This, in turn, can make it very hard to develop a new life away from home. (29)

Also, there are often difficulties obtaining the right careers advice. One young person who is 18 and has moderate learning difficulties had been in mainstream school and moved onto college. She wanted to work with disabled children, but was ill-advised and is now studying catering and sign language. There was little contact between the school and home.

Various anomalies exist during the move to adult services, especially the loss of short term breaks which is a key service for young people and their parents.

One Asian mother drew attention to the need for culturally sensitive services for the whole family. *'That transitional period has got to have some more services linked. Not just for the young person, but for families as well. The adult services do not cater for ethnic minorities. They need to be more in tune with cultural differences. They look at adults, they look at children, they do not look at the middle period when it's the hardest.'*

8. SIBLING RIVALRY

CASE STUDY Rebecca and her husband Derek have three children: Billy (8), Tommy (5) and Catherine (4) who has Down's Syndrome and needs constant one-to-one support. Tommy and Billy are jealous of Catherine because she needs so much attention. Although they love her, they do feel left out and Tommy sometimes displays attention-seeking behaviour. Billy goes to a local group for young carers and Rebecca finds that this has been very helpful. Tommy will go when he's older.



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The needs of a disabled child can make non-disabled brothers and sisters jealous and resentful at times. They can feel marginalised within the family and be desperate for more time with their parents. This can manifest itself in bad behaviour to attract parental attention. Equally, parents feel very guilty and unable to give sufficient attention to their non-disabled child.

Young carers' groups are a good source of support, but they cater more for the needs of younger children: little support is available to older non-disabled siblings.

‘When things come up in school I just can’t afford them’

One young woman with two disabled sisters has been treated for depression. In another family, the mother finds it increasingly difficult to meet the needs of her non-disabled daughter and to go out as a family. *‘We won’t go to McDonald’s for a meal now. Last time we did, my daughter started screaming at everybody, “will you stop looking at my brother!”’*

Generally, siblings cannot participate in the same social activities as their disabled brother or sister. Both children and their parents find this very excluding. Parents feel very strongly that services must be inclusive, if brothers and sisters are to cope better with the impact of having a disabled sibling. Shared activities also give families better opportunities to participate in their communities.

As most of the families live on a low income and have to meet the extra costs of disability, they often cannot meet the material needs of all their children. Non-disabled brothers and sisters frequently have to miss out on activities such as school trips. One mother said: *‘When things come up in school I just can’t afford them. My daughter had a chance to go to France at the end of the year but I just didn’t have the money to give her. It was near to £400.’*

9. CULTURAL ISSUES

CASE STUDY Samaira (16) has a severe learning disability, no verbal communication and is visually impaired. She is the eldest child in a family of eight children. Her parents are Pakistani Muslim and their first language is Punjabi. They speak only a little English, and do not read or write English. Because of communication and language problems, Samaira’s parents – Ditta and Noor Bibi – have limited knowledge of the services or benefits they are entitled to receive. No information or leaflets about benefits or other services have been given to them in Punjabi. The family feels that many professionals come in and out of their lives making false promises to them. They describe the various council departments as a *‘huge disappointment’*. Ditta and Noor Bibi need help with everyday mundane tasks, but know of no local information services where they can get advice or support.

A Chinese Buddhist family, a Pakistani Muslim family, a Pakistani British family and a black mother married to a white father are included in the families interviewed for this report. In the case of the black mother, the family has not experienced any cultural barriers. The other families have had problems.

The most common cultural barrier is accessing support services, especially when English is not the first language and there is no one to act as an advocate. On the other hand, the Chinese Buddhist family, who have a very limited knowledge of English, have effectively accessed various services through a Barnardo's social worker.

