

Helter Skelter: Families, disabled children and the benefit system

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CASEpaper 92
February 2005

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Editorial Note

Gabrielle Preston is Policy and Research Officer at the Child Poverty Action Group. The research for this paper was done when she was Policy and Information Officer on the Big Lottery funded Combat Poverty Unit at Disability Alliance, and was on secondment to the ESRC Centre for Analysis of Social Exclusion in 2004 as a User Fellow.

Acknowledgements

I am grateful to Tania Burchardt from CASE who invited Disability Alliance to apply for the Fellowship and provided supervision and support and detailed comments on the report. I would also like to thank her colleagues Jane Dickson for providing administrative support and Abigail McKnight for editing the report. I am grateful for the funding and support from the ESRC Centre for Analysis of Social Exclusion at the London School of Economics, and to the Big Lottery which funded my post at Disability Alliance.

I am indebted to the welfare rights advisors who put me in touch with the families who participated in the research. They were generous with their time, expertise and knowledge. Their in-depth knowledge of families and the benefit system helped to clarify both issues and presentational aspects of the report. Special thanks are due to all the families who gave their valuable time to talk to me about their views and experiences. Many thanks to my colleagues Paul Dornan and Pauline Phillips from Child Poverty Action Group for their helpful comments. Finally I would like to thank Lorna Reith, Chief Executive at Disability Alliance, for enabling me to undertake the User Fellowship and for commenting on the report.

Supported by



Abstract

Families with disabled children are susceptible to poverty because low income is compounded by high costs. Combining caring with employment is extremely difficult, so families are heavily reliant upon benefits. But do disability benefits provide financial security for families who are susceptible to high levels of poverty and social exclusion? This qualitative study, based on semi-structured interviews with 20 families who have a disabled child or children, investigates their experience of applying for disability living allowance (DLA) and how they use additional benefit income. Families report that DLA makes a significant difference, not just for the disabled child but for the whole family. However, the fact that DLA is repeatedly downrated or withdrawn generates considerable fluctuations in income and high levels of stress and ill health. The report outlines issues that must be addressed if reduce poverty amongst disabled children is to be reduced.

JEL number: I38

Key words: appeals, benefits, disability, employment, extra costs, poverty, services, social exclusion, special needs, social inclusion, take-up, welfare rights

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Foreword: Definition of ‘disability’

The children in this study experienced a range of conditions and impairments including learning difficulties, behavioural problems, autistic spectrum disorders (including Asperger’s Syndrome), attention deficit and hyperactivity disorder (ADHD), physical and sensory impairments and epilepsy. In the interests of clarity, and in order to distinguish between children who have additional needs and their siblings who do not, I refer to ‘disabled’ and ‘non-disabled children’. Even though a number of parents indicated that they are uncomfortable with the term ‘disabled’, and prefer to think of their child as having special needs, I hope that they will understand that this clarifies a potentially cumbersome issue.

The fact that the term ‘disabled’ continues to distress parents clearly reflects the fact that the medical rather than the social model of disability is rooted in the public’s perceptions. A number of parents in this study commented that they did not consider their child to be disabled because they did not have a physical disability. As Trisha, who has recently applied for disability living allowance for her four-year-old daughter Sylvia, comments: ‘I thought it was for people in a wheel-chair, blind people, people without legs or arms – something you can notice...’

A distinction also needs to be made between impairments and health conditions and ‘disability’ (which arises from society’s failure to respond to the needs of people with impairments). Although for many people ‘disabled’ remains a pejorative notion, I have used the term in this study because all the families report that their children’s physical or emotional impairments result in them experiencing a wide range of ‘disabling’ situations – at school, with services, and in society as a whole.

Glossary

Attention Deficit and Hyperactivity Disorder (ADHD). Although the symptoms vary in their severity, children with ADHD will usually find it difficult to control their behaviour, or to concentrate.

Autistic Spectrum Disorders (ASD) are a group of lifelong developmental disabilities that affect the way a person communicates and relates to people around them. People with ASD experience difficulties with social interaction, social communication and imagination known as the 'triad of impairments'.

Carer's allowance (CA) a benefit for people who regularly spend at least 35 hours a week caring for a severely disabled person. They don't have to be related to or live with the disabled person. It is available even if they've never worked. It is available to people who receive DLA or attendance allowance (AA), who care for somebody who gets the middle or highest rate DLA or AA. Carer's allowance is £44.35 a week. If somebody gets CA, a carer's premium of £25.55 will be included in their applicable amount for income support (IS), income-based jobseeker's allowance (JSA), housing benefit and/or council tax benefit.

Disabled Facilities Grant – There are two types of grant: mandatory and discretionary. They are designed to help meet the cost of adapting a property for the needs of a disabled person.

Disability living allowance (DLA) – DLA is a non means-tested benefit which has two components. The care component is paid at three rates according to assessed need for supervision and help with personal care (highest – £58.80, middle – £39.80 and lowest – £15.55 a week). A mobility component is also available. It is payable at two rates, £55.55 for the higher rate and £41.05 for the lower rate. DLA can be claimed by anyone under 65 but over five. Eligibility for the high rate mobility component has recently been reduced from age five to age three. DLA provides a gateway to other important forms of support, including CA plus additional premiums within income support and elements within child tax credit (CTC).

Premiums within income support

- carer's premium – £25.55
- enhanced disability premium – £17.08) now incorporated
- disabled child premium – £42.49) into CTC

Elements within child tax credit

- disabled child element within CTC – £2,215 a year
- severely disabled child element within CTC – £890 a year

Direct payments – Direct payments allow a person who has been assessed as needing services to receive cash to arrange and pay for them. They can have a combination of some services provided directly by social services and others arranged by themselves with direct payments. To get direct payments a person must be: disabled; a carer; aged 16 and over; assessed as needing community care services or services as a carer; willing to have payments; and able to manage payments. Parents in England, Wales and Scotland can receive direct payments to purchase services for disabled children.

Family Fund – The Family Fund provides discretionary grants and information to ease the stress on families arising from the day-to-day care of a severely disabled child under 16. It is an independent charity financed by the Government. Any family caring for a disabled child at home can apply. The family fund cannot give help which should be available from your local authority, but can complement the help they give. It can help with: holidays or leisure activities for the whole family; washing machines; bedding and clothing; transport expenses; driving lessons for main carer; play equipment.

Global Developmental Delay – When a child has failed to achieve one or more developmental milestones. It may affect a child's speech and language development, their fine or gross motor skills, their personal and social skills, or all of these.

Poverty and Social Exclusion Survey (PSE) - Published by the Joseph Rowntree Foundation, this is the first national study to attempt to 'measure both the scale and severity of poverty and the relationship between poverty and social exclusion.' On the basis of interviews with a nationally representative sample of adults, a checklist of household items and activities was drawn up that more than 50% of the population believe 'all adults should be able to afford and which they not have to do without.'

Social fund – The discretionary social fund provides grants and interest-free loans for needs that are difficult to meet from weekly benefits.

Tax credits

Child tax credit (CTC) - A means-tested payment for people who are responsible for children whether or not they are in work. It replaces the children's tax credit and the increases for children within working families tax credit and disabled person's tax credit. It replaces the child allowances within

income support and income-based jobseeker's allowance, along with increases for child dependents paid within non-means tested benefits (such as incapacity benefit). The intention is to provide continuity of financial support for children whose parent-carer is moving between low paid work and periods of unemployment. It has a number of elements, including a disabled child element and a severely disabled child element.

Working tax credit (WTC) – A means-tested benefit for people in work on low wages. There are additional amounts for disabled people. It replaces working families' tax credit and the disabled person's tax credit.

Childcare element – is payable within WTC for people who work 16 hours or more a week. This is a tax credit equal to 70% of eligible childcare costs up to a maximum of £135 costs for one child or £200 for two or more children. (This will rise to £175 for one child and £300 for two from April 2005, out of which families will be able to claim 80% of costs.) Childcare tax credit is included for a lone parent working at least 16 hours, or one of a couple and both work at least 16 hours a week, or one of a couple and one works 16 hours a week and the other is 'incapacitated'. Childcare must be provided by a registered childminder (or equivalent).

1. Introduction

1.1 Aims of the report

There are around 800,000 children under the age of 16 ‘with a limiting long-standing illness or disability’ (Prime Minister’s Strategy Unit, June 2004). Over 98% of disabled children are cared for at home. Families with disabled children are particularly susceptible to poverty because low income is compounded by high costs. It is estimated that that 55% of families with disabled children live in, or on the margins of, poverty.¹ Given that the majority of families with disabled children find it difficult to combine caring with full time employment, most are dependent upon benefits. Although the Government recognises that families with disabled children incur extra costs, and has introduced a number of significant improvements to disability benefits (see glossary), their impact on families’ lives is under-researched. Furthermore, while there is much debate about the adequacies – or otherwise – of disability benefits, little is known about the day to day financial needs of families with disabled children, and even less is known about how families spend additional income when awarded benefit.

This qualitative research study – which is based on semi-structured interviews with 20 families who have a disabled child or children – investigates the additional costs they incur and their experiences of applying for Disability living allowance (DLA) which is intended to cover additional disability-related costs. Although this small study reinforces previous research findings on families’ needs and inadequate support systems, it differs in the way in which it investigates the impact that additional income (primarily DLA and associated benefits) has on families’ lives. How is additional income spent? What are families’ spending priorities? Does benefit income cover the extra costs of caring for a disabled child? What happens to families who do not claim (or are not awarded) the benefits to which their disabled children are entitled? What happens if benefit is taken away?

Although disability and carer organisations have long argued that extra cost disability benefits such as DLA do not cover the additional financial needs of disabled people and their carers, it does provide crucial additional financial support to families with disabled children. And yet disability organisations

¹ See Gordon, David. *Disabled children in Britain: A reanalysis of the OPCS disability survey* (The Stationery Office, 2000). ‘Almost 55% of the families with children with disabilities were living in or on the margins of poverty in 1985 – according to a definition of poverty that would be accepted by a large majority of people.’ This figure is now accepted by the Government, see Disability Project – Analytic Report, p. 67.

suspect that an unacceptably high percentage of families whose children are entitled to DLA do not claim it. Although lack of information and a complex social security system prevent many families from applying, the 'welfare to work' focus of Government policy may inculcate discriminatory attitudes that put families off applying for the benefits to which they are entitled. The fact that the media and tabloid press stigmatise people who are reliant upon benefits as indolent (and possibly fraudulent) beneficiaries of an absurdly indulgent system who squander their money on cigarettes and alcohol, may discourage families from seeking financial support. Although this study reveals that DLA plays an important – indeed essential – financial role, stigma and shame were cited by a number of families as a major obstacle to claiming disability and carer benefits.

This study indicates that, once families do receive additional benefit income their spending priorities certainly do not accord with scurrilous media speculation. But how secure is benefit income? Researchers emphasise that movements into and out of low income are as important as data that provide 'snap shots' of experiences of poverty. However, while researchers consider the income trajectories of people over a whole life cycle (Sefton and Rigg, 2004) little is known about the impact that repeated and abrupt changes in disability benefit income has on the lives of families with disabled children. One of the early findings of this research is that such families experience significant fluctuations in income as a direct result of the way in which in the benefit system is currently administered. Families report that their child's DLA (which is usually awarded for between two and five years, depending on the severity of their disability) is regularly downrated or removed and then, more often than not, reinstated at appeal.²

Unfortunately DLA and associated benefits do not have the sort of tapers that have been put in place to ease the transition from benefits to paid employment via the tax credit system. And so, while families with disabled children may experience a significant increase in income when awarded DLA and associated benefits, its removal generates a sudden and often traumatic drop in income. As a result, far from providing the 'security' the Government intends, families view benefit income as erratic and unreliable. Their experiences reveal serious gaps in Government policies which are designed to avoid financial 'cliff edges' for

² In a written response to a parliamentary question, Maria Eagle, Minister for Disabled People, indicated that to July 2003, around 54% of appeals for DLA were successful. (Hansard, 17 September 2003, column 757/8W). Responding to a parliamentary question about the number of appeals made in relation to benefit assessments in the last 12 months, Mr Norman Egan from the Appeals Service provided a table which revealed that in the last 12 months, out of a caseload of 2,398,000 applications for DLA, 84,120 went to appeal. (Hansard, 25 October, 2004, Column 1030W).

low-income families. A benefit ‘run on’ would give families whose children’s needs have not changed time to lodge an appeal and enable families whose children’s needs have changed to prepare for a reduction in income.

This piece of research highlights those areas where Government initiatives to reduce child poverty are working, but exposes how they are being undermined by a cumbersome social security system that is failing the families who need it most.

1.2 Policy context

Child poverty

On 18 March 1999 the Prime Minister, Tony Blair MP, delivered his pledge that the Labour Government would ‘eradicate’ child poverty by 2020. In his speech the Prime Minister proclaimed that the Government’s strategy would focus upon ‘Work for those who can, security for those who can’t...’ but warned that ‘welfare will be a hand-up not a hand-out.’ (Walker, 1999).

The Government acknowledges that ‘disabled children are ... more likely to suffer from child poverty and they are more likely to be worse off as adults’, (Prime Minister’s Strategy Unit, June 2004). Although ‘welfare to work’ remains central to its strategy to eliminate child poverty, is an employment-driven solution to poverty relevant or appropriate for families with disabled children who experience significant barriers to the labour market? Such families are much more likely to leave paid employment to care for their children than make the transition from welfare to work. They are therefore disproportionately reliant upon benefits. While some families receive additional benefits (such as carer’s allowance) if they leave work to care for their disabled child, most report a significant drop in income. Is the social security system meeting their needs?

Since 1997, the Government has introduced a number of improvements to financial support for low-income families with disabled children. For example, the disabled child premium in income support has doubled, from £21.45 to £42.49, and the carer’s premium has increased from £13.65 to £25.55. For families on income support, an award of DLA, carer’s allowance, and disabled child premium within income support/child tax credit (CTC) may lead to their income almost doubling. This is a vindication of the Government’s anti-poverty strategy. However, while the Government insists that the social security system will continue to safeguard the incomes of people who – for whatever reason – are unable to work, high levels of poverty in workless households pose questions about the adequacy of benefits.

Social inclusion

The Government has long argued that childhood deprivation, lack of opportunities in education and employment, poor housing, inequalities in health and other factors act together to create a cycle of disadvantage. (DWP, 2002) The Social Exclusion Unit was set up in 1997 with the broad remit to reduce social exclusion ‘by finding joined-up solutions to inter-connected problems’ (Social Exclusion Unit, 2004). Although the Government now accepts that in families with disabled children ‘parents, child and siblings – are at risk of social isolation from wider community and work networks because of being disproportionately home-based’ the current focus is very much on poor service provision rather than unmet financial needs.

1.3 Existing research

Poverty and disability

The link between poverty and disability has been well documented by independent researchers (see, for example, Burchardt, 2003, and Jenkins and Rigg, 2003) and by the Government itself. The Department for Work and Pensions (DWP) accepts that there is ‘considerable empirical evidence, from both the Family and Children Study (FACS) series and other research, to assert that quality of health among household members holds consequences for families’ living standards. Ill-health and disability are both a cause and a consequence of income poverty and disadvantage – poor health lowers people’s ability to get and retain jobs while not being able to hold a job leads to fewer resources for a healthy lifestyle and consequently poorer health.’ (DWP, 2001) The recently published findings from the 2002 FACS confirm the close connection between worklessness, poverty, and ill-health. It indicates that mothers with a longstanding illness are more likely to be living on the lowest income quintile and to have other health problems or disabilities (DWP, 2004).

◆ Extra costs

It is widely accepted that disabled people are at particular risk of poverty because high living expenses (due to extra heating, laundry costs and the need to finance special equipment or personal support, goods and services that non-disabled people can do without) are compounded by a greatly reduced earning capacity.

Measuring extra costs is problematic because of the need to distinguish between what disabled people and their families *actually* spend, what their needs are, and what they *would* spend if they had the money to meet these needs. Various approaches to measuring extra costs have been developed in an attempt to resolve this issue (see Asghar and Burchardt, 2003 and Dalley, 1991). Most recently, the Centre for Research in Social Policy (CRSP) has formulated budget standards for disabled people with different needs arising from physical

or sensory impairments. Developed by disabled people themselves through a series of focus groups, the budgets reveal the minimum essential resources necessary to meet disabled people's needs, so that they would achieve a 'level playing field' with people without disabilities (Middleton et al, 2004). For the moment however, neither quantitative nor qualitative calculations are utilised in Government statistics on poverty.