The Chinese Buddhist family believes that even when there is not a language barrier, greater effort needs to be made to understand families. Another mother said *'I would say some support services do not understand our cultural differences.'* The family's main complaint is that filling in forms can be very complex. *'It would be useful to have the forms in Chinese on which we could write our answers in Chinese.'*

Both Asian families feel that there is still a stigma attached to disability. This makes them more reticent to seek help, even from the family. In one household, most of the extended family live in Pakistan or a few hundred miles away, so they feel totally isolated. Also there is a strong belief that families, particularly mothers, should be able to manage. *'Culturally, we've always been taught that women should be able to cope. We don't go to people for help, we don't tell people our problems.'* Another family feels that more information and awareness-raising of disability issues both within the Asian community and amongst professionals is urgently needed.

10. ACCESS TO COMMUNITY LIFE

CASE STUDY Tom is 5 years old. He was born three months prematurely and was diagnosed with cerebral palsy when he was eight months old. Tom needs around-the-clock care. *'He can't feed himself,'* explains his mother Jackie, who is a single parent. *'Basically I have to do everything for him.'* Very little support is available for Tom in the six weeks' school holidays. His mum feels housebound most evenings, but this is made worse in the summer months, when she cares for Tom 24 hours a day, seven days a week. Suitable activities for Tom are very expensive: an hour in the local hydrotherapy pool, which is private, costs £50. *'I am disillusioned with the way they cater for our children in the school holidays,'* says Jackie. *'Everything is a struggle.'*



'Everything is a struggle'

Disabled children have equal rights, and the same needs, as other children to be part of their local community. But a lack of resources and restrictive rules that exist within play, leisure and recreational services, mean that it is rarely possible for them to exercise these rights. Parents, especially lone parents, find the six-week summer holidays a time of great stress and increased isolation, as there is no break from constant childcare. Suitable activities are difficult to find and expensive.

Also, most leisure activities do not cater for both disabled and non-disabled children so families have no option but to segregate their children. Something as simple as going to the park can be an impossibility. One mother said that she finds it impossible to negotiate a pram in the town centre because of swinging doors and the lack of changing facilities for older children. The lack of equipment necessary to help with lifting and handling, and health and safety issues, is also a barrier to participation in community life.

3 Do government initiatives help?



GOVERNMENT INITIATIVES TO TACKLE POVERTY AND SOCIAL EXCLUSION

The government has stated that the main route out of poverty for all children – including disabled children – is by increasing families' incomes. Preferably this should be achieved through paid employment and is underpinned by numerous policies to support families. This chapter considers the government's initiatives and how they impact on the families interviewed in this report.(30)

I. State benefits

By April 2001, the government's improvements to state benefits were estimated to have increased the income of families with a disabled child by approximately 10 per cent. The changes were described as '*a significant development in helping families of disabled children out of poverty*'.(31) The

main benefit changes are as follows.

- In April 2001, the Disabled Child Premium of Income Support was increased by £7.40 to £30 per week. It was increased again in April 2002 to £35.50 per week.
- Parents on Income Support whose children receive the highest component of Disability Living Allowance (DLA) are now entitled to the enhanced disability premium, worth £11.25 per week.
- The higher-rate mobility component of DLA has been extended to 3- and 4-year-old disabled children.
- Invalid Care Allowance (ICA) – available to those whose children receive the middle or higher component of DLA – has been increased. So has the ICA earnings' limit.

2. Making work pay

To encourage parents back to work and to ensure that their wages are not absorbed by childcare, the government has introduced the following changes.

- From October 2000, the Disabled Child Tax Credit, paid through the Working Families Tax Credit or the Disabled Person's Tax Credit, gave an extra £30 per week to working families with disabled children.(31)
- By 2003, the government will bring all available tax credits and Income Support premiums for children under the umbrella of the Child Tax Credit.
- The government intends to introduce new form of approved childcare called home childcare, that will be based in a child's home. From April 2003, parents using approved home childcarers will be able to get support with the costs through the childcare element of the Working Tax Credit.(32)

3. The National Childcare Strategy

The National Childcare Strategy aims to get parents back into paid employment in two ways: through the new, more generous childcare credit and by creating more childcare places. A number of area-based initiatives have been developed to support the strategy.

- Area-based policies developed within the National Childcare Strategy, include early excellence centres and, more recently, neighbourhood nurseries, as well as the Sure Start programme
- Early years development and childcare partnerships have been established in every local authority to co-ordinate the wide range of services spanning early years and education. These include the provision of services to disabled children. Sure Start has committed itself to reducing by 5 per cent the number of children with speech and language difficulties that require specialist interventions by the age of 4.

THE IMPACT OF GOVERNMENT INITIATIVES ON THE FAMILIES

Government initiatives such as increases in social security benefits and the National Childcare Strategy – especially Sure Start – show a real attempt to tackle child poverty and are of substantial benefit to parents with disabled children.(33)

However, some critics argue that disabled children and their families are often the '*hidden form of poverty*' and are under-acknowledged by Labour's anti-poverty campaign. Much of the evidence suggests that the government's targets for ending child poverty will not be achieved unless the needs of disabled children and their families are adequately addressed.(34)

3

The Sure Start partnership has been influential in helping to identify impairments in early childhood and ensure early intervention and support, but there is evidence that disabled children are not benefiting from the childcare strategy. Despite the increase in after-school and holiday schemes, only one in 20 after-school schemes accept children with a health problem or a disability.(35)

At present, disabled children continue to be excluded for many reasons and there needs to be greater awareness of disability issues. This is not just a question of making premises accessible to those with mobility problems. Staff practices and skills need changing. Until then, children with quite moderate needs, for example regular medication or regular refreshment of a particular kind, may be excluded.(36)

Loss of 'passported' benefits

Passported benefits provide free access to a range of services and provision, like eye tests and dental care. One family interviewed was angry about losing out on passported benefits because the father was in paid work. Because of this, the family has to pay for prescriptions and dental and eye care. They also have to provide for school meals and uniforms. They feel strongly that they should have same benefits as unemployed people. They feel that means testing is unfair and acts as a disincentive to work. One couple believe that they would be better off financially if they were not together.

Adequacy of income

What is adequate? Most of the families spoke of struggling financially and having to budget carefully to make ends meet. *'My money is Tuesday to Tuesday, so I live Tuesday to Tuesday,'* said one mother. Even where families can meet daily costs, they find saving for emergencies and one-off bills an impossibility.

Most families do not feel that the recent increases in benefits have made a great difference. Three families stress that they are only surviving due to Invalid Care Allowance and Disability Living Allowance and child benefit: *'Income Support would not be enough,'* one parent said, describing it as *'a pittance'*.

Anna, whose child needs intense care, said: *'As parents, we're saving the government huge amounts of money by caring for our children. We should be adequately compensated. They charge over £1000–£2000 a week in homes for children like Geordie – and I'm doing it for not even that a month.'*

Parents feel that disability and carers' benefit should be increased because current amounts are not realistic or in line with the amount of work involved. At present, the government does not compensate a family when one parent has to give up work to look after a disabled child full time. Jacqui, whose daughter Katy needs one-to-one care around the clock, said: *'I do think they could increase the*

mobility (DLA mobility component) in line with what people charge for a car.' She describes the care allowance (ICA and DLA care component) as 'a laugh' and said: 'I would get more for signing on, but I can't because my partner works. It's just a vicious circle really.'

One family where the father works four days a week and receives the Working Families Tax Credit (WFTC), which includes Disabled Child Tax Credit, said that it is a much easier system than family credit and 'it's made a big difference'.

Two families who live in Greater London stress the need to take the higher living costs there into account in benefits and tax breaks. 'It's blanketed for the whole of Britain. If I was back in Wales it would be a lot cheaper, but in London I have to pay nearly double, because the cost of living is so high.'

Families try their best to make sure that all their children do not go without the basics – but parents often miss out. 'It tends to be mum and dad that don't get, it really does,' said one parent. Some families approach charities for holidays and to replace essential household goods. But money is a constant worry. One family said that their own health needs are the lowest priority. 'If I took sick and needed an antibiotic I would go without. We can't afford to go down and pay £6 or something for a prescription or go to the dentist.'