◆ Extra costs – disabled children

Research undertaken in the USA highlights the difficulty associated with measuring 'costly' childhood disabilities from the child's perspective (Meyers, Brady and Seto, 2000). The researchers emphasise that while many childhood disabilities and illnesses reduce children's capacities in ways that have implications for their human capital and long term earnings, this is hard to quantify. Measurable costs therefore tend to focus on the short term financial demands and the reduction in a child's everyday experiences. (On the other hand there is concern in Britain that the Government's focus on children as adults-to-be neglects the concerns and experiences of childhood itself.) (CPAG, 2004.)

In 1998, researchers from CRSP brought together parents of disabled children to form 'budget standards committees'. Drawing on the information provided, it was calculated that it costs three times more to bring up a child with a severe disability than a non-disabled child (Dobson and Middleton, 1998). Although the researchers argued that at that stage benefits needed to increase between 30% and 50% to meet minimum essential budgets, they emphasised that many families were not getting their full benefit entitlement. The minimum standards study was updated in 2001 (Dobson, Middleton and Braithwaite).

In 2002, Barnardo's influential report *Still Missing Out* (Barnardo's, 2002) indicated that, despite changes to disability benefits, many of Britain's disabled children and young people are still 'entrenched in poverty'. These findings were echoed in a briefing paper issued by the End Child Poverty Campaign in 2003 (End Child Poverty, 2003).

A recent report from the Family Fund reveals that families with severely disabled children need an extra £104.68 per week (£5,443.35 per annum) over and above their current incomes because of the 'significant additional expenditure related to the needs of the disabled/seriously ill child.' (Family Fund, 2004.) Coping on incomes that do not cover additional disability-related costs pushes many families into debt. Contact a Family and the Family Fund reveal that on all indicators of debt, families with disabled children fare worse than families who do not have disabled children. Many families attribute this

situation to the added expense their disabled child generates. (Contact a Family and Family Fund, 2004.)

◆ Fluctuating incomes

Save the Children recently published *Britain's poorest children* which highlights different dimensions of childhood poverty (Adelman, Middleton, Ashworth, 2003). One of the most significant findings of this quantitative analysis is that children who live in families that experience a fluctuating income – because they are in transition between having workers and no workers in the household, and between receiving and not receiving benefits – are particularly vulnerable to persistent and severe poverty. Although the researchers conclude that ‘Children with a long-standing illness themselves were no more likely to be in poverty – severe or non-severe’ this reflects the inadequacies of large-scale statistical surveys to capture the financial realities of life for families with sick or disabled children. Certainly the experiences of the 20 families who participated in *Helter Skelter* suggest that they are particularly vulnerable to poverty because of a combination of extra costs, difficulties accessing employment and the unreliable and erratic nature of disability benefits as a source of income.

◆ Poor services

That families with disabled children are particularly poorly served by statutory services has been well documented (Beresford, 1994, 1995, and Beresford et al, 1996). However, despite the Government’s commitments to improve public services, the situation is changing very slowly. A recent report by the Audit Commission found a lottery of services for disabled children, young people and their families (2003). It remains to be seen whether the Government’s National Service Framework for Children will resolve these problems.

◆ Health inequalities

The Acheson report (1998) on ill-health and poverty established that class differences are significant in health inequities. Families with disabled children are not only more likely to be poor because they live in households with a limited earning capacity, but poor families are more likely to have chronically sick or disabled children. Their children are more likely to suffer accidents in the street and in the home. Children in the poorest families are twice as likely to die by age 15 as children in the highest social class (Roberts, 2000).

Recent research indicates that access to welfare benefits advice in primary health care settings has a beneficial impact upon an adult individual’s health and

facilitates social inclusion.³ Although it is not known what impact additional income has on a disabled child's health, this study indicates that the loss (or lack) of benefit income may have a detrimental impact on a child's long term development.

◆ Family breakdown and poverty

The link between disability and lone parenthood is clear. Findings from the 2002 FACS study indicates that children whose health was reported by a parent as being 'not good' were twice as likely to live in a lone-parent family than a couple family (4% as opposed to 2%). Nineteen per cent of children living in lone-parent families had a long-standing illness or disability compared to 15% in couple families. Three in ten lone parents (29%) have a sick or disabled child. Thirty five per cent of non-working lone parents have disabled children. (Prime Minister's Strategy Unit, 2005.) Five per cent have two or more children with a health problem, and 7% care for someone with an illness or disability (DWP, 2004). It appears that raising children single-handedly may render lone parents more susceptible to ill-health themselves. The 2002 FACS report reveals that a longstanding illness or disability is higher amongst mothers living in lone parent than couple families (16% as opposed to 9%) and that it is more common among mothers who are not in paid work.

◆ Benefits and poverty

Very little is known about how people spend additional income from benefits. However, a study undertaken by the Universities of Hull and York for the National Audit Office explores the impact of additional benefit income for older people (primarily from attendance allowance and minimum income guarantee) (Craig et al, 2003). The following themes emerged:

Older people used additional income to access:

- ◆ Essentials (eg food)
- ◆ Mobility (better transport, etc.)
- ◆ Goods and services
- ◆ 'Lumpy' items (large pieces of equipment)
- ◆ Personal forms of expenditure (clothes)

The researchers found that an increase in income enhanced social inclusion, and facilitated:

³ See, for example, *What is the impact on individual health of services in primary health care settings which offer welfare benefits advice?* (The Health and Community Care Research Unit, University of Liverpool, 2002) and *Tackling pensioner poverty: Encouraging take-up of entitlements* (National Audit Office, November 2002).

- ◆ Independence (financial and social)
- ◆ Participation (engaging with wider community, family and friends)
- ◆ Identity (feeling more ‘normal’, engage with others)

Will these findings hold true for families with disabled children?

1.4 Structure of the report

The main body of this report focuses on the issues that the 20 families raised during interviews.

Chapter 2: describes the methodology, which was based on in-depth, semi-structured interviews with 20 families.

Chapter 3: discusses families’ experiences of claiming DLA for their child. Anomalies and discrepancies within the administration of the benefit system exacerbate underlying structural problems and condemn families with disabled children to an insecure and fluctuating income. This chapter highlights the difficulties families experience accessing information about benefit entitlement, the trauma of filling in forms, the frequency of incorrect assessments and high numbers of appeal tribunals. It provides an overview of misconceptions and misunderstandings about DLA, and emphasises the important role that welfare rights advisors play in ensuring that families receive their full benefit entitlement.

Chapter 4: considers the extra costs incurred by families, which range from high levels of wastage, additional heating and laundry costs, to the need to buy special toys and equipment. It discusses ways in which inadequate statutory systems sap family incomes – and energy – and considers other costs, such as exclusion from paid employment, social isolation, and high levels of ill-health and disability among parent-carers.

Chapter 5: establishes that receiving disability benefits can make the difference between a family getting by and not being able to cope. This is a vindication of the Government’s anti-poverty strategy. The chapter considers how additional income results in both financial benefits and social inclusion for the disabled child, the parent, and indeed all the family. It considers how financial fluctuations influence families’ spending priorities.

Chapter 6: considers how families cope when they lose benefit. An overnight loss of benefit can plunge the whole family into crisis because their income goes down but the additional costs associated with caring for their child do not. Savings and security are sapped and families are often forced into debt. High levels of stress, poor health and low self-esteem generate additional demands on

support services, and compound poor prospects of future employment. It also considers the adverse impact a sudden drop in income has on disabled children, who, in addition to a lack of material items, may be forced to give up leisure activities or much needed therapeutic support services. It considers how families whose child has not been awarded DLA cope when their income support (which is already below the poverty line) is sapped by additional disability-related costs.

Chapter 7: assesses families' attitudes to employment, and to the Government's 'welfare to work' strategy. It reports that although the majority of mothers would like to be in part time work, they readily relinquish the possibility of paid employment in order to care for their children. However, they do not feel that their role as carer is acknowledged or respected. It discusses the barriers parents face to employment, studying and voluntary work, and their aspirations for the future. It considers the advantages and disadvantages of paid work for both mothers and fathers, for lone parents and couples. It emphasises that reducing benefit will *not* compel a parent who wants to care for her child to enter employment.

Chapter 8: discusses the various ways in which fragmented statutory services compound rather than alleviate the financial problems experienced by families with disabled children. For parents, the lack of 'joined up' services remain the weakest link in the Government's strategy on child poverty.

Chapter 9: seeks to place the families' experiences into theoretical investigations of social exclusion. Tony Atkinson has identified three common elements that should underpin any discussion of social exclusion (quoted in Hills, 2002):

- ◆ Relativity (people can only be gauged relative to others in a given time and place).
- ◆ Agency (where people are excluded due to action of some agent).
- ◆ Dynamics (where exclusion may come about because of dim future prospects and not just current circumstances).

Does this framework provide an appropriate model for assessing social exclusion among families with disabled children?

2. Methodology

2.1 Why qualitative?

Given that so little is known about the day to day income needs of families with disabled children, and that even less is known about how they spend additional benefits, it seemed important to provide parent-carers with sufficient leeway to

introduce their own themes and topics. I felt that the best way to achieve this was to conduct in-depth structured and semi-structured interviews with a limited number of families.

Locating families

It was clear that locating families – some of whom I hoped would fall into the ‘hard-to-reach’ category – would be extremely difficult. I therefore recruited the support of three local authority welfare rights advisors who are engaged in benefit take-up campaigns targeted at families with disabled children who put me in touch with other welfare rights advisors. The advisors provided a wealth of information that was used to inform the topic guide, the personal interviews – and indeed the report. They all put me in touch with families. Three welfare rights advisors who put me in touch with families have disabled children themselves.

Introductory letter and consent form

Families were sent a letter of introduction, a consent form, an ethnic monitoring form and a freepost envelope. Families who agreed to be interviewed were offered a £5 Boots voucher and a copy of the *Disability Rights Handbook* published by Disability Alliance. The pack included a covering letter from the welfare rights advisors emphasising that families were not obliged to participate. One of the welfare rights advisors discussed the research directly with parents.

Criteria for selection of families

In order to assess the impact additional income has on families’ lives, I was keen to talk to families whose benefit (predominantly DLA) had been awarded, downrated or withdrawn in the last year. Most of the families who participated in the research fell into this category.

I was also interested in talking to families who had either moved into, or out of, paid employment in the last year. None of the families who participated in this study had moved into employment. Three fathers had recently moved out of paid employment. One mother reported that she would shortly be moving out of paid employment, another was considering whether or not she could afford to give up her part time job, and a third mother was seeking to reduce her hours.

Topic guide

I devised a detailed topic guide that focused on themes that had emerged from research I had undertaken at Disability Alliance into the extra costs incurred by families with two or more disabled children (Disability Alliance, 2005), the wider policy context and theoretical research findings. This was adjusted in discussion with welfare rights advisors and with families themselves.

Interviews

The interview schedule comprised a mixture of open-ended and structured questions based on the topic guide. All of the interviews took place with mothers. Most of the families expressed a preference to be interviewed in person rather than by telephone. Apart from one mother, the families were happy for me to visit them in their homes. Two mothers (Emily and Maggie) had their severely autistic sons present during the interview. One mother (Latoya) had her two non-disabled children present. Although a father was present on one occasion, he did not contribute to the discussion. All of the mothers were happy for the interviews to be recorded. Interviews took between an hour and half and two hours, and were often very emotional. Although mothers seemed grateful for the financial support they received, having somebody there to discuss their needs often unleashed a torrent of painful memories and feelings of anger. Although the mothers were all touched by the idea of a Boots token, I felt that what they needed was a great deal more support. Telephone interviews (which lasted a similar length of time to personal interviews) were, on the whole, less fraught. All names in the study have been changed. A number of the mothers chose names for themselves and their children.

I also interviewed two welfare rights advisors whose comments: are incorporated into the text.

The questions in the interview covered:

- ◆ Basic information about the family, including tenure, household composition, ethnicity, marital status, employment, information about their children, etc.
- ◆ Experiences of applying for disability benefits (primarily DLA)
- ◆ Family's income needs (extra costs)
- ◆ How family spent additional income
- ◆ How family coped when income went down
- ◆ Family experiences of employment
- ◆ Family's experiences of services

Disabled children and poverty: a child-centred approach

Although it had been my hope to interview some of the disabled children in order to provide a child-centred focus, this did not prove possible. A number of the children were non-verbal. Others were not available at the times I was visiting their mother. This is an area of the research that certainly needs further investigation.

2.2 *Composition of families*

The composition of the families was dictated by the specific focus of the take-up campaigns run by the three local authority welfare rights teams. Because all three areas are targeting families who are less likely to claim DLA, the children tended to have ‘invisible’ disabilities such as autism, ADHD, asthma, eczema, and Global Developmental Delay. This restricted the range of conditions and disabilities represented in the study.

The families interviewed include couples and lone parents. Although the majority were white, there were a number of families from black and minority ethnic groups. There was – inevitably – a different composition in the three different boroughs, with the most marked difference being between the two inner London boroughs and the a borough outside London.

Number of interviews and brief description of characteristics

I sent out 130 letters and consent forms. Ten telephone referrals were received. I interviewed 20 parent-carers, all of whom were mothers.

Marital status/ethnicity/employment

Twelve couples and eight lone parents participated in the study.

Couples	Black African	Black Caribbean	Bangladeshi	White	All
Some employment	1			8	9
No employment	1			2	3
All	2			10	12
Lone parents					
Some employment			1		1
No employment	2	1		4	7
All	2	1	1	4	8

Out of the 20 families, nine couples and one lone parent report that earnings were their main source of income. One lone parent works full time. Two of the mothers who lived in a couple household worked part time. Of the families reliant upon benefits, four are couples and seven are lone parents. Of the couples, three fathers were out of paid work and one father was on ‘compassionate carer’s leave’. One couple were dependent upon income support. One couple are living off savings. One lone parent was living on savings.

- *Inner London Borough* – all three mothers who participated were lone parents. One was Black British (her mother is Black Caribbean), one was Black African, and one is Bangladeshi.
- *Inner London Borough* – five lone parents (one was Black African, four were White British.) Four couples (two were Black African, and two were White British.) One father was in full time employment.
- *Borough outside London* – all six participants were white British, and lived in couples. All of the fathers were in full time employment.
- *Families provided by other sources* – one mother, who was White British and lived in a couple. The father had recently left work and become a full time carer. A mother who was not interviewed contributed some observations on employment. She was White British and lived in a couple.

Children

Out of 20 families, there were 51 children, 28 of whom the mothers reported as being disabled or having special needs. Of the 28 disabled children, eight were girls (age range 21 months to 16) and 20 were boys, (age range 3 ½ to 17). Of the 26 non-disabled siblings, 17 were girls and nine were boys (age range – 21 months to 17). Six families (including two lone parents) had two disabled children out of whom three families also had non-disabled siblings. One family had three disabled children.

A number of the children had a variety of overlapping conditions

Condition	Number of children
Autistic Spectrum Disorders	14
Global Developmental Delay	13
sensory impairment	2
behavioural problems	16
mental health problems (in addition to ASD)	7
chromosome disorders	2
cerebral palsy	3
ADHD	5
eczema, asthma etc.	6
fragile-x syndrome	2
Tourette's Syndrome	1
chronic pain syndrome	1

Parental ill-health

The majority of the mothers reported that coping with their children's needs without adequate support has taken its toll on their own health. Eight of the 12 mothers who lived in couple households reported that their health had suffered and four reported that their partner's health had also been adversely affected. Six out of eight lone parents reported that their health had suffered as a result of high levels of stress. Two mothers reported that they are disabled.

2.3 Method – thematic analysis

All interviews were transcribed in full. The framework used for analysing interview transcripts was based on the themes which emerged from Craig et al. (2003), described in section 1.3 above.

3. Benefits – a 'secure' source of income?

3.1 Disability living allowance

For families with disabled children, DLA is the primary source of additional income. It is a tax free, non means-tested, non contributory benefit which is not only ignored when assessing income for means-tested benefits but can lead to an increase in means-tested benefits. DLA is an extremely important benefit as it not only constitutes a significant boost to families' incomes, but an award of the middle or highest rate care component provides a gateway to other important forms of support (see page 6). However, despite this package of support for families with disabled children, benefit income varies enormously because of lack of information, low take-up and incorrect assessments which lead to a high number of successful appeals.⁴ Unfortunately, not all families get that far. It seems to be the case that some families accept an inappropriate award because they are worried they might lose their DLA completely, assume decision makers know what they are doing, or are too exhausted to fight. As a result families may lose out on a crucial form of support – sometimes for years. (The initial DLA cannot be backdated to earlier than date of claim. Entitlement to carer's allowance can only backdated for three months.)