Access to benefits and advice

Most parents do not get official advice about benefits or other forms of government support. Parents believe that such information should be more actively promoted at places such as day centres where the parents of disabled children go. Some of those spoken to are not aware of recent increases in benefits and tax breaks for families with a disabled child. One low-income Asian family, who own their own shop, think benefits don't apply to them.

'I think it's a struggle to get the information, knowing if there's anything out there that can actually help with the difficulties we've got,' said one parent. 'And filling in the long tedious forms, and not actually knowing if am I putting the right thing on the form or not? And then finding out at the end of the day that you can't get it for one reason or another.'

Families welcome the lowering of the age at which DLA is paid. However, one household has had to reapply and found the process distressing. They know of other families in similar circumstances who have had to do the same thing. Constant reassessments for benefits is frustrating and makes families feel insecure financially.

Advice about benefits is often through word of mouth and one parent found out by accident that she had lost a lot of money in the past as she is entitled to Income Support. 'The DSS don't tell you a lot. You learn from other parents. I've told quite a lot of parents of their entitlements. They've lost a lot of money too.'

'I would get more for signing on but I can't because my partner works. It's just a vicious circle really.'

'The benefits and disability people do not and never have worked in conjunction with each other.'

3

Families want information in an easily accessible format *'I wish that the government would provide us all with one idiot-proof booklet, the easy guide to what you are entitled to,'* said one mother.

Families find the process of applying for benefits very time-consuming and confusing. *'Every single week there's at least one day I dedicate to sitting down dealing with paperwork,'* said one frustrated parent. *'I mean they must all be inter-linked with computer information somewhere or other. Why burden us with all this unnecessary paperwork?'*

Having someone to tell parents about all the benefits has helped some families. Rachel, who has two disabled children and speaks little English, received all their benefits and entitlements after advice and support from a Barnardo's social worker. So although money was tight, they were reassured and managed on what they had.

By contrast, Ditta and Noor Bibi, who have eight children including a disabled teenage daughter Samaira, feel that they have a limited knowledge of what they are entitled to due to language barriers. Both parents need to attend interviews and as they cannot find someone to look after their four pre-school children they often miss deadlines and keep having their benefits stopped. They are reticent about seeking help, as they do not want to air their problems in public.

One parent experienced delay in getting her child diagnosed, which resulted in the loss of benefits for a long time

Benefits and young people

The problems that many families face in getting benefits advice are magnified when their children reach adulthood. Anomalies between child and adult systems add frustrations and difficulties at a time of life that is already very stressful.

Many young disabled people fall through the loopholes in the current benefits system. For example, one mother has been told that if her 17-year-old daughter Joanne is to claim entitlements in her own right, she will need to sign for them regularly. But Joanne cannot read or write. If her mother, Chris takes power of attorney for her daughter, they will lose access to a number of services and entitlements, like Housing Benefit and Council Tax. This is because Chris cannot be seen to be benefiting from her daughter's disability. Joanne would then only get Severe Disablement Allowance (now Non-contributory Incapacity Benefit) or Income Support. If Joanne gets Income Support, she can't get Housing Benefit, because Chris is the tenant. Feeling very exasperated, Chris said: *'It really is a minefield out there and nobody wants to listen to us. Please simplify it, make it easy.'*

Transport

The government lowering of the age limit for entitlement to the higher rate of DLA mobility component (from five to three years) has been very welcome and will help a great number of families affected by disability. However, this has resulted in a surge of applications to Motability and a backlog in processing them.

One mother was told that it could take at least a year even to look at her application. So she has had no option but to lease a car. Unfortunately though, the car had to be returned back in its original condition, so after raising £800 for tracking and to install a ramp, she would have had to pay another £1000 before the car could be returned.

Another family could not afford to participate in the Motability scheme and surrender the mobility component of DLA for a specially adapted car, as they need the money for the more immediate needs of their disabled child.

4 Conclusion and recommendations



'Tackling child poverty requires a comprehensive strategy, with work for those who can and financial support for the families who need it most. It also requires access to excellent public services for children and young people, their families and the wider community.' (HM Treasury, 2001)

The messages from the families in this report support the research evidence that central government initiatives to tackle childhood poverty and social exclusion, as well as the agencies responsible for the delivery of mainstream services and targeted initiatives, are not meeting the needs of disabled children and their families. Disabled children and their families are still socially excluded.

WHAT NEEDS TO BE DONE?

- All mainstream programmes and targeted initiatives should have a specific focus on disabled children and young people, with clear targets and indicators which are monitored as part of *Opportunities For All*.
 - Funding streams such as the Early Years Partnerships and the New Opportunities Fund should take into account the high cost of alternative care for disabled children when making grants.
 - Targets are needed to increase significantly by 2005 the number of childcare places and specialist trained childminders available for disabled children.
 - The introduction of the new tax credits in 2003 should be accompanied by a review of how these are working for families with disabled children, including regional variations, and an assessment of the extent to which families are gaining from work after meeting childcare and additional costs.
 - There should be a performance requirement within best value for all local authorities to meet targets on the provision of information on local services for disabled children, young people and their families in all formats, languages and in ways that are culturally sensitive.

- Government should establish a minimum income standard which includes targeted support to meet the extra, essential costs of caring for a disabled child.
 - The hospital fares scheme should be extended to cover the costs of visiting a child in hospital, as well as taking a child for treatment.
 - The eligibility criteria for passported benefits to families in receipt of Disability Living Allowance should be extended so that those in work but on low incomes can benefit.
- The benefits system should be reformed so that it is understandable and accessible, and encourages take-up.
- A government-funded national awareness campaign on disability benefits should be developed to increase take-up through the provision of information which is clear and accessible, in all formats and in different languages.
- Housing policy should be reviewed so that all disabled children can grow up safe and warm in homes which are accessible and suitable for their needs.
 - The Disabled Facilities Grant should be reviewed for housing adaptations, with a view to ending significant regional variations, delays and difficulties for families.
 - The Winter-Fuel Payment should be extended to all families receiving Disability Living Allowance middle or higher-rate care component or higher-rate mobility component.
 - Government should extend the Home Energy Efficiency Scheme Plus, by which older people receive up to £2,000 to have central heating installed, to families in receipt of Disability Living Allowance.
- There needs to be an economic analysis of the investment required to ensure that government programmes aimed at lifting children out of poverty also reach disabled children.

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- 34 Dobson et al. (2001), as in 7 above.
G.Vaux (2001) Social Security, 2001, *Research Matters* April–October (pp6–8).
- 35 Land (2002), as in 20 above.
N.Watson, M. Priestley (2000) *Life as a Disabled Child: a Qualitative Study of Young People's Experiences and Perspectives. Final Report Submitted to ESCR Research Programme: Children 5–16: Growing up in the 21st Century*.
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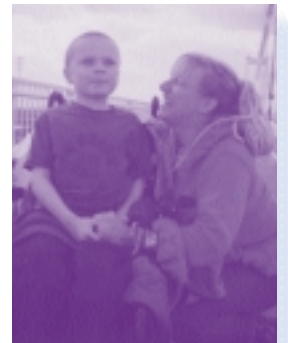
Appendix

Profiles of the families

South West England

ADAM, 7

Sara is a lone parent with two children, Charlotte (9) and Adam (7), who has significant autism and high care needs. Adam has very difficult behaviour, but because he does not have a physical impairment, Sara has had a battle to convince professionals that he is disabled. She gets very frustrated at always being told that he is not disabled enough. Sara is very active within the community and speaks on behalf of carers at a number of forums and meetings. She is a committee member of the National Autistic Society and a member of a Barnardo's forum.



SIMON, 16

Simon has Asperger's Syndrome and lives with his mother Jane, father Tim and his younger sister Rosalind. Simon is fascinated by technology and loves dismantling and reassembling his computer and video player. He is academically very able and attends a local comprehensive school. Simon and his family take part in a number of activities organised by a Barnardo's project in the South West. He is also hoping to go to university.