3.2 Take-up

The Government does not have statistics of the number of people who are entitled to claim DLA but fail to do so. However, an unpublished report produced in 1998 estimated take-up of DLA care component to be between 30% and 50% and take-up of DLA mobility to be between 50% and 70%. (DSS, 1998.) Given the additional time constraints on families with disabled children,

⁴ Around 54% of appeals are successful - see footnote 2, page 6.

and the fact that increasing numbers of children have ‘invisible’ conditions their parents may not deem to be a disability, it seems likely that take-up is particularly low amongst this group.⁵

Furthermore, research indicates that ‘socially disadvantaged’ families are less likely to apply for DLA and carer’s allowance and are more likely to be turned down if they do apply, or to be awarded lower rates than families with similar needs (Roberts, Lawton 1999). Families from minority ethnic groups are even more disadvantaged than already disadvantaged white families with a disabled child (Chamba et al, 1999). Families with disabled children clearly incur significant additional costs and require extra financial support to help them cope. Does the system put families with disabled children off applying for the benefits to which they are entitled?

When asked what previously prevented them from applying for DLA, families mention reluctance to be on benefit and the fact that they do not consider their child to be ‘disabled’ but as having ‘special needs’. Caroline, a lone parent who applied for DLA for her three-year-old son Sam who has Global Developmental Delay comments: ‘... I think there is a very very big divide between disability and special needs, which is a much softer more encompassing term ...’

Negative press has also taken its toll. Lily, a disabled mother, explains: ‘You feel quite sort of inadequate... we don’t like asking people for money, we don’t like claiming for benefit ...I feel quite guilty – I feel like I’m sponging off the system – that’s how you’re made to feel...’

Other mothers are reluctant to be on benefits. Jane, whose son Marcus has severe ADHD, comments: ‘I hate to be thought of as a sponger – it looks like sponging – I want to prove I can be as good as everybody else ...’ Zoe, a lone parent who lives on income support comments: ‘I hate the stigma of being at home... I hate being dependent on the DHSS...’ Trisha, a lone parent who has only recently applied for DLA for her four-year-old daughter Sylvia, agrees:

⁵ In the *Child Poverty Review* published as part of the 2004 Spending Review, the Chancellor reports that financial support for disabled children (triggered by an award of middle or highest rate DLA) has increased by 70% since 1997. The numbers of children receiving DLA has increased by 30% since 1997, and by nearly 5% in the 12 months to February 2004. 256,000 severely disabled children currently receive DLA. On the subject of take-up he notes that ‘The DWP is working toward improving the claim process for disability benefits and developing a new DLA form appropriate for those looking after disabled children. It will be much shorter and responsive to customer needs. A more personal and responsive service will remove barriers and encourage people to claim.’

‘I’m very grateful to be on income support, but you know ... I feel like a second class citizen...’

Other barriers include:

- ◆ *Accessing information:* Caroline explains: ‘Everybody kept telling me this is a child with special needs ...but nobody actually told me that I was entitled to help – my health visitor, my GP, my social worker – I’m on good terms with all of them but they didn’t tell me.’
- ◆ *Getting hold of forms:* A number of families report that DWP employees who deal with telephone enquires and send out forms can seem obstructive and difficult and may proffer incorrect advice. The problems applying for DLA for a disabled child may put off a parent-carer applying for it for themselves or other family members. Margaret, a disabled mother who has three disabled children, explains: ‘The people on the phone aren’t very helpful – I’ve rung the office and you’re made to feel that if you’re going to complain you’re going to lose it, be thankful for what you’ve got. Your back’s against the wall before you’ve even got the pen out, and you start thinking maybe you shouldn’t apply...Sometimes you feel it’s a Friday afternoon and you think you’ve just got the wrong person.’ The experiences she has had claiming DLA for her children has put her off claiming it for herself.

Keeping track of an application can also be difficult. Caroline explains: ‘I got a printed letter saying “We are dealing with your application if you have any queries please phone us” so I did phone them and I got this woman who was so unhelpful - “No I can’t tell you anything because it’s confidential”, I said, “it’s my son ...”’

- ◆ *Filling in the forms:* Families have to balance applying for DLA alongside their other caring responsibilities. Although the forms have to be returned within a certain time, filling them in is often distressing and can take weeks. Anastasia, who has four children, two of whom are severely disabled explains: ‘It’s so heart-breaking – the first time I did one I cried buckets ... There’s this awful, awful diagnosis – and then you’ve got to fill in all these forms and you don’t know what day of the week it is and you’ve got to fill in the intimate details... you have to write “my poor little boy shits himself” and “you can’t take him shopping or let the gas man in because he’ll attack you or them”... it’s really traumatic once it’s in black and white. You can’t even begin to put every little detail down – a lot of parents are too embarrassed to put everything down and they don’t get what they’re entitled to...’

Lily, who is disabled herself, explains: ‘...you’ve got to do it when you feel okay, and that isn’t often...’

Applying for DLA is particularly difficult when parents are juggling other demands on their time. Alison, who applied for DLA for her son Jack and was turned down twice, explains: ‘Becky was in hospital at the time, you know, and I was going to the hospital all the time and I filled this in on the train ... I thought I had put everything down ...but of course a lot of the questions aren’t relevant to autistic children...’

Incorrect assessments

Although families are grateful for any additional financial support, they express frustration at the sort of injustices, anomalies and sheer incompetence that seems to characterise the decision-making process. Families identify a number of problems, including a fundamental lack of understanding of their child’s particular condition.

Zoe, whose 13-year-old son Adam has Down’s Syndrome, has always received middle rate care. Although she thinks she should qualify for the higher rate she comments: ‘I’m not going to go there any more, I’m not going to beg, but it’s absolutely ludicrous – my son is Down’s he’s therefore going to need care for the rest of his life, he cannot speak properly, I have to feed him, he’ll never be able to cook, I have to put him in bed, and check on him at night...’

Lily is a disabled mother. Her son Steven has dyspraxia, serious allergies and asthma and has received DLA middle rate care and lower rate mobility for three years. She comments: ‘I should have appealed for that care aspect – he needs day and night. I was just happy to get what I could, because if I’m not well I use his DLA to pay people to help with him.’

Emily, who has three children, two of whom are disabled, comments: ‘I think sending doctors around about the DLA is a very bad thing... because autism is not something that shows, it’s not an illness ... where you can see it. They could look at him and say “oh ...he’s all right” – but he has the skill level and the emotional level of a toddler.’

Additional difficulties are created when decision makers ignore a family’s specific request to get supporting evidence from an informed and trusted practitioner (for example, a consultant at Gt Ormond Street). Welfare rights advisors confirm that the DWP seem more inclined to contact a school than a medical practitioner, irrespective of the family’s wishes. Although families report that schools are often a valuable source of support, problems arise if there

is conflict – for example over securing special needs provision or a statement – or the school has failed to recognise and address their child’s particular needs.

Kathy, whose son Charlie has ADHD, recently lost his DLA, wearily comments: ‘maybe it’s what the school wrote...Because they’re on the tablets ... the children are like zombies... And yet... he’s got a statement, they’ve given him a Dictaphone, he needs extra classes, they have him for literacy, he has classroom assistants...’ She adds ‘You wonder whether they (the school) understand the implications of what they’re doing.’

Alison comments: ‘When I saw ‘advice sought from headteacher’ I didn’t even have to read it ... it used to be that they asked doctors but now they go to the school which is ridiculous because (the headteacher) doesn’t really know what’s involved at all ...’

Diagnosis

Although a firm diagnosis is not necessary to claim DLA, families may postpone applying until they can get medical confirmation of their child’s condition and detailed medical reports. However, a diagnosis is not always helpful.

When submitting evidence for an appeal, Alison wrote, ‘Jack has been diagnosed with mild autism. This to me is like saying a little bit dead. Autism affects you profoundly in every aspect of your life... Autism is *lifelong* developmental disability. There is no cure. So life for Jack will always be a struggle.’

Submitting subsequent claims

Submitting subsequent claims for DLA seems to be as difficult and stressful as the first time around. The initial experience may put families off re-applying.

Siddiqua explains: ‘When Taqi was very young he was given DLA lower rate care for four years. When it finished I couldn’t struggle with it again so I didn’t reapply. I thought, I can’t go through this again...’

Appeals

The majority of families in this study have been, or are in the process of going through, an appeal. For parents with disabled children, attending appeals for DLA often runs alongside educational tribunals and this imposes a huge stress upon a parent, the welfare advice sector – and presumably the benefit system as a whole.

Alison – who had her application for DLA for Jack turned down twice before the decision was overturned on appeal – showed me the paperwork involved, which included detailed reports, a summary of the issues written by the welfare rights advisor, and hand written evidence she compiled herself. It was about six inches deep. She comments: ‘I lost a stone and my hair fell out ...’ She was awarded middle rate care and low rate mobility for three years at appeal. She reports: ‘It was on technical point, I mean I know about Jack’s needs but I do not know the legalities...’

DLA mobility – misconceptions and misunderstandings

Families may not know that there is an additional mobility component within DLA to which their child may be entitled, or they may not think their child will qualify because he or she does not have a physical disability. They often use their child’s care component to subsidise their transport costs.

DLA mobility component – age limit

Parents whose child is under three are not entitled to apply for the mobility component. However, Rachel, who has 21 month old twins one of whom has cerebral palsy, is well qualified to comment on differences between her girls. ‘Most children will walk at two unless they have a problem... I don’t know that they appreciate that you’re physically carrying from room to room, and up the stairs. And at toddler group I am sitting with her constantly and I can’t go to (her sister) as easily ... I find it difficult when I’m out and about...’⁶

Motability

Problems arise when the mobility component is awarded for only two years, so families cannot apply for a Motability car (a charity that allows disabled people with higher rate DLA mobility component to buy or rent a car, but is only available to people with at least three years still to run on their DLA award). Lily explains: ‘...if a child is sick, you’re going to be toing or froing to hospital for three years – If we *knew* he was getting higher rate mobility for three years we’d go and get a Motability car ... But we can’t get it because we don’t know’

Carer’s allowance

Although applying for carer’s allowance (which triggers access to a carer’s premium for people on income support) is clearly significantly easier than claiming DLA, a number of parents were unaware of their entitlement. Families

⁶ An early day motion (a petition that all MPs are entitled to sign which seeks to raise topics which there is no time to discuss during the proceedings) calling for the a change in the rules so that children under three would be entitled to claim the mobility component of DLA was tabled in 2004 (EDM 484).

who do get carer's allowance view it as an essential if wholly inadequate source of income. Families with two or more disabled children are particularly aggrieved at its shortcomings. Although both members of a couple who have two or more disabled children can claim carer's allowance if neither works, a lone parent can only claim one carer's allowance irrespective of the number of disabled children and/or adults he or she cares for.

Alison, who has four children, two of whom are autistic, observes 'When Becky was in hospital it cost £500 a day ... I mean £43 a week for looking after a child like Becky.' Angela has recently been awarded DLA for her son Jack. She comments: 'I just assumed with the second DLA that I would get another carer's allowance, I mean maybe not the same amount, but a little bit extra ... I mean somebody said to me once "going from one child to two is like going from one to ten" ... but if it's a disabled child it's like hundred times harder...'

Income support

Although the carer's premium and the disabled child premiums within income support are an invaluable and welcome source of support, families report that when they are awarded the middle or high rate care component of DLA, their income support is not automatically adjusted to reflect this additional entitlement so families miss out on much needed additional support – sometimes for years.

Benefits and children aged 16+

The situation seems to get worse when your child turns 16. Anna, who has 17-year old twins, one of whom is severely disabled, explains that although she has been claiming DLA since her daughter was born and knows the system well, she still had to prevail upon her local welfare rights advisor to resolve difficulties claiming incapacity benefit for her daughter.

Tax credits

Families are confused about tax credits. Anna comments: 'My husband earns £700 a month – so I assumed we didn't qualify for tax credits, anyway the press put me off because it sounds like a nightmare...' Childcare tax credit is particularly hard to access – primarily because of problems finding registered childminders. It does not, in any case, cover the costs of specialist childcare provision.

Claiming DLA – the importance of advice

Families who participated in this study report that for them, the advice and support of a welfare rights advisor was critical at every stage of the procedure.

Caroline explains: ‘If it hadn’t been for (my welfare rights advisor) I know I wouldn’t have filled in the form correctly...I certainly wouldn’t have got any benefit and I certainly wouldn’t have got the level of benefit I had, because it has to be done in a particular way and she knows the particular way of doing it.’

Because families are in contact with a bewildering number of services, a welfare rights advisor can provide the sort of personal input and continuity of support they crave. Jane, who has recently applied for DLA for her 12-year-old son Marcus who has ADHD, explains: ‘They don’t act like benefit officers, they’re behind you all the way ... she always said “just ring me”... She was doing a course at the time on children with ADHD ... I thought she was mad when she told me I’ll get this much more a week – it was the first time ever somebody came up to give me money.’

3.3 Discussion

Failure to receive DLA and associated benefits renders low-income families with disabled children particularly vulnerable to high levels of poverty and social exclusion. And yet this chapter reveals that although families are in touch with a large number of professionals spanning educational, health and social services, hearing about DLA is a very random business. Even families whose children have been awarded a statement of special educational needs from their local authority may not know about their child’s potential entitlement to DLA.

Without a take-up campaign run by local welfare rights units as part of the Local Government Association’s ‘Quids for Kids’ campaign, the majority of families who participated in this study would not have heard of DLA and associated benefits, let alone applied for it. Although it would be helpful if the Government ran a national information campaign targeted at families with disabled children, this needs to be underpinned by a well-financed local authority and independent advice sector that can provide long term advice and support with appeals and reapplications.

Families and welfare rights advisors identify a number of other problems that prevent disabled children receiving their full benefit entitlement. Families who have applied for DLA report that information emanating from the DWP can be unhelpful and is sometimes incorrect. Difficulties arise when decision makers do not know enough about ‘invisible’ conditions like autism, or fluctuating conditions like ADHD, ignore parent’s understanding of their child’s condition and/or ignore parent’s suggestion about who would be most suitable to provide additional evidence. The Disability and Carers Service has introduced a programme of specialist training for decision makers, and is currently piloting two modules on ADHD and children’s mental health. This is very welcome and will, hopefully, improve the quality of decision making. However, short term

awards of DLA widen the scope for conflicting or contradictory decisions and are a source of considerable and unwarranted stress to families and the benefit system alike.

4. Families' income needs – extra costs

It is widely accepted that families with disabled children incur higher costs than families without disabled children. What are these extra costs and do the families in this study highlight anything new?

4.1 Financial costs

Staying in

◆ Wastage

Children with emotional and behavioural problems associated with conditions such as ADHD and some autistic spectrum disorders, can be both destructive and wasteful. Families in this study refer to the constant need to replace furniture, carpets, wallpaper and equipment. Although families are keen to emphasise that their children can't help being destructive, this tendency generates additional costs both inside and outside the family home.

Jane, who lived on income support without DLA for some years, explains: 'I had to pay to replace neighbour's windows when Jake was younger. I could have really done with (the DLA) then... all that damage to gates and fencing...'

Maggie, a lone parent whose two sons, Elliott and Emmanuel aged nine and eight, are both severely autistic explains: 'Emmanuel ... just wants to touch the food and throw it in the bin ... wanting to get into cupboards taking things, not to eat it but to play with it, taking drinks, drinking half – throwing it down the sink ...' She adds 'The two boys copy each other – both of them do tearing of clothes, they chew the clothes when they're frustrated, they rip the clothes ...'

Alyssa, whose nine-year-old son Gregory has been diagnosed with autism, explains: 'And in the bathroom – my shampoo or toothpaste, you know you've bought it but he takes everything, and then I've got to replace it. You've bought it but it's gone – or he puts the toilet paper in the water.'

◆ Food

Providing nutritious and healthy food for their children is a priority. However, children who are autistic often watch television obsessively and are particularly susceptible to advertising for expensive products or fast food restaurants.

Alyssa explains: ‘...instead of cornflakes Gregory wants Cheerios which cost £2.99 ... He wants the juice from the nice carton – the expensive one, he won’t drink the cheaper ones...when he sees a McDonalds, or Pizza Hut or KFC ... he won’t want to move, he’ll want to go in there...he’ll start screaming (and) when we go to McDonalds he doesn’t just have the Happy Meal – he wants five cheese burgers and no chips.’

Maggie, has had similar experiences. ‘When you’re out and he sees McDonalds ...he’ll want to go in there, he won’t move, he’ll start be screaming “Pizza Hut!”, “KFC!”...’

Alison, whose daughter is autistic and has a compulsive obsessive disorder, comments: ‘Becky only has selected food, because everything’s got to be microwaveable, and she likes certain sandwiches from Marks and Spencer’s that they don’t do (locally) ... I generally spend over £20 on Becky on certain things because it’s got to be special food...’

◆ Clothing

Replacing clothing is a constant expense. Jane, whose son Jake aged 12 has ADHD, explains: ‘... he destroys everything – he burns a lot of clothes and writes on them... School uniforms are extremely expensive, but we’ve had six school jumpers – he loses them in school and you don’t see them again. We’ve got through four coats this winter – he leaves them wherever he’s taken them off...’

Latoya, whose eight-year-old son Thomas has Global Development Delay explains: ‘He’s a big boy – it costs so much to clothe him. He wears (clothes for 13 to 14-year-old s) and adult shoes. I bought him a pair of football trainers (a month ago) the front toes are kicked through already. He gets through shoes and clothes a lot.’

Kathy’s son Charlie, who has ADHD and eczema, also wears men’s size clothing. ‘He has to have leather shoes – which cost a lot of money – and also cotton clothing – I buy his vests in Marks and Spencer’s, men’s vests, and they’re £10 a vest, really expensive, but what can you do?’

◆ Heating and laundry

It is well known that families with disabled children incur high costs because of constant washing and the need to keep the house warm day and night.

Anastasia, who has four children, including Oscar and Archie aged six and five both of whom have autistic tendencies and severe behavioural problems,

comments: 'I'm thinking of taking out shares in Persil...it's nine or ten loads of washing a day... I'm scrubbing the carpet ...it's everything.'

Zoe, a lone parent on income support who has thirteen-year-old twins, one of whom has Down's Syndrome, explains: 'Adam's not the cleanest of kids – he needs his clothes changing – there's a lot of washing – I've got a tumble drier and a washing machine ...and heating bills are £200 – it's a very cold house.'

Despite additional costs, families may not access the support that is available. Margaret, who has three children with different disabilities aged 17, 14 and 11, explains: 'Ryan wet the bed until he was seven, nobody told me he could get nappies ...or a covered mattress...'

◆ Toys and equipment

Entertaining children who spend a great deal of time indoors at home can be both costly and exhausting.

Elisabeth's four-year-old son Mark who is on the autistic spectrum is obsessed with listening to music. Often it's the only thing that will calm him down, particularly at night. 'I buy cds, hundred and hundreds of cds...'

Susan, whose 12-year-old daughter Victoria has experienced a deterioration in her eye sight and is now registered blind explains: '...I might have to get a widescreen tv to help her see it, if she's to play computer games she really does need a wide screen. And things like a laptop for school...'

Anastacia reports: 'We have sky telly – if we didn't my six-year-old would be absolutely horrendous. He doesn't want to go out and do other things. He will just rip your face off ...That's £45 a month that comes out of his DLA.'

Alyssa comments: 'Gregory loves electric toys that make noises and move around – but they need batteries. He doesn't like toys that don't move.'

◆ Families with two or more disabled children

Caring for two or more disabled children is extremely costly, particularly when they have very different needs and preferences. Maggie, a lone parent whose two sons aged eight and nine are autistic, explains: 'Elliott likes staying in and Emmanuel likes going out...' She either has to drag Elliott out or have Emmanuel climbing the walls at home. She has attempted to resolve this dilemma by providing outlets for Emmanuel at home. '...I bought the rocking horse when I moved here, it was £250 – I bought him the trampoline, I bought him the swing ...'

Going out

◆ Transport

Transport is one of the biggest sources of additional expenditure for families with disabled children.

Emily, who does not receive the mobility component for her severely autistic son Joseph, explains: 'Because I can't get the mobility – I have to do it all myself. I had to buy the car – it cost £4,000. I paid £500 deposit, but it's HP, £151 plus £86 insurance. That's £237 a month – if only they gave him the mobility ...'

Susan explains that although Victoria has always been very independent, things have changed since her eyesight deteriorated. '...she can't see bus numbers, so I'll have to look into getting taxis... she can't judge the traffic...'

Even without financing a car or cabs, transport costs are often higher for families with disabled children. Margaret reports that she had to buy a large pram when her daughter was born which was big enough for both Ryan and the new baby. '...at least they were both facing me, so I could see what he was doing to her.'

◆ Hospital visits and medical appointments

These are particularly costly. Zoe recalls the problems she had juggling hospital appointments when the twins were babies '... it really was such a struggle. I had to get cabs everywhere. People forget that I didn't just have a Down's syndrome boy I had another baby as well ... my whole life was geared around ... double feeds – and umpteen hospital appointments, and I had no choice, I had to take Melanie, and Adam was in hospital with bronchial pneumonia, asthma ...'

Susan outlines the costs involved in taking her daughter to Moorfields. 'We go by train ... if two of us go in the rush-hour plus Victoria it works out at £17 per adult, and if you get an early appointment you can't get a cheap day return... We usually go to McDonalds or something after the appointment, which is another tenner... so it's about £50 just to go to Moorfields...'

Lily, whose son Steven is in hospital, explains: 'He's allergic to hospital bedding, so we've had to take bedding in for him. They do have a washing machine, but we take everything home ...we're got duvet covers and sheets coming home every day and we're doing the washing at home.' Meanwhile, her husband has taken unpaid leave to care for Steven – whose DLA stopped because he had been in hospital for more than 84 days (see page 52).

Medical appointments cost money even when they are for the parent. Anastacia, who has two severely disabled sons, recalls an occasion when she had to take the boys with her when she had to see her doctor. ‘They were both a bit poorly and my car broke down so I had to go by cab. As soon as we got there the eldest one crapped himself. The other little one was in the buggy. He was violently sick. The doctor told me to go home. That was another £8...’

◆ Safety issues

Keeping the home environment safe can be expensive, as can going out. Alyssa, a lone parent who has recently moved house, has a nine-year-old son Gregory who is on the autistic spectrum. One of the reasons they had to move was because the location of their previous house was too dangerous. ‘He climbed from the window – and we were near the north circular...’ Although she reports that getting a bigger house has made a big difference because she now has a garden, she still needs safety glass. Furthermore, Alyssa doesn’t like taking Gregory to a park near the house ‘...because if he knows where it is he will run away ... So if I take him to a park, I make sure it’s one a long way from the house...’

◆ Childcare

Although specialist childcare is extremely expensive, families often forgo the additional support they can get with childcare tax credits because they can’t afford a registered childminder. Elisabeth, whose three-year-old son Mark has recently been diagnosed as being autistic, works part time. She comments: ‘...I can’t afford a registered nanny. They said you can take an au pair (but) for a child who is special needs I was told it was £700 a month...’

Parents who can’t afford childcare sometimes prevail upon friends to help out. However, this still imposes costs. Siddiqua, a lone parent, whose son is severely disabled explains: ‘Friends come and sit with him and chat with him (sometimes) they stay. I provide food for them...’

◆ Leisure pursuits

Keeping children entertained when it’s difficult for them to play with other children is expensive. Maggie, a lone parent explains that when she lived in a flat with communal gardens, she couldn’t let her autistic son Emmanuel out (‘because he would be biting and pinching the other children, pushing them off the swings...’) but she couldn’t keep him in the flat either (‘he would be banging on the window because he’s seeing the children outside ...’). She therefore tends to take him to places where he can burn off his energy, but which cost money – such as Clown Town, Animal World or swimming. This becomes even more expensive when she has to pay someone else to take him, so she can care for her other autistic son at home.

Susan, whose daughter Victoria is now registered blind, comments: ‘...I have to pay to go in (to the pool) and I sit and drink a cup of coffee while she swims whilst other parents will drop their children off – and also I take a friend to help her in the changing room, so basically I pay for her, her friend and I go.’ The same is true for ‘free’ activities. ‘If Victoria wants to go shopping she can’t read the labels and so I have to make sure there’s somebody with her so if it’s a friend you always feel you have to invite them back to lunch or take them to the cinema as a thank-you – yes, it is a reciprocity, but it costs.’

◆ The cost of ill-health

Maggie’s own health has suffered because of the stress of caring for her two autistic sons and this generates additional costs ‘...because there’s times I’m sick ... I have to pay somebody to take Emmanuel out because he can’t stay in the whole day ...’

Lily, who is herself disabled, explains: ‘Even when he was on the middle rate and the lower rate – it’s not enough to employ somebody to take him to the park for two hours ... It’s £9.50 an hour once or twice a week, that’s £20 a week.’

4.2 Medical and therapeutic support

Disjointed services and NHS waiting lists force many parents to finance additional services and therapies that help their child’s development. Parents worry that if their child doesn’t get extra support during the early years it may be too late.

Jennifer, who has four children, two of whom are on the autistic spectrum, explains: ‘The occupational therapist we took John to six times ... made a great difference, but it was £60 for 45 minutes. And the speech and language therapist – it’s £400 for the initial assessment and then it’s £80 a week...’ Jennifer is also paying for intensive one-to-one therapy for between 30 and 40 hours a week for her four-year old son Nick who is on the autistic spectrum. Although this is sapping the family’s savings, she believes that early intervention is vital for his future development. ‘...I’m seeing it as a time when I’m just going to pour out the remains of my savings and we will hopefully go back to work in the future.’ The therapy will last between two and four years and costs about £8,000 a quarter.

Supporting evidence for DLA

Families who have applied for DLA sometimes pay for a private assessment to facilitate the process. Emily, a lone parent, has three children, two of whom are disabled. Hannah, aged eight, has learning and behavioural difficulties and Joseph, aged four, is severely autistic. She explains: ‘Two years ago my partner paid for Hannah to see a private psychologist to assess and identify any learning

difficulties – because it was private we got an immediate response – what you’re paying for is a report...’

4.3 Social costs

Over and above additional financial costs, caring for a disabled child without adequate support imposes social costs. Often the two overlap.

Families report that they often feel the whole family is disabled. Anastasia observes: ‘Having a disabled child is a lifestyle. It affects everything – what shops you go to, and who you have around to visit you and where you go, and whether you can socialise. We don’t tend to socialise ...’

Dealing with public opprobrium is an additional source of stress, and often prevents families from going out.

Emily recalls: ‘...I stopped going out, I used to get a family friend to do the shopping for me, I couldn’t handle other people’s attitudes to Joseph, and I couldn’t get him off the bus ... and I had him diving all over the road ... it was just a nightmare...’

Alison has four children. Becky (14) and Jack (8) are both on the autistic spectrum. She vividly describes what happened when she took her three younger children to the zoo. ‘This man said “Oh madam I’ve been watching you and you have no control over your children whatsoever” and Jack had flipped and he slapped Paula around the face, and I had a real go at him, and I asked him “Why did you do it?” and this man’s telling me I’m being a bad mother – it was a scorching day... and I thought Jack was going to run under a bus, and I said to him “Please mind your own business, he’s got autism...”’

Families with disabled children often find it difficult to balance employment with their caring responsibilities. Many will be out of employment for many years. Some believe that they will never be in a position to get a job. This often results in families feeling both isolated and useless. They do not just miss out on additional income, but on paying for national insurance, pensions and accumulating savings. They worry about their own future, as well as that of their children. This generates high levels of stress. (This is discussed further in Chapter 7.)

Social isolation

◆ Parents

The difficulties of finding a childminder mean that parents rarely get out. Extended family may not live locally, or may feel daunted by the prospect of providing support. Alison comments: ‘You don’t get much chance to socialise

...because if they're difficult to handle you don't get babysitters – even my sister said she'd have my girls over but she won't have Jack because he's always whining and crying and running off ...and my mum's too old, she's 78 and she couldn't cope with them at all.'

Latoya is a lone parent with three children. She has recently applied for DLA for her eldest son Thomas. She can't afford to pay a childminder but does not have family back-up. 'My dad died when I was pregnant with Susie, just before she was born. My mum died in 1999 and my brother died soon after. I have been through a tough time and then to have a baby ...' She adds 'I'm always in the house ... I don't really have many friends...I'm on my own.'

◆ Children

Mothers report that their children may be unable to engage in everyday activities enjoyed by other children of the same age – like going shopping, visiting a friend's house, or having somebody over. They often have to pay for 'inclusive' activities that are free for other children, such as football. Furthermore, children are sometimes excluded from after school clubs or play schemes that are available free to other families because of behavioural problems. Families may end up having to finance alternative arrangements or care for their child at home.

Maggie explains that although disabled children in the Borough are entitled to 25 days a year in a play scheme run by social services, Emmanuel has been banned since June 2003. '...so next week (half-term) he will be with me. He won't even have two days...'

Nicole's son Alexander is on the autistic spectrum. She explains: 'Because of his problems he couldn't attend the after-school club which is free (for other children) They say "We can't have him at the club" – he's denied even that in the school, so we had to pay for it.'

4.4 The cost of social exclusion

Family breakdown

The relentless stress of caring for a child with special needs or disabilities without adequate support imposes a huge strain on relationships.

Alison comments: '...I've always felt (like a lone parent) because he couldn't handle the children. You get a lot of single parents with families with disabilities because you have no time to work on that relationship whatsoever.' Alison is now separated from her husband.

Elisabeth, whose son is severely autistic, reports on the strain this has placed on her marriage. 'We were also having a crisis here with my husband because of the child. We're all tired. My husband's diabetic and has to have insulin...We are almost breaking down...'

Anastacia recalls that when her husband was working full time their relationship was put under considerable stress. 'He didn't realise what it entailed. On the rare occasion that we did see him we'd be screaming at each other.'

Ill-health and disability among parent-carers

It is hardly surprising that most of the parent carers report that their own health has been adversely affected by the stress and strain of caring for their children without adequate support. Mothers report on high levels of depression and anxiety. Fathers as well as mothers suffer.

Anastacia reports: 'I had a breakdown and I'm on anti-depressants, (my husband)'s been registered as an insomniac and is on anti-depressants.'

Alison also has stress-related health problems. 'I just feel totally tired all the time and then you get depressed and now with this strike out thing with the LEA that was like a body blow...the way I feel at the moment I don't think I'll be here that much longer – it really grinds you down.'

Margaret reports that the stress of caring for three disabled children without adequate support has had a devastating impact on her health. 'It was the strain and stress of fighting for everything that the children need, I got shingles in my right ear which resulted in encephalitis on the right side of my brain ...I lost 80% of hearing.' Margaret's husband had to take time off work to help care for the children while she was in hospital, and to look after her when she came out. The family was thrown into crisis when Margaret developed the same condition in her left ear. 'They said it could never happen twice...'

Maggie, a lone parent whose sons are both on the autistic spectrum, comments: 'I get arthritis and could get physically run down, it's extremely difficult for me to get up and do things ... it can affect me looking after the kids ...when you're actually really at your lowest physically it's difficult to get up and do anything – that's when I worry ... it's hard to do things for my kids.'

Additional caring responsibilities

A number of the families have additional caring (and indeed financial) responsibilities for sick or disabled members of their extended family – including spouses, grandparents, siblings, nieces and nephews.

Zoe comments: 'It's not just one, you know, I had my sister who had a stroke, my dad's been very poorly, I have Adam who has the Down's Syndrome ... and my twin sister's son – my nephew – is schizophrenic. People don't realise that you do have extra responsibilities.'

4.5 Discussion

This chapter confirms that families with disabled children incur a range of additional expenses, including significantly higher transport costs, hospital appointments and the need for additional equipment and extra laundry and heating. Additional costs sap income whether or not the family is receiving their full benefit entitlement.

Families emphasise that material costs are compounded by disjointed services and NHS waiting lists. Parents often finance private medical and therapeutic support for their child. Additional costs have an impact in both the short term and the long term. Early interventions are often viewed as essential for a child's development, while difficulties accessing paid employment depress current income levels and diminish future financial security. Social costs – such as family breakdown and social isolation – are compounded by high levels of ignorance and discrimination amongst the public as a whole, and indeed amongst some service providers.

5. Impact of an increase in income

For low-income families, disability benefits can make the difference between a family getting by, and going under financially. As Maggie, a lone parent with two autistic children, observes: 'I would not be able to cope if I didn't get DLA and extra support – I would not.' In families on a higher income, extra costs still sap finances, and prioritising expenditure is a source of endless anxiety. DLA provides a psychological sense of entitlement. While much additional income is sapped by the extra costs involved in caring for a child who is sick, disabled or has special needs, the whole family often benefits from extra income.

An award of DLA often alerts families to other sources of support for families with disabled children – for example, the Family Fund. Latoya, who had not received DLA at the time of the interview, has successfully applied to the Family Fund with the help of an advisor. 'It's fantastic,' she says, 'I'm definitely going to apply every year!'

5.1 Spending priorities

How families spend their additional DLA income varies according to how long they have been receiving it, whether they have received a lump sum in

backpayment, and if they anticipate losing it in the future. As will be discussed in Chapter 6, families report that they do not view benefit income as a secure or long term source of income, and this uncertainty has an impact upon day to day financial decisions.