Midlands

JOANNE, 17

Joanne lives with her mum, Chris. Joanne contracted a rare strain of meningitis when she was 13 months old, which left her with brain damage, complex learning difficulties, epilepsy and cerebral palsy. Joanne needs constant personal care. Joanne has a sister Suzanne, who was a toddler when Joanne contracted meningitis and has spent most of her life helping to care for her sibling. She has now left home and is running a pub in Wales. Chris's marriage broke down shortly after Joanne contracted meningitis. Chris and Joanne are in contact with a Barnardo's project in the Midlands.



TOM, 5

Jackie has one son, Tom who was born three months prematurely and was diagnosed with cerebral palsy when he was eight months old. He loves going for long walks in the countryside with his mum and looking at the trees and the wildlife. He also adores swimming in the hydrotherapy pool. Jackie is a lone parent whose marriage broke down when Tom was still a baby. Tom's dad lives abroad and flies over once a month to spend time with his son. Tom needs intense care: *'He can't feed himself. I have to do everything for him basically. I'm his legs and arms and goodness knows what.'* Jackie has been involved with a Barnardo's project in the Midlands.

North East England



KATY, 2

Jacqui and her partner John have two children, Hannah (6) and Katy. Katy was diagnosed with a tumour of the nervous system when she was seven months old. She is registered as disabled and needs intense one-to-one care. Jacqui said: *'She's basically like a six-month baby. She can't hold a bottle, she can't take her dummy out, she can't sit or anything, she cannot walk.'* Katy goes to a family centre twice a week and also attends a Barnardo's project once a week where she's described as 'a sweetie'.



CATHERINE, 4

Rebecca lives with her husband Derek. They have three children: Billy (8) Tommy (5) and Catherine. Catherine has Down's Syndrome, a hole in the heart and damaged bronchial tubes, which mean that she suffers from serious recurring chest infections. She needs constant one-to-one support. She loves music and dancing and her favourite television show is *The Tweenies*.

Rebecca has been in touch with a Barnardo's project in the North East since Catherine was five months old and heard about the project through the health visitor. Rebecca is writing a book with other mothers about their experiences of having children with Down's Syndrome.

MEGAN, 4

Megan lives with her mum Hayley and her stepbrother James (16). Hayley is divorced but still good friends with her ex-husband who helps care for Megan three or four times a week. Megan has severe autism and she needs a very high level of personal care. She responds to and enjoys music and noise, although her intellectual development is limited.

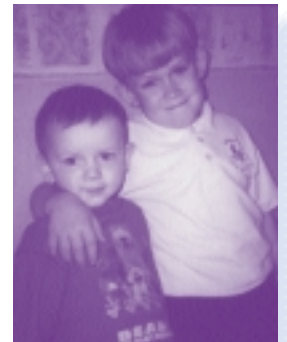
Hayley has been in touch with a Barnardo's project in North East England for the last three years. She was hesitant at first but says *'I realised it was all for children with disabilities so I was really happy about that. Pity there's not enough of them (centres) like this.'*



CHARLES, 7

Shelley lives with her partner and their two children, Ross (3) and Charles, who has a condition that will not allow him to grow to the height of a normal adult. He also has scoliosis of the spine, has only 50 per cent lung capacity because his chest is protruding, and has a growth spur on his heel which makes walking painful. Charles can communicate verbally and feed himself but has a high level of care needs. His condition is very rare – only about 40 people in the world have been diagnosed with it.

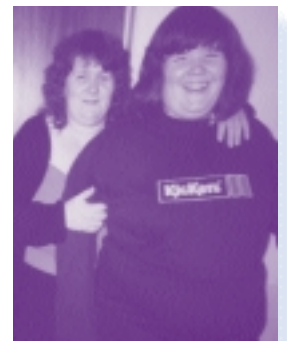
The family started going to a Barnardo's project in the North East when Charles was 18 months old.