On the one hand, families who are able to do so desperately try to save up to cushion fluctuations in income. Anna, who has twin daughters aged 17, one of whom is severely disabled, comments: ‘You have to put things aside every week – you do have to save ... otherwise I don’t know if you can cope, if things crop up suddenly it’s very hard...’

Families on low incomes who may be unable to save have to take each day as it comes. Maggie observes ‘...I’ve learnt to deal with stress in a different way... I’m not looking to the future. If they take it away in the future I’ll deal with it when it comes, because there’s always something...’

5.2 *Financial benefits and social inclusion for disabled child*

Staying in

◆ Creating a welcoming home environment

Children who are disabled or have special needs often can’t play outside with their friends. They may spend a disproportionate amount of time at home. Trying to create a welcoming environment for all the family is viewed as crucial.

Nicole’s son Alexander is on the autistic spectrum and has ADHD and severe behavioural problems. She recently received support from the Disabled Facilities Grant. ‘... It’s made a really big difference – he’s not in with his brother arguing ...he’s able to have friends around. He’s just had his first sleepover. All he wants in life is to be normal and experience life. I think he thinks of me and the school as ‘jailers’. Having the space means getting him used to being responsible for his own things and his own space and developing life skills ... he feels he’s like everyone else.’

A more pleasant environment can be created if broken furniture is replaced and rooms re-decorated. Alison who lives with her four children, two of whom are on the autistic spectrum, constantly worries about the state of her home. When she recently received DLA backpayment for her son Jack it made a real difference. ‘I used it for some of the things I needed to replace that he had damaged – he really takes it out on the furniture...’

◆ Home entertainment

Television and computers are often viewed as vital pieces of equipment for disabled children who spend more time at home. The ability to buy new games

not only keeps the children entertained at home but may facilitate interaction with other children. This can take some of the strain off the rest of the family. It also helps children interact with their peer group. Jane, who uses her sons' DLA to buy X-box computer games, comments: 'They can go to their friends and swap games – people won't swap if you've got nothing to swap with...'

◆ Educational equipment

Parents will do anything to help their child's development. Additional income often enables them to buy extra pieces of educational or sports equipment that might otherwise have been beyond their means.

Susan, whose daughter Victoria has recently experienced a significant deterioration in her sight, explains: 'I will use (the DLA) to buy equipment that I can't get through statutory sources – CCTVs that you can get at schools but you can't get at home where you run like a gun over words and it comes on a screen.' She has also bought a large print French dictionary, which cost £28. She is hoping to buy a wide screen television for use at home, and a laptop for school.

Emily uses PECS (Picture Exchange Communication System) with her four-year-old son Joseph who is severely autistic and is non verbal. She explains: 'When I received the £300 backpay – I was able to laminate pictures and photographs for his communication... I make little picture books ... you've got to buy the camera...'

◆ Treats

Disabled children sometimes feel guilty about the stress their needs place on their parents and are therefore reluctant to ask for anything extra. Additional income can reduce guilt in the child. Siddiqua, a single parent whose 15-year-old son Taqi is severely disabled, comments: 'I can afford treats for my son because he doesn't ask for anything...'

Going out (participation)

◆ Goods and services

A number of families use additional income to secure services they might otherwise have problems accessing – such as speech therapy, occupational therapy (OT), educational assessments or alternative therapies. Families point out that giving their children extra support in the short term will improve their long term social, emotional and physical development.

Caroline comments: 'I do believe in alternative therapies, so I have spent quite a lot of money taking Sam to cranial osteopathy and reflexology. (The DLA) will

ease the situation by paying for these therapies.’ She adds ‘...if people aren’t getting the help now they will be a burden on the NHS as they get older ...’

Jennifer pays for activities such as music therapy (which costs £20 for 20 minutes) for her five-year-old son John who is on the autistic spectrum. ‘I don’t think it’s like doing OT or speech therapy – but he loves it, and it’s so good for him to be good at something ...I’d say it was these slightly more fringe activities which are good for the children but not absolute necessities of life. I feel entitled to get them for John. In a way you just want to do the best you can with a special needs child – so if you want to give them osteopathy, music therapy, speech therapy – anything – I will throw it in his direction because you want to give them the best possible chance...’

◆ Going to the cinema, swimming, museums

Zoe’s 13-year-old son Adam has Down’s Syndrome. She explains: ‘Mainly it’s ... taking Adam out and entertaining him... things like outings to the swimming pool and I bought a paddling pool, and although he’s thirteen he needs the stimulation and it keeps him cool ... I’d love to see him ride a bike but ... he wouldn’t be able to stop because he’d get too excited – so I got him the scooter...you have to be careful what you buy them as well...’

Emily’s daughter Hannah loves going to the science museum and the London transport museum. ‘...I let her buy her little bits to show she’s been to the museum – they bring them home and make a scrap book, a collage.’

Maggie has two boys who are autistic. The younger one needs to burn up a lot of energy. The DLA means she can pay somebody to look after Elliott, who prefers to stay at home, while she takes Emmanuel swimming. ‘I take him swimming when it’s spring, and in the summer it’s three times a week ...’

◆ Paying for socially inclusive activities

Families often have to pay for socially inclusive activities to compensate their child because they are unable to join in activities that are free for children who can go out on their own – for example to shop, play football in the park or ride a bike. It helps children who may have difficulty feeling socially accepted to participate in every day activities.

Sports clubs: Nicole observes: ‘Because Alexander’s lacking on the social side and has difficulties playing out with other children, we’ve tried to integrate him in other ways – it also helps him to burn off energy.’ She is keen for him to attend clubs that enable him to socialise with other children in a way that he wouldn’t be able to do in an unstructured environment. However, it is expensive. ‘His football club costs £60 to affiliate plus all the gear and he’s in

the swimming squad, which costs £22 a month.’ It’s not just Alexander who benefits – the whole family does. ‘...it allows him to be with other children – and it gives the other children in the family a break, because he’s hard work when he’s here.’

Susan explains that since her daughter Victoria’s eye sight has deteriorated she has done everything she can to minimise the impact on her life. Although Victoria’s dreams of being an Olympic athlete may not now be realised, Susan is determined to help her daughter continue to run. ‘(The DLA) does make a difference ... I’ve got to pay a club athlete to run with her because she’s fast, and you can’t expect people to do it for nothing...I get about £53 a week – and if you’re paying a guide runner, they’ve got to be there quite early on and stay throughout the competition ... it’s £30 a competition and you’re doing one a week during certain seasons...’

Play schemes: Families sometimes pay for their child to go to play-schemes which not only helps their disabled child socialise, but gives them time with their non-disabled children. Alyssa takes her nine-year-old son Gregory to a Saturday play scheme which gives him the opportunity to interact with other children and gives her precious time with her two daughters.

Reducing stigma, increasing choice

Children who have special needs may be only too aware that they are different in some way, and hanker after being like other children. Additional income can help to reduce feelings of inadequacy and help them feel ‘normal’. Small things – like eating the same food as other children at school – makes a big difference. Jane who was on income support when her son’s DLA and her carer’s allowance came through comments: ‘If the boys say “Can we have cheese strings this week?” I can say “Yes, okay” whereas before I’d say “Do you know how much those cost?” It makes a difference for the children at school – they used to come home and say “The kids are laughing at me because I’m eating marmite sandwiches”, but now I can put things into their lunch boxes that the other kids have...’

◆ Clothing

Additional income sometimes enables a parent to buy new clothes for their disabled child, thereby avoiding them being further stigmatised and deflecting criticism of themselves as ‘bad parents’. Anastacia, who has four children, two of whom are severely disabled, comments that receiving DLA means ‘I don’t have to rely on handouts regarding clothing ...’

◆ Going shopping

Families with disabled children often feel criticised by members of the public when they go out. The ability to go shopping for food – and avoid tantrums, by saying “Yes you can have that” or feel that they are buying the same food as other people – reduces stress and enhances a sense of belonging.

Jane explains: ‘When we go shopping now I don’t have to buy the cheap labels – I can buy something a bit special – I can have the same shopping as the person next to me... I don’t feel ashamed – I can buy Walker’s crisps, or Bird’s Eye fish fingers...’

Where it is possible and appropriate, families let their child know about their DLA award, and give them the opportunity to choose how they would like to spend additional income.

Alison comments: ‘Well, they get that money because they’re disabled – I’m not disabled – it’s not for me ...’ When Jack was awarded £2,000 in backpay she explains: ‘I told him it was for him, he was so pleased, he does choose things ...I left £1,000 in his account and if he wanted a treat you know... he’s actually got a bit of an obsession with bouncy castles and I bought him one that cost about £200 and you know it was a lovely thing for him – the (carer’s allowance) is mine but that’s his ...’

Margaret, who has three disabled children, explains: ‘We have a family conference and ask how are we going to spend it.’

Emily comments: ‘I say “Mummy’s got a little bit of extra money, would you like to go to this club this week, or would you like to wait until half-term?” I do tell her it’s for her, but I don’t say it’s called DLA and you get this much this month, but I give her the opportunity to make choices, and tell me what she’d rather do. ...’

5.3 Social inclusion for the whole family

Staying in

When going out is difficult, it makes a difference being able to eat together at home as a family. Anna comments: ‘The DLA and (carer’s allowance) just got sucked into the general family budget, but it was good to pick the cash up every week – it meant if we’d had a bad week and wanted a takeaway we could just buy it without feeling guilty.’

Families on a low income experience high levels of stress around Christmas time. Additional financial support helps them feel more like ‘an ordinary family’. Alison recalls ‘At Christmas for example (I used the backpay) and got

some nice treats ... I bought them presents ...and I could buy some nice food – not caviar or anything, but nice chocolate biscuits, and it made such a difference this year. We had a really lovely time, and otherwise I don't think we would have had anything very much...'

Siddiqua, a lone parent whose son is severely disabled, comments: '... I enjoy having friends and family over for a meal – I love to cook. When was on income support... I had to think how I could manage – but now I say come on over...'

Going out

An increase in income is often used to take the whole family out. Jane comments: 'Before it was constantly empty promises – you say you'll do something maybe at the weekend or the holidays, but it never happened. You say it to shut them up at the time – it makes you feel like a terrible mother...'

Margaret – who has three disabled children – explains that the DLA enables the family to go on outings such as bowling, or visiting the science museum. She recently bought all the children roller blades. 'The mobility helps get us into London – we can go to Hyde Park – it's something we can do as a family – we wouldn't have been able to do it before...'

◆ Transport

Access to a car is seen as vital, particularly when there are two or more children. Anna, who has 17-year-old twins, one of whom has cerebral palsy recently bought a second-hand van that has been adapted to take a wheelchair. 'The DLA went on the car – that cost £6,000... It was a real good investment and it was what the family was in need of and is still in need of.'

A number of families use their child's DLA to pay for driving lessons to ensure that they do not become completely housebound. Emily explains that because of the difficulties she experienced taking her younger son on public transport, she was unable to leave the house and had to ask friends to do her shopping. Emily used Joseph's care component to finance driving lessons and put down a deposit on a car just before Christmas. 'I never thought I'd pass my test because I went three times... I was thinking I have to do it for Joseph – and I felt I'd let him down...I spent up to about £2,000 on lessons and driving tests. I wouldn't have been able to do that without the DLA.'

◆ Holidays

Although the Poverty and Social Exclusion in Great Britain Survey (PSE) (Gordon et al, 1999, see page 7 for further details) designates 'a holiday away from home once a year not with relatives' as a 'necessity' and not a luxury, few

families with disabled children can afford this. However, Alison is using Jack's backpayment to take the whole family away. 'It was lovely ... I've put down a deposit for Euro Disney with that money ... because I've been saying to Jack that I would take him to Euro Disney since it opened and Jack was little really, and I've never had the money ... it's a lovely treat for Jack and it is something we'll never do again, ever, and he's thrilled to bits...'

Kathy, who has recently been awarded high rate DLA and middle rate mobility for Charlie, explains: '...my friends are going to Ireland for a party just for the weekend and me and Charlie might go, it would be nice, because we don't really go out...'

◆ Eating out

Jane, who has recently been awarded DLA for her 12-year-old son Marcus, comments: 'It enabled us to go out as a family ... I could take them out to a restaurant and teach Marcus how to have manners in public places. There's no way we could have done that before (getting DLA and CA)... The trouble is, I can't leave out the other two. If I take one out for a meal, I've got to take out all three. It means I can think and plan ... "It's going to cost £35 to go to the restaurant" or "£15 to go to the cinema."'

◆ Visiting family

Jane reports: 'I can say to my family – pop over and I'll make you a Sunday dinner – or I can take a bottle of wine to my parents ... I've always been made to feel that I haven't been able to do what's good enough – now I can hold my head up and say "There's a bottle of wine that cost £10..."'

5.4 Parents, financial security and social inclusion

It is difficult to quantify social inclusion as opposed to financial benefits. Additional income brings about both. Mothers report that they (and indeed their children) feel less anxious, and that their self-esteem rises because they feel they are providing for their children.

Increase in self-esteem

A poor self-image may compound feelings of inadequacy and isolation. Jennifer, who has four children two of whom are autistic, comments: 'I don't go shopping and buy clothes and I feel very dumpy – it sounds frivolous but the self image thing – if you feel you're frumpy ...' However, additional income enables mothers to give themselves an occasional treat. Siddiqua comments: '... and I could buy clothes for myself – I love to buy clothes ... I still can't afford any luxuries ...'

Jane explains: ‘I feel a member of society again – before I felt such an outcast ... I feel I’m providing better for my children.... I’ve been given back a bit of self respect and self worth. As an adult you want to be a provider for your children, and you want to be seen as somebody who does provide and has standing in society. Once you’re on income support you have to be beholden to them – you no longer have your own life – you have to tell them if your boyfriend comes around, but with DLA (you don’t have) anybody telling you what to do with it.’

Latoya, whose son Thomas has recently been awarded DLA, reports: ‘It makes a big, big difference. I just feel better inside. It’s hard to explain but I feel better about myself.’

Reduction in anxiety – for parent and child

Parents constantly worry about their child’s health, their education, and their future. An increase in income resolves one major source of anxiety. Clearly all the children benefit if their parent-carer is less stressed. As Jane observes: ‘It gives you more freedom – you think “Yes I can buy that – I don’t have to worry.”’

Siddiqua reports: ‘...when we were on income support it was very, very hard – I was always worried, and my son worried about me. When we got the DLA my son felt less worried about me...’

Kathy confides: ‘I won’t have to think I have to start putting away for shoes, for this and for that – I’ll be able to not just worry...’

Joining support groups

Parent-carers often feel isolated and unsupported. Attending support groups helps them understand their child’s condition better and brings them into contact with other families whose children have similar needs.

Alison comments: ‘I made a point of joining MENCAP ... I joined the National Autistic Society, sometimes they have lectures, and they cost £60...’

Emily attends meetings on Autism Spectrum Disorders which enable her to understand Joseph’s particular needs. ‘I can help a lot more now (but sometimes) they want you to make a contribution ...’

Financial security

◆ Saving and paying off debts

Families are often concerned that their child may not be able to attain educational qualifications in the short term, or access paid employment or

independent living in the long term. They worry that their children will never be financially independent, and wonder what will happen when they are no longer around to care for them. Despite the difficulties involved in doing so, they try to put money aside for their children's future.

Alison reports that, although it imposes additional strains on family finances, she puts all of Becky's and some of Jack's DLA in ISAs and intends to set up a Trust Fund for the whole family. 'Becky's long term prospects aren't very good if she hasn't got any qualifications – and things like getting herself up and getting herself to work, sometimes she doesn't even know what day it is... she says to me "I'm not going to get a job because you'll be there to look after me" (but) you could go out and get run over by a bus and there doesn't seem to be anything out there ... What happens to the children? Presumably they go into care, and you don't know who's looking after them... she won't be able to get, you know, nice things ...'

However, Alison concedes that saving is extremely difficult and is an additional source of stress. 'I know Jack will let me have it if I'm desperate ...you know I've borrowed the £400 (from Jack) and I feel very guilty, that's why I like to tie it up because if you haven't got the money it is very, very tempting...'

Parents with disabled children are often unable to access paid employment, pay national insurance or finance pensions schemes. They worry about their own future as well as their children's.

Nicole explains: 'My husband and I have only just taken out pensions – I use my carer's allowance to fund a modest stakeholder pension for myself...If Alexander's not able to go off and function on his own, our income will dwindle – we're both in our 40s, we've got to have the means to live ourselves...'