North West England

SUSANNAH, 18, LUCY, 17 AND LAUREN, 13

Cathy is a single mother who lives in Chester with her three disabled daughters. Susannah has moderate learning difficulties, and enjoys her college course and socialising with friends. Lucy and Lauren are registered disabled. Lucy has behavioural difficulties, which have caused her to be violent in the past, and a recent hip operation has left her with slow mobility. She enjoys swimming and line-dancing, and hopes to work with animals. Lauren's care needs are greater and she has cerebral palsy and epilepsy: she needs one-to-one support all the time. Cathy has been involved with a Barnardo's project in the North West since 1990, which has played a key role in helping the family access various support services. *'I don't know what I would have done without their help and support. They've been like friends.'*



Northern Ireland

SHARON, 6

Sharon lives with her mum Pam, her dad Peter and her two brothers Andrew (4) and Fred (2). Pam is a full-time mum and Peter works. Sharon is registered disabled and needs intensive support around the clock. She has a condition called West Syndrome and needs help with most aspects of daily life, including dressing and feeding. Pam feels that some of the time Sharon is unaware of other people, although she does react a little to light – bright light on early mornings will wake her.

The family has been in touch with a Barnardo's project in Northern Ireland for about four years. A special needs nurse organised contact and Barnardo's organised a Link Family service using Peter's parents.

GEORDIE, 13

Geordie lives with his mum Anna and his 12-year-old sister Janice. The father does not have any contact with the children. Geordie is registered disabled with a non-specific condition and needs constant one-to-one attention. He has learning difficulties, limited verbal communication and night-time epilepsy. Because the family moved around a lot it took a long time for Geordie to be diagnosed. Some doctors felt he had autism and others didn't. He does have dyspraxia – his motor skills do not function properly. Anna has been in touch with a Barnardo's project in Northern Ireland for about three years.

GARY, 5

Gary lives with his mum, Liz and his two older sisters aged 13 and 9. Liz is separated from her husband. Her view is that he couldn't cope with Gary and this contributed to the break-up of the marriage. Liz describes herself as black and her husband is white. Gary is registered disabled; he has epilepsy, cerebral palsy and learning difficulties. He is mobile and unable to communicate verbally. He is able to make his needs known to close members of his family. Gary needs to be constantly supervised and needs a high level of personal care. He has no sense of personal safety. He sleeps with his mother, in case he has a seizure at night. The family has been in touch with a Barnardo's project in Northern Ireland for two years.

Wales

JENNIFER, 11

Jennifer lives with her mother Linda and her elder brother Liam in Monmouthshire. Jennifer loves listening to music and going for long drives in the countryside. Jennifer was born with a chromosome disorder, which her parents were told was life-limiting, and has left her with physical impairment and learning difficulties. The family receives a short-break service from a Barnardos project in Abergavenny.



South East England

COURTNEY, 18, AND JAMIE, 11

Rachel and Paul live in London and have three children, two of whom are disabled. Courtney is severely disabled and needs constant care and support. Her brother Jamie is autistic. They also have a 3-year-old sister, Tracey. The family are Chinese Buddhists and speak some English. They receive services from one of Barnardo's projects in Greater London.

HARRY, 8

David has two sons, Harry (8) and Stewart (2). David's wife died some months after Stewart was born. Harry was born 16 weeks premature and as a result is severely disabled and needs constant care and support. David is a working father and is coping with the demands of raising a baby and a child with special needs. He receives support from a Barnardo's project in Greater London, which he has found to be invaluable.



Yorkshire

SAMAIRA, 16

Ditta and Noor Bibi live in Yorkshire and have eight children, seven girls and one boy. They are aged 16, 14, 12, 7, 5, 3, 2 and 1. Their eldest daughter Samaira, has a severe learning disability, has no verbal communication and is visually impaired. Samaira attends a special needs school. The family are Pakistani Muslims and their first language is Punjabi. Both parents speak only a little English and neither can read or write in English.

Scotland

NASSER, 7, AND ZAINAB, 3

Ali and Tasneem have three children: Rahenna (9), Nasser (7) and Zainab (3). Both Nasser and Zainab have learning difficulties and behavioural problems and are registered disabled. They need constant supervision and care on a one-to-one basis. The family has been receiving a service from a Barnardo's project in Scotland for the last three years.




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