Anna comments: '(The DLA)'s all going to be put by because we don't know what will happen in the future – we've spent all our savings on the adaptations to the house – so any extra money is replenishing our savings.'

Families get extremely anxious about being in debt and do their best to make ends meet. (Jane's views that 'I'd rather not have anything than go into debt...' are echoed by many.) While a sudden drop in income may force families to borrow money, a rise in income enables them to pay off some of their debts. Kathy, who lost her DLA completely just before Christmas, borrowed money from her mother to help get by. When she was awarded high rate care and middle rate mobility at an appeal, she was 'over the moon'. Previously she had

planned on paying back a little bit every month out of her income support, but now she can pay off her debt completely.

◆ Financial autonomy

The mothers in this study tend to shoulder the primary financial and caring responsibilities for their children, even when they live in a couple. They are therefore heavily reliant upon their partners or husbands to provide for them financially. Fathers who are at work all day may not fully appreciate the financial demands involved in caring for disabled children. In a world in which women often feel powerless, mothers welcome having carer's allowance paid into their purses.

Alison comments: 'This is my money and I don't have to keep going to him, that's a little bit to make life a little bit easier for us really... if you ask he says "What do you need that for, I gave you £20 yesterday?"... Having carer's allowance makes a difference because sometimes I can get them a little treat you know ... a little toy, or fancy food we wouldn't normally do, that is wonderful.'

Jane recently moved off income support after her partner moved in with her. She explains that getting DLA and carer's allowance gives her a certain amount of financial autonomy. '...they're not his children – I can use the money for the children and myself without having to ask him (their father doesn't give them any money...) I'm going away with my partner for four days tomorrow ... if there's anything I see to buy for myself or the children – I don't have to ask him for the money.'

Jennifer comments: 'I was pleased to get the DLA because ...it makes me feel better about certain things I spend on John. I feel I'm not taking away from the other kids.'

◆ Transitions out of employment

If all goes well, additional benefit can cushion families who are in transition out of employment. Anastacia's husband recently gave up full time work because of ill-health brought on by the stress of combining working and caring for their two seriously disabled boys and their two non-disabled sisters. He is now in a position to help care for the two boys on a full time basis and – like Anastacia – can claim carer's allowance. Anastacia observes: 'The DLA and (two lots of carer's allowance) made a big difference – it worked out about the same as being at work really... the higher rate DLA made the difference, we really would be on the breadline without it... we would not be coping at all...'

Nicole comments that because her husband's income from earnings fluctuates, the DLA and carer's allowance provides some continuity and financial security for the whole family. 'It's a bit of a lifeline for us really – we could get periods when my husband's not working ... it really does tide us over as a family...'

5.4 *And for siblings...*

Families fear that their non-disabled children feel that they have to come second, and welcome the opportunity to give them treats.

Jennifer and her husband both worked full time when their eldest son Andrew was young, but she gave up work after the birth of their twins, and her husband lost his job soon after because of his caring responsibilities. She explains: 'I think the other siblings have a rough deal – I think it's hard to quantify that ... Andrew has very strong memories of his young time, and he does feel it's different – and I think he's very angry – in fact he's so angry at the moment we're giving him a birthday party on Saturday – even though it's not his birthday...' She adds 'I usually give him half a cake and half a party but I thought this year that isn't going to be good enough – he's got to have everybody in his class...'

Anastacia, who has two severely disabled sons, observes '...and the girls don't get what they need because the boys get all the attention...' However, she has now started giving her daughters, aged nine and eleven, an allowance.

Alison frets about the state of the house and worries that her non-disabled daughters are reluctant to ask friends over. When she recently received DLA backpayment for her son Jack, she was able to replace some of the items he had broken which improved the home environment. She is also in a position to take the whole family to Euro Disney. '...it's good for the other children, and you know particularly for my second one Laura, I mean since Becky's come out of hospital she wants her there all the time and I think it will be lovely break for Laura, and for the little one ... they suffer in a dreadful way that other people that don't have children like that just don't realise...'

5.5 *Discussion*

This chapter indicates that receiving DLA and associated benefits makes a significant difference to families' lives. For low-income families, an award of DLA provides gateways to additional premiums and elements within Income support and child tax credit that may lead to family income almost doubling. (For a lone parent on income support who has one disabled child, an award of DLA highest rate care and higher rate mobility, along with addition premiums and elements, will increase weekly income from around £100 to nearly £200.)

Families view DLA as being for their disabled children, and use it to compensate them for both social and educational problems that are a direct consequence of their condition or impairment. They use additional income to secure services they might otherwise have problems accessing or to pay for structured, socially inclusive activities that help their child interact with their peer group.

A rise in income often results in an increase in self esteem for both parent and child. Mothers feel that they are better providers. They report that having carer's allowance paid into their pockets gives them financial autonomy, a finding that reinforces research into child benefit (Pahl, 1989). However, it is clear that families do not view benefit income as a secure or long term source of income. This uncertainty has an impact upon day-to-day financial decisions. Saving for the future is viewed as particularly important for families who may be out of paid employment for many years and fear their child will never be financially independent. However, struggling to put money aside further saps income levels and is an ongoing source of stress and anxiety.

In many ways, the findings in this chapter tally with research undertaken into the impact of additional benefit for older people – *Underwriting citizenship* (Craig et al, 2002). As with older people, an increase in income is spent on a combination of items, including 'essentials', 'mobility', 'goods and services' 'lumpy items' and 'personal forms of expenditure'. Greater autonomy and choice can enhance the whole family's sense of 'independence', 'participation' and 'identity'. Older people who experienced a rise in income viewed 'reciprocity', for example the ability to buy grandchildren presents, or take turns paying for petrol, as particularly important – as indeed did families in this study. However, while the families in this study raise similar issues to the pensioners who participated in *Underwriting citizenship*, the impact is perhaps more wide-ranging, because additional income has an impact on four aspects of family life: the family as a whole, parent-carers, the disabled child, the non-disabled siblings and their wider peer group.

6. Coping with falls in income

6.1 Benefits – a source of financial insecurity?

While an award of DLA brings about huge improvements in family finances, its removal has a profoundly adverse affect on the whole family. (A lone parent on income support whose severely disabled child loses DLA highest rate care and higher rate mobility and associated benefits will see their income halve from around £200 to just over £100 a week.)

Feelings of insecurity

Disability living allowance is notoriously difficult to apply for, and awards are inevitably subjective. Families whose children do not fit into 'physical' concepts of disability are particularly susceptible to different decision makers reaching conflicting conclusions. As a result, their child's DLA is regularly downrated, withdrawn, reinstated at appeal and then downrated again. As a consequence of this, most of the families in this study experience significant fluctuations in income. Families living on income support are ill equipped to cope with sudden drops in income. It is virtually impossible for them to build up financial safety nets upon which they can draw if their income unexpectedly plummets. They are therefore likely to be forced into debt (Contact a Family and Family Fund, 2004). Clearly the system generates considerable financial uncertainty.

Anastacia, a mother of four children, two of whom are severely disabled, explains: 'There's the added fear that ... sooner or later they're going to pull the rug out from under our feet. If you're working at least you can get another job, but in this life you're relying on them....you're frightened they will take it away. You don't feel financially secure.'

A false sense of security?

Families who do not understand the system can be lulled into a false sense of security. They may assume that their child will continue to get DLA at a particular rate so long as their needs remain the same.

Maggie, a lone parent who is on income support has two severely autistic sons. Her elder son Elliott's DLA was recently reduced from highest rate care (£57.20) to middle rate care (£38.30). 'I was shocked because he still needs a lot of attending to ... his needs haven't changed...' Meanwhile her costs remain the same. (Maggie has recently had Elliott's high rate care component reinstated at appeal.)

Elisabeth, who has applied for DLA for the first time for her severely autistic son, was dismayed when he did not receive the award she had expected. 'When it came back it was DLA middle rate care component, he was too young for mobility ...all they gave us was £38. Just before Christmas ...'

Families who know the system all too well can also be taken by surprise. Alison, who successfully claimed DLA for her eldest daughter Becky who is on the autistic spectrum, was astonished when her application for her younger son Jack, who has also been diagnosed as autistic, was turned down. 'I was quite shocked to be quite honest because I thought maybe he wouldn't get as high a

rate ...but it was when he didn't get it at all and I couldn't understand it, I couldn't understand it at all...'

Income support

While all families on income support find it difficult to cope, families with disabled children whose child does not receive disability benefits are at particular risk because extra costs sap an income that is already too low to live on. Although families on income support do notice a significant difference if awarded higher rate DLA and linked benefits, they experience an instantaneous and potentially devastating drop in income when DLA is downrated or removed.

The entire family can be thrown into a state of crisis if a child's DLA is downrated or removed. Alyssa, who is on income support explains: 'Getting DLA – there was a big change – but the situation has got much worse. I got the high rate for five years... Then it was reduced ... it's gone down by about £100 a month. They took it away in July 2002 and I didn't know how to appeal...'

Unfortunately this is an experience families are likely to go through repeatedly. Kathy, a lone parent who is on income support, and has a 13-year-old son who has ADHD, graphically describes the problems she has encountered over the years. 'I was on middle rate for two years, and then I was on low rate for two years... Then it was taken away. It took a whole year to get it back. (A welfare advice worker) filled in the form – but they rejected it so we appealed... I was awarded low rate on eczema and asthma... then he was diagnosed with ADHD and we applied for an increase, and it was put up to middle rate care. I had to reapply last August when he was 13. We tried our best – we sent (the forms) off – but they turned me down completely, I got no DLA at all. They said basically he's old enough to cope – basically he's at the same level as other children – but they're not on tablets, they're not on medication...' When Charlie's DLA was removed, Kathy's income was virtually halved and she now lives on £109 a week. '...it was a big dip, it's a terrible struggle...'

Kathy's son Charlie was recently awarded high rate care and middle rate mobility after a successful appeal. When the award comes through – and her carer's premium, and disabled child elements within CTC are reinstated – her weekly income will increase to nearly £200. For the moment however, she is finding it difficult to make ends meet because she still incurs extra costs, and has had to borrow money from her mother. Although Kathy will receive a substantial backpayment in due course, Charlie's DLA will be depleted by having to pay off her debts. Furthermore, although Kathy is delighted with her award, she is loath to be complacent about the future. 'I don't know if I'll get the high rate again ...' She worries about having to go through the whole

process in two years' time. 'They gave it to me for two years, and then it's one more year until he's 16 – and (my welfare rights advisor) said "Oh no, we'll have to go through it all again for one year"…'

Emily, a lone parent who is on income support, has three children, two of whom are disabled. They both get DLA. Although her son Joseph has been awarded DLA care component for five years, her experiences with her daughter's DLA have undermined any sense of security this might have brought. 'They stopped Hannah's (DLA) without any warning – there was something on the computer. There was quite a big investigation. It stopped for about a year, and we were really struggling badly. There was nothing I could do to help her at home with her school things, and I felt quite cross because it was having a big impact on her – and I lost my (carer's premium) – and they still won't backdate that. I did get the DLA backdated – it was over £1,600.'

Other aspects of the system compound fluctuations in income and can plunge a family into a state of financial crisis.

Hospital downrating

Payment of both the care and mobility components of DLA stop if a child under 16 has been in hospital for more than 84 days (which are added together if your child has been readmitted to hospital within 28 day periods). This rule poses huge problems for families whose child needs regular hospital admissions.

Lily's son Steven, who has dyspraxia, allergies and asthma, has received DLA for three years. Unfortunately Steven recently developed leukaemia and has been in and out of hospital over recent months. As a consequence of this, his DLA has stopped and Lily has lost her carer's allowance. The family's financial problems have been greatly exacerbated because her husband has had to take compassionate leave to help care for his son while he is in hospital. Lily bitterly observes: 'It's not paid – what's compassionate about that?'

Lily is angry that benefits are reduced just as the family's costs go up: 'You're living on less ...but the costs are higher...' She adds 'If you didn't have parents staying there would be an outcry with the nurses, they'd have to employ more people to cope, parents are doing the nurse's job – they don't have time to bath your kids or do their toilet needs, or run up and down and get food and clothing – and yet benefits are downrated...' Keeping track of Steven's DLA is an additional source of stress. 'They add it up as you go along...you notify them when he's out, and then notify when he's back in...'

Lily, who is herself disabled, is particularly upset because she can't stay with her sick son because of accessibility issues. She explains: 'There's no real room

for a wheelchair in isolation – I get up there on crutches and sticks.’ While her husband is in hospital with Steven, Lily needs extra support to help her look after her three other children back home. High levels of stress and anxiety triggered a severe relapse in Lily’s own condition, and she too ended up in hospital.

Social Fund

Although families are reluctant to apply to the Social Fund, they are often forced to take out a loan to help ends meet when they lose DLA. Kathy, a lone parent who lost her son’s DLA in August 2003, comments: ‘Truthfully I’d rather borrow from my mum – if something goes that you’ve got to replace – like a fridge – there and then but if it’s something that you can wait for...’

Families whose child receives DLA report that this may be targeted when they apply for a Social Fund grant, even though it shouldn’t be. Emily observes: ‘I sent off a form yesterday because my fridge freezer is breaking – I’ve asked them for a grant – not a loan – they look at me and say you get so much every week, we want £44 a week to pay off the loan ... because they know I get DLA...’ Families sometimes turn to the Family Fund instead.

6.2 *Living without additional benefit*

Latoya and Trisha are both lone parents who are on income support. They have both been struggling for years to meet the extra costs involved in caring for their disabled children without additional support, and experience high levels of poverty and social exclusion. They have only recently applied for DLA for their children.

Trisha, who moved to the UK ten years ago, has no family back-up or support. Her four-year-old daughter Sylvia has severe language delay. She only heard about DLA thanks to a local take-up campaign and recently applied for DLA for Sylvia with the help of a welfare advisor.

Latoya has three children aged nine, eight and 13 months. Her eldest son Thomas (whom she had when she was just 17) has Global Developmental Delay. Although Thomas has experienced significant problems since starting school, and received a statement of special educational needs when he recently moved school, nobody told Latoya that he might be entitled to additional financial support. She too only heard about DLA because of a local take-up campaign. She recently applied for DLA for Thomas with the help of a welfare advisor.

Poverty and social exclusion

Latoya cannot afford to take her children out, or go out herself. She wistfully comments: ‘... sometimes I wish I could take the kids to the cinema – like, there was a half-term, and I didn’t have money to take them out ... they’re bored – it’s just school and home for them ... we don’t go out at all.’ Living on a low income has taken its toll on her health and self-esteem. ‘...I neglect myself because I don’t have the money. It makes me think like “Oh I’m not good enough”. Sometimes I get up, and I think I’ll just go back to bed, but I can’t... At times I get really low, I don’t go out, and because I don’t have money to go out – they all suffer.’

Poverty and ill-health

Both Latoya and Trisha report that their own health has suffered as a result of worry and stress, and that they suffer from depression.

Although Latoya has only applied for DLA for her eldest son Thomas, coping on income support has taken its toll on her own, and her other children’s, health. Her middle daughter suffers from asthma and eczema, which is rendered worse by damp in the winter and heat in the summer. Her baby, who was born prematurely and was ‘small for dates’, also has serious health problems. She comments: ‘I do suffer from depression... I have been through a tough time and then to have a baby – it hit me when she was born...’

Trisha also struggles with depression. ‘One day I was so depressed I went to my health visitor and asked her “Will you help me?”’

Exclusion from services

Although Trisha’s four-year-old daughter Sylvia will be starting an intensive speech therapy course for three days a week, her mother is concerned that without the DLA she will have difficulties getting her there. She has to be at the speech centre at 9.30 am and will therefore be unable to buy a cheap family travel card. With a weekly income of around £108, paying for a daily or weekly travel card will constitute a substantial dent in the family’s finances – and undermine Trisha’s ability to buy food and pay bills. Trisha may be forced to think twice about taking Sylvia to speech therapy.

Debts

Latoya’s income support is depleted – amongst other things – by £18.50 a week which is deducted to pay back a Social Fund loan of £525. ‘Really and truly I got the Social Fund to help me out over Christmas time, to buy food and to buy presents – my Income support couldn’t help me ... by the time you do the meter, the gas, you pay the bills...’ Her loan has rendered a difficult situation significantly worse: ‘...because my money has been reduced it’s harder now for

me to cope ... At the moment I'm living on £124 after they've taken everything out.'

Extra costs

Because of Thomas's particular needs Latoya incurs higher costs than other families in a similar situation. For example, she has additional laundry costs because Thomas is still wetting the bed, and has regular hospital appointments. There are other additional costs. 'Toilet paper – he gets through so much, I'll have to buy 12 rolls – he has problems wiping his bum – I think his motor skills aren't very good. Life is pretty expensive ... without any extra support, it's a struggle. Thomas eats a lot, he's a very messy eater – drinks fly – that's why I put the (floor boards) down myself – I had a carpet but it was ruined... when it comes to the end of the week I'm running really low.'

Latoya is worried that Thomas will be stigmatised because of his disabilities, and does what she can to protect him. She spends more on items which she feels will help Thomas integrate with his peer group at school. For example, although Thomas has NHS glasses she has spent £129 having the lenses shaved down. 'People might call this a luxury but I don't want people to laugh at him... So every week I pay for it in the opticians – that's another £5 a week....'

Trisha also incurs additional costs. 'I'm finding it difficult, because I need things ... like toy farm animals to help her with her speech – but they cost...' To try and help Sylvia's development Trisha has always taken her to playgroups and drop-ins. While some of these are free, the better ones expect a contribution: '...there's things like story time, and children sitting down and adults reading stories, there's a bouncy castle – there's an afternoon routine – sometimes there's printing – not children just running around....'

Both Trisha and Latoya have recently been awarded DLA middle rate care for their children. Latoya reports that, although 'things are still very tough' the DLA has made a huge difference to their lives. 'Before, I didn't know how I was going to cope, but things are definitely easier.'

6.3 *Surviving a reduction in benefit income*

Families who are in receipt of DLA may be plunged into crisis if it is downrated or removed. A drop in income – particularly when a family is on Income support – can be catastrophic. The income goes down, but the extra costs associated with having a disabled child do not.

Impact on disabled child

◆ Reduced access to services

A number of families report that with certain conditions, such as autism, early and intensive interventions can bring about a crucial improvement in their child's development. Because of the unreliable, sporadic or sometimes non-existent nature of statutory support services, a lot of families buy extra support for their child (such as music therapy or speech therapy) or pay for their child to attend play schemes and after school clubs that help with social development. A sudden drop in income can interrupt such a programme, with potentially damaging effects on the child's future development.

Alyssa, who lives with her husband and three children, recently had her son Gregory's DLA downrated (resulting in a drop from around £228 a month to £153). She explains that the loss of income has had an impact not just on Gregory, but on the whole family. Alyssa reports that when Gregory was able to go to his Saturday play-scheme, it improved his behaviour and gave his sisters a bit of a break: '... it's the activities – the play-scheme on a Saturday.... These activities help him a lot – there's less screaming and I've had to stop some of them. I've stopped the music therapy ...'

Kathy explains: 'Ever since I've got that DLA I've paid for dyslexic lessons for Charlie because I've tried so hard to give him support, and he's stopped his English now when I lost the money – it was a lot of money – I was thinking how am I going to cope...?'

Emily, whose daughter Hannah had her DLA withdrawn for over a year, explains: 'I had to give up a lot of the social groups that I attended because you have to make a contribution for the teas and the coffees and refreshments – I gave up all that, there was no money to fund it – so it had a negative impact on her social development...'

◆ 'Don't ask for that...'

It is extremely difficult for a parent to explain to a child with emotional, behavioural or learning difficulties that items and activities that they previously enjoyed are no longer available. Parents may avoid taking their child out for fear that they will demand things they cannot afford, and yet be less able to keep them entertained at home.

Maggie, a lone parent who is on income support and has two children on the autistic spectrum, explains, 'When the DLA was downrated it did have an impact, because I was using the money ...Elliott is into more computer games...he has an X-Box upstairs so when we go out to the shopping centre he says "I want it", and has serious tantrums when he can't get them, he likes all

these gadgets, they're part of his life - they're what he seems to think is life. It makes him happy, he doesn't like too much social interaction...' Since Elliott's DLA has been downrated Maggie has to heave him away from shops. 'I have to lift him to get him to leave (and) he's getting quite heavy...' Maggie thinks it's easier not to go out at all.

Kathy explains: 'When (Charlie's DLA) was taken away I did say to him we didn't have so much, so don't ask for this and don't ask for that...'

◆ Meanwhile extra costs remain high...

Kathy comments: 'I was asking how can I buy his shoes, or his glasses, how am I going to get this, how am I going to get that ... it was a shock to the system losing it, you do lose quite a lot...' She adds 'I'm struggling at the moment – just before Christmas he broke his bed and he broke his lamp and I had to replace them ... and new bedding – because I got him a four foot bed because he's a big lad – it all costs...'

Impact on non-disabled siblings

Families do their best to shield their disabled children from the impact of a drop in income, however they also worry about the impact it has on their non-disabled children.

Elisabeth was recently awarded the middle rate care component for her three-year-old son Mark who is severely autistic. She does not receive carer's allowance because she works part time. She does not think that Mark's DLA comes close to meeting the extra expenses she incurs as a result of his needs, and feels that this has an impact on her younger son. She explains angrily '...all they gave us was £38...I'm thinking of my baby – I'm so worried about him. Before he used to go to the playgroup... but now he is stagnant – he is missing out, all I do is take him to the door – I want to send him some place, half a day, two days a week, if we had the means - I'm worried about this child.'

Impact on the whole family

◆ Staying in

Losing benefit often has an adverse impact on the whole family. Alyssa reports: 'If I don't get that money I think Gregory will just have to stay at home this summer with all the children. We won't be able to go out at all, because if you take him out and you can't give him something he'll be screaming and screaming ... all the children have to stay at home.'

◆ Going into debt

Although the mothers report that they are good at coping financially, and try to put money aside for when they need it, a sudden drop in income can plunge

them into debt – particularly if they are on income support. Where possible, they turn to other family members or run up bills on their credit card. If the worst comes to the worst they are forced to turn to the Social Fund. Loans, and not grants, are usually on offer.

◆ Savings and security depleted

The majority of mothers with disabled children are unable to work. They worry about their future. (Zoe observes ‘I have to think about the long term – I’m 52, I might live until I’m 80...’) Sometimes a drop in income forces families to dip into savings they had hoped would safeguard their own, and their children’s future.

Jennifer and her husband David have four children, two of whom are on the autistic spectrum. They are digging heavily into their savings while he is looking for work. ‘The worrying thing about using the savings is, in the longer term, we have no idea where Nick will be ... and you worry about being an older parent and you worry about your income ...and our capital is going just like that – it’s scary but necessary.’

◆ Food

Although parents struggle to provide good food for their disabled children, when there’s a drop in income, sometimes the rest of the family suffers. Alison, who has four children, does her best to provide her daughter Becky with the food she likes: ‘the fact that she’s eating at all is wonderful because when she was ill she wasn’t...’ However, she has to stint on food for the rest of the family: ‘... half the time we just have chips for our supper because we haven’t got enough money ...we do eat, but it’s often chips and nothing...’

◆ Transport

A number of families use their child’s DLA care component to finance their transport needs. Emily explains that after her daughter’s DLA was stopped for a year. ‘It affected the whole family. I had started driving lessons and I had to give them up, and I’d only specifically started to do that to help her with her mobility ...’

Alyssa previously used Gregory’s high care component to pay for cabs. However, since it was downrated the family have become virtually housebound.

◆ High levels of stress and humiliation

Elisabeth, who is finding it difficult to cope with her severely autistic son’s extra needs, explains: ‘The social worker ... said “Why don’t you appeal to some charities?” I said “You want me to beg for money?” If you’re ill or crippled or if you’re unable to work, beg for help – but I’m not sick, I’m not the

only one with a disabled child. I can't beg for money, if they don't want to give it we will struggle along without it...'

Hopes for the future

Although families are often depressed and downhearted when they lose benefit, they try to plan for the future.

Alyssa observes that if her son Gregory's DLA is reinstated at the high rate and he gets the mobility component, they will buy a car. This would mean they could all go out together as a family. 'At the moment ... maybe I stay with the other two, while (my husband) takes Gregory out, or one of us stays with Gregory while the other one takes the other two out. If we could get a car we could all go out together...' She also plans to buy things that will help compensate Gregory for a restricted lifestyle. 'I want to buy a swing for Gregory because he can't go out on his bike... I want to put down a patio in the garden, because he likes to be outside and play with water – maybe get him a paddling pool. I want to take him to his music thing again because he's stopped...'

Latoya does her best to make her flat look nice. 'I put the floor down, I decorate, I can wallpaper, I can't use a drill... I'm just trying to make the place look homey...' However, she worries about Thomas's bedroom. If he is awarded DLA she will make it more comfortable for him. 'I'd probably put down lino and a rug – it's not like a bedroom – it's just a bed and that's it – I want him to be more cosy, he can't relax on the floor...' She adds 'I would love to go on a nice short break...I'm always in the house.'

6.4 Discussion

The Government has introduced a number of improvements to financial support for low-income families with disabled children, and these are very welcome. However, families indicate that flaws within the system are actively undermining policy initiatives to improve financial support for disabled children.

The vast majority of families with disabled children are unable to boost their incomes by accessing employment and are therefore disproportionately reliant upon benefits. Families with disabled children who are on income support are particularly vulnerable to high levels of poverty and social exclusion and yet many do not know about or apply for DLA. Income levels that are already too low to live on are further sapped by disability-related costs. Trying to cope on an inadequate income sucks families into a downward spiral of debt, depression and ill-health. To maximise the impact of improvements to disability benefits, it is essential that families access the benefits to which they are entitled.

Increasing take-up of DLA is essential if poverty is to be reduced amongst a particularly vulnerable group of children.

Furthermore, the impact of improvements to disability benefits for children will not be fully realised unless they are accompanied by improvements to the administration of the social security system. Families who need to plan and budget for their children's day-to-day needs – and indeed, for their future – are dependent upon benefits that are regularly withdrawn or downrated. Short term awards and erratic decision-making accentuate rather than mitigate fluctuations in income. Instead of providing financial security for families with disabled children, DLA is viewed as an erratic and unreliable source of support. This is the opposite of the Government aspirations to safeguard the health of vulnerable children, and is undermining its commitment to provide 'security for those who cannot work'.

Ironically, while improvements to disability benefits result in incomes rising higher than previously when DLA is awarded (particularly for families on income support), they have much further to fall when it is downrated or removed. An unexpected drop in benefit income can plunge a family into crisis. It is particularly stressful for families on Income support who find it virtually impossible to build up financial safety nets upon which to draw if benefits are taken away. Coping without additional benefit has a negative impact on the whole family. Loss of income disrupts disabled children's access to services and social activities – which has a knock-on effect on their non-disabled siblings. It also generates a surge in anxiety amongst parent-carers with direct consequences for their physical and mental well-being. High levels of debt and stress generate cumulative social and material costs that may sap DLA's ability to meet extra costs as and when it is reinstated. Despite the Government's best efforts, it seems that some of Britain's most vulnerable children are on a financial roller coaster that is damaging their current lives and jeopardising their future chances.

7. Employment – a feasible option?

The Government emphasises that work is the primary route out of poverty. However, despite Government initiatives to draw mothers – specifically lone parents – into paid employment, combining working (or studying) and caring for a sick or disabled child remains extremely difficult. The fact that employment is failing to provide a route out of poverty for families with disabled children is starkly illustrated by current statistics. Only 3% of mothers with disabled children are in full time employment (compared with 22% of mothers with non-disabled children) and only 13% manage part time work

(compared with 39% of mothers with non-disabled children) (HM Treasury, July 2004). Eighty five per cent of mothers with disabled children are not in paid employment (End Child Poverty and Council for Disabled Children, 2003). However, according to a survey undertaken by the Council for Disabled Children, 85% would like to work – at least part time. (As Anastacia points out, ‘It would mean I could put my feet up, have a rest, and just be Anastacia.’)

The majority of mothers with disabled children are forced, or choose, to give up paid employment to care for their children. Unlike other families, they do not do so for a year or two, but may end up out of the labour force for many years. Some believe that they will be caring for their children for the rest of their lives. As Alison, who has four children, two of whom are severely disabled, observes: ‘Unless things change dramatically I can’t see me ever getting a job, I think I’ll always end up at home...’

However, mothers resent being told that they are not working. Zoe, who has five children, one of whom has Down’s Syndrome, bitterly observes: ‘Give me a title – carer’s fine, but carer’s not good enough – I see myself as everything, teacher, carer, nurse, doctor, social worker, cook and night worker...’

7.1 Barriers to employment

Low-paid employment and lack of support

Parents who may have given up their studies, or a career, to care for their children resent being encouraged to return to low pay, low status jobs. A welfare rights advisor who provided some families for the study comments: ‘...you get used to thinking “I’ll take a year off work” ...but then it’s four years off work, then it’s ten or fifteen – and you come out at the end of it, and there’s very little support. (Government policy) is about supporting parents into low paid demanding work – parents say “I was in the middle of doing a law degree – I don’t want to pack shelves at Asda” – but support is not geared at supporting parents in a career sort of way...’

Maggie, who has two severely autistic sons, explains: ‘There are all these initiatives to get carers into employment – and I’m really quite interested – but what is there to support you into employment?’ Maggie is particularly frustrated at the lack of appropriate childcare. ‘I have a child with autism who needs routine ... there’s change, change, change. Sometimes the children won’t accept the support worker, sometimes the support worker would find the children too demanding. They’d be told they were supposed to be supporting both boys but they’ll send one support worker...’ She concludes ‘If I had a good job ... I would pay somebody to come to my house and wait for the bus to drop the boys off.’ Until she gets appropriate childcare, however, she will find it difficult to complete her studies.

Lost skills

Latoya would like to train as a probation officer, but is finding it difficult. ‘When I was at school I had such good grades – but now it’s mum, mum, mum all the time.... I was six months into (the course) when I had to give it up. I do know quite a lot about it – but I haven’t been in school for a long time, and I need to get my skills back.’

Jennifer gave up a highly paid job as a financier to care for her four sons, two of whom are on the autistic spectrum. ‘...It would be very difficult (to return to my previous job). I’m already a dinosaur – and I don’t see how with four children you can do it ...’

Inflexible employers

Mothers report that it is difficult, if not impossible, to find employers who will allow them to take time off at short notice. The fear of letting people down prevents them from taking on paid – or even voluntary – jobs.

Anastacia comments: ‘I’m always up at the school (or at) doctor’s appointments – I’d have to have an incredibly understanding boss...’

Lily is a trained nurse. She comments: ‘I’d like to go back to nursing or do counselling – but you can’t let people down...’

Childcare/childcare tax credit

Accessing childcare is a perennial problem. Mothers report that they sometimes prefer to use friends or an unregistered childminder (because it is cheaper) and so they cannot claim childcare tax credit. Elisabeth, who works part time, did not claim childcare tax credit because she preferred to use a student she had flown out from her home country than a registered childminder. ‘She was studying – I did three days to coincide with her study – we both benefited...’

Gillian, whose daughter has cerebral palsy, has recently given up her job as a part time primary teacher, primarily because of her childcare costs. Although her nanny is highly experienced, she is not a registered childminder so Gillian does not get the childcare tax credit. Gillian concedes that there are other problems. ‘It’s too stressful trying to fit in all her appointments and go to work.’

Even when families do get childcare tax credit, they report that it is not sufficient to cover specialist childcare (see page 7). In any case, not all families with disabled children qualify for the full amount. Susan, who works part time, receives only £16 a month because of her husband’s salary. ‘It doesn’t cover my childcare costs at all.’

Mothers worry about the quality – as well as the costs – of childcare. Nicole comments: ‘I wouldn’t be happy leaving Alexander with somebody – even his one-to-one supporter at school isn’t trained.’

Professionals encourage parents to stay at home

Families who do struggle to combine working and caring for their children are frequently exhausted and stressed. Professionals who represent their children’s needs often advise them to stay at home.

When Maggie told the manager of the Disabled Children Team that she was studying for an Open University degree, he was astonished ‘(He said) the state is helping you to care for the children - I don’t know why you’re worrying yourself.’ She adds ‘... I told him I didn’t envision my life full time caring for the children until they are adults ...’

Although at the time of the interview an exasperated Elisabeth announced ‘I think I’ll kill the next person who asks me “Why are you working?”’ she is currently considering whether she can afford to give up her job – at least for the time being. ‘I’m so tired, so very very tired...’ However, she is worried about her chances of returning to work in the future. ‘Jobs are not easy to come by, I’m wondering, will they keep my job?’ (Unfortunately, even if Joseph is awarded the highest rate care component and Elisabeth gets carer’s allowance, it will not cover her loss of salary or her mortgage costs, so she cannot give up her part time job.)

Fears about losing benefit

Some families worry about the impact that paid employment will have on their benefit income. Others who have struggled with DLA for many years simply can’t face more administrative hassle. Zoe, whose 13-year-old son Adam has Down’s Syndrome, worries about moving into paid employment. ‘Your benefits change, you’ve got to fill this form in that form in, it’s a nightmare.’

Child’s ill-health

Apart from the need to be available for day-time appointments, a child’s ill-health renders certain kinds of employment extremely difficult. A welfare rights advisor who provided families for the report comments that one mother cannot return to work as a nurse because of ‘an unacceptably high risk that if she picked up a bug from one of the patients, she might give it to her child who has cystic fibrosis’.

Older children

The situation doesn’t necessarily get any easier as the children grow older. Anna comments: ‘...now the girls are 17 I find that a lot of my friends have

gone back to work and the children are off their hands ... but it would be difficult to work because she's the last one picked up in the mornings – at 8.50 and she's brought home at 3.45 – it doesn't leave much time to go to work...'

7.2 *Staying at home*

Mothers are often happy to remain at home and care for their children. However, while they readily relinquish the possibility of paid employment, they feel unsupported and unappreciated.

Angela cares full time for her four children, two of whom are autistic: 'You can't get out to work'. However, although Angela is grateful to get carer's allowance, she thinks it is inadequate compensation for caring for two severely disabled children (see page 26).

Jennifer is happy to be able to care for her four children full time. 'I used to work from 7 in the morning until 7 at night – how can you have a life with the children?'

Kathy's 13-year-old son Charlie has ADHD. He still needs to be dropped off at and picked up from school. 'Well I'd rather be there for him myself ...' Reducing benefits would not constitute an incentive for Kathy to work. She observes: 'If I hadn't got the DLA I wouldn't have gone back to work, I would have just scraped by ... I would have coped – anything to help Charlie...'

7.3 *Combining caring and paid work*

Despite seemingly insurmountable problems, five of the mothers in this study are in paid employment. Siddiqua, a lone parent, works full time. Susan, Elisabeth and Margaret work part time. Gillian – who worked as a part time primary teacher – recently gave up her job.

Advantages of paid employment

On the plus side of paid employment, Susan cites 'being better-off' and 'having an interest outside of the home'. Siddiqua reports that although she is not much better off in work (because of lost benefits) stress levels have gone down for both her and her son. '...My son kept saying "Get to work mum!"'

A flexible and understanding employer is the biggest bonus when combining caring responsibilities and paid employment. Siddiqua's employers know her son is severely disabled. '...Despite this they gave me the job.' She adds 'I would like to go on working here ... because I can get home easily. The whole environment is good – people are very helpful with each other.'

Susan, whose daughter Victoria has a visual impairment, works 24 hours a week. She explains: ‘When I first got my job in 1998 my son ... was on DLA and had days when he couldn’t walk, and they took me on knowing the situation and giving me total flexibility – I would not have taken the job without it. The days that he couldn’t walk I just didn’t work, or I worked from home ...’ However, even with an understanding employer it is a difficult juggling act. ‘You’ve got five weeks to cover in the summer and with a deteriorating situation I can’t predict what’s going to happen ...I don’t have anyone [to help]...’ Susan has recently reduced to 10 hours a week during holidays.

Disadvantages of paid employment

Although working can bring psychological as well as financial advantages, combining caring and paid employment has many drawbacks.

◆ Stress and family breakdown

Working mothers report that they would prefer to spend more time with all their children and that they have less time to spend on themselves and their partner. Family relationships – with both partners and children – can be put under stress.

Although Siddiqua loves her job, she concedes that when she’s not working ‘Things are different at home, there’s a more friendly atmosphere – it’s subtle – a closeness that isn’t there when I work full time.’

Anastacia recalls that when her husband was working full time, there was considerable tension on the home front. ‘I told him, “I don’t want you to work 90 hours a week, I want you here.”’

Jennifer admits she felt a guilty sense of relief when her husband lost his job. ‘Although he appeared to be there 100% he didn’t take any of it on board, he thought Nick was fine. I found that very difficult...He’s not the sort of person who walks out, but who knows...’

◆ Poor health

Susan comments that since her daughter’s eye-sight has deteriorated, work has become more stressful. ‘I do think my health has deteriorated, I feel more stressed and tired, my blood pressure is higher...’

At the time of the interview, Elisabeth was at the end of her tether. ‘I can’t afford to take time off work, it’s taking its toll in my health, on my life...’

Margaret has suffered severe health problems as a result of caring for three disabled children and working part time. She has ended up in hospital on two occasions over the past few years. She observes: ‘I feel if I’d got the three

carer's allowance it might have persuaded me to give up my job – so my health might have improved.'

◆ Appointments

Balancing work and day-time appointments is always a struggle. However, Susan comments: 'I'm always there, I wouldn't miss them – I work around them.'

Finding the time to attend appeals adds to stress levels. Margaret recalls 'Last year, on the day of appeal, I took the day off work. I just said "I won't be in". I was just going out the door when the phone went. It was the assistant saying "Sorry but the panel have been given the wrong paper work" ...and I'd arranged childcare (for three of them)...'

Fathers and employment

Although lone parents with disabled children face almost insurmountable problems accessing paid employment, couples are also seriously disadvantaged by an inflexible employment culture that contributes to high levels of stress and family breakdown. Out of thirteen couples in the survey, two fathers (Anastacia's and Jennifer's husbands) have recently had to give up work to help care for their children. Lily's husband has taken several months unpaid, 'compassionate' leave.

◆ Inflexible employers

Like working mothers, fathers suffer from inflexible employment patterns. However, they are more susceptible to male prejudice in the work place. Jennifer's husband David – who lost his job three years ago – now helps care for their four children, two of whom are on the autistic spectrum. Jennifer comments: 'David was basically rushing around between hospitals and trying to fit in a job as well as dealing with all of us. I wouldn't say (his employers) directly made him redundant because of that particular period – but the image of somebody builds, and I think they decided that he had too many family responsibilities and there was too much going on and he'd never be fully engaged in work...' Although David 'is job hunting all the time' the longer he remains out of the labour market, the more difficult it will be to get back in. David feels that prospective employers will view the time he has spent as a full time carer as an unacceptable gap in his employment record, rather than a contribution to society.

◆ Loss of income – and status

The men find the loss of status, as well as income, particularly difficult to deal with. Jennifer observes: 'I think for a man it's very difficult ...for women I think they're more conditioned to give up their work.' She adds that her

husband ‘feels desperate about the money. Rationally he can see there are advantages but emotionally it’s unbearable ... I think he feels he’s not providing properly for us, whereas I feel that he doesn’t have a chance because he’s so busy with the children, and all these appointments...’

Anastacia’s husband has recently given up full time employment, partly because of ill-health, partly to help care for his severely disabled sons. She feels that, although in her opinion the advantages outweigh the drawbacks, it has had a negative impact upon his self-image. ‘...He’s the sort of man who needs to work – that’s his role. His job is to go out and put food on the table, and now he can’t do that, he can’t treat me or buy a bunch of flowers – now he just gets the carer’s allowance...’

◆ Stress and marital breakdown

Mothers report that if fathers work full time, it is sometimes difficult for them to understand their children’s needs and this can put relationships under stress.

Jennifer comments: ‘All these people who ring me up from this autistic charity have all lost their husbands ... because these men are at work. It’s not their fault (they) don’t see (their child) hitting other children or not interacting at playgroups. They see them looking pleased to see you and looking sweet and they think “oh she’s making it up” and the mother gets more and more isolated – I mean, I used to go to playgroups and just cry ...’

Alison, who has four children, two of whom are disabled, has a husband who works full time. She observes: ‘My husband always says it’s a behavioural problem ... he doesn’t understand it at all.’ Their marriage has been put under serious stress and they are now separated.

Advantages of giving up paid employment

Mothers report that although losing paid employment has an adverse impact on family finances and their partner’s self-esteem, there are advantages to having them at home full time – particularly if they have two or more disabled children. Being available to attend medical appointments keeps the father both involved in and knowledgeable about his child’s condition. This has a positive impact on relationships. Jennifer comments: ‘...in terms of keeping the marriage together I think it’s key ... He always thought John was fine – and I found that very difficult. If he hadn’t been at the appointments he would have ended up thinking I was mad and he would have walked out or something...’

Anastacia agrees. ‘...I wouldn’t like him going back to work – I have benefited emotionally...’ Anastacia’s family have recently moved to Wales in quest of

better services and to be near an excellent special school, a decision that might have been impossible if her husband had continued to work full time.

7.4 Employment – a fluctuating source of income

Moving in and out of work

Given the problems associated with combining caring with employment, parent-carers who are in work tend to move into and out of employment, or are forced to take unpaid ‘compassionate leave’, resulting in significant fluctuations in family income.

Siddiqua, a lone parent, is a lawyer and speaks four languages. Although she currently works full time, in the past finding jobs that fit in with her caring responsibilities, has been extremely difficult. Over the years Siddiqua has oscillated between working part time, working full time, studying and being on income support. She has experienced dramatic fluctuations in income as a result. She recalls ‘With his asthma he was not sleeping nights, I was holding him all the time thinking he was going to die. I was working and studying at that stage.’ Retaining employment has been difficult. ‘There was no-one to look after him, so I had to leave my job... I was still doing night courses.’ When Siddiqua was forced onto income support, the family experienced ‘a significant drop in income...it was very, very hard’. Siddiqua thinks that living on such a low income sapped her self-esteem and ability to look for a job. ‘I didn’t know how to get back to work living like that...’

Unpaid and carer’s leave

Where a partner in a couple has to give up work to help care for a sick or disabled child, the drop in income can have a devastating impact upon the whole family. Taking compassionate leave generates a drop in income may be compounded by difficulties or delays applying for benefit.

Lily – who is herself disabled – explains that although the family is grateful that her husband has been awarded eight months’ compassionate leave so he can help care for their son Steven who has leukaemia and is in and out of hospital, the impact on family finances has been appalling. They have experienced real problems accessing benefits to see them through this difficult period. At the time of the interview, they had not received income support, housing benefit or council tax benefit. Steven’s DLA and Lily’s carer’s allowance had, however, been stopped. ‘We are’ Lily bitterly comments, ‘living on nothing, absolutely nothing...Our current financial situation is desperate – I’ve had to rely on family to help us out. My carer said there is a crisis loan on income support – but you’ve got to pay that back so why should you get yourself into debt...?’

Ironically, the need to take time off work to care for a sick or disabled child is often accompanied by a sudden increase in costs, which renders such a move financially difficult. Susan, whose daughter Victoria's eye-sight has deteriorated suddenly and significantly, currently works 24 hours a week. She reports: 'I would quite like not to work for a period of time – to take a carer's break, which I could do, and keep my job and come back later, but I couldn't afford it...'

Losing paid employment

Jennifer reports: 'There definitely was a catastrophic drop in income' when her husband David lost his job. It affected every aspect of the family's life. She observes 'We haven't been on holiday, I don't buy clothes for myself or for the children ... in terms of the children we've tried to economise on obvious flashy things like parties. We did take three of them to 'The Snowman' at Christmas but we try not to go to the cinema or any of those things...'

7.5 Training and educational development

It's not just families' incomes that fluctuate: their education and training is constantly interrupted by their caring responsibilities. Nevertheless, a number of mothers are struggling to continue their studies in the hope that, if more support is provided, they will in due course be able to access paid employment.

Some of the mothers hope to use the skills and knowledge they have acquired caring for their children in their future career. Maggie – who is studying to become a social worker – wants to work with families with autistic children. 'I want to work as a social worker – not for the local authority ... but for an organisation that will really help service users and clients, that's my long-term goal....I would still be involved with my kids, but knowing I have something else I'm doing apart from the children – that I'm somewhere in the community doing something, helping others.' She also hopes that qualifying as a social worker will put her in a stronger position to argue her case with the local authority. 'You have to be in a certain position to express your views in certain meetings – high up in education, social services, health care...I feel if I have something against my name and I'm not just talking as a carer but as somebody who has studied social work and the law, it means somebody will take me seriously and listen to me.'

However, attaining her goals is clearly a struggle. Maggie's studies have been constantly interrupted, partly because support services have let her down, and partly because a sudden deterioration in her son's condition – and her own health – has impeded progress. 'I've had help from social services and they've sent somebody from an agency but it's been extremely unreliable... I was so ill (and the) behaviour of my younger son deteriorated so badly ... I couldn't

manage to do my course work, I couldn't concentrate, I couldn't even open a book ...so I took time out, now I'm much better and I want to start again ...'

Jennifer fears that the skills she and her husband have acquired as carers are not transferable. Although both of them are now experts on autism, medical diagnoses, therapeutic interventions, educational tribunals, the health service and the benefit system, she comments wearily: 'Unless you can turn it into a job – it's useless knowledge... I was a finance person.' Nevertheless, unlike her husband, she remains optimistic about the future. 'I'm sure I can do something – I have a much more optimistic outlook – I don't feel too worried. I won't ever earn what I did before – I feel more confident but I think David has a more chequered record.'

Alison explains: 'I did try distance learning at one point (but then) Becky became so ill ... a friend of mine started at Middlesex, and she's now in her third year and doing brilliantly and will get her degree, and here's me and I still haven't written one word but there's not much you can do about that...'

Trisha, who is training to be a nursery nurse, comments: 'I want to get back into work, but first of all I want to get my daughter's problems sorted...'

Latoya reports that, since her son Thomas was awarded DLA, her confidence has improved and she is determined to train as a probation officer.

Other mothers would like to do something completely different, to get a break from their caring responsibilities. Zoe comments: '...I'm just so tired – I'd rather be a tea lady or go and work in the shop where (my friend) works – I'd love to do that...'

Voluntary work

A number of mothers report that they have undertaken voluntary work, either to improve their future careers, or simply to 'put something back' into the system. (As Zoe points out: 'I wouldn't mind doing voluntary work – I'd feel I was contributing...') Although this gives them an opportunity to share their expertise, they do not receive any help with their childcare costs. Anastacia would like to be a social worker. She has done voluntary work for MENCAP advising people on benefits ('I'm an unpaid social worker (but) I know what you're entitled to...'). However, because of childcare problems she has recently had to give up her voluntary job.

7.6 Discussion

In some ways, families in this study confirm previous research findings, which indicate that the main barriers to employment are the need to be available for

day-time hospital appointments, half-terms and holidays, inflexible employers, expensive and inaccessible childcare, worries about losing benefit, and the fact that parents are often advised to give up their jobs by professionals who represent their children's needs. Stress-related health conditions – such as depression and insomnia – sap parent's ability to study and work. Although some mothers would like to share their knowledge and/or develop new skills by undertaking voluntary work, attending lectures, or studying at home, there is very little support (for example, with childcare). Parents who care for their disabled children resent the implication that the only valuable contribution to society is paid employment.

Mothers and fathers seem to have different attitudes to employment, perhaps because caring responsibilities consolidate gender stereotypical roles. Despite the financial difficulties involved, some mothers (particularly those with two or more disabled children) would prefer to have their partners at home helping to care for the children and live on a lower income. They report that sharing caring responsibilities results in an improvement in family relationships. A reduction in stress improves the outcome for all the family, and may enhance both parents' and children's future chance of employment. However, some mothers report that their partners perceive their role as 'breadwinner'. A macho work ethic generates concerns, particularly amongst fathers, that even short gaps in employment due to their caring responsibilities will be viewed as unacceptable by prospective employers. Differing priorities may contribute to stress and relationship breakdown.

For the minority of mothers who combine working with caring for their disabled children, paid employment provides a tenuous, erratic and very stressful route out of poverty. Parents with disabled children tend to move in and out of paid employment as their caring responsibilities change, resulting in fluctuating incomes for both couples and lone parents. This generates high levels of anxiety and financial uncertainty.

8. Services for disabled children – the weakest link?

Given the amount of income families pour into financing additional support for their children, it is clearly impossible to assess their financial needs (and the adequacy of benefits to address these needs) without considering the role played by statutory services. The provision of coherent and responsive support systems would certainly ameliorate the impact of an inadequate or fluctuating income. As it is, lack of 'joined up thinking' within public services greatly compounds families' difficulties on a day-to-day basis. Although families value many of the services provided, they perceive some services (primarily within the benefit

system) as obstructive, judgemental and suspicious. Although all the families in this study cite individual practitioners who have provided high levels of support and understanding, the overall system does not seem to address their needs in a sensitive or proactive fashion.

Life is a constant battle. Maggie observes: ‘I’m really fed up ... because I’m always battling one issue or another, and it’s not just one child, it’s two children and I find I have to fight, go and get other people and other organisations to help me. It takes up time, so there’s not time for my own personal needs and personal growth ...’

Parents often feel judged and blamed because of their child’s needs. Alison comments: ‘Everybody says ‘it’s a parental thing, it’s a behavioural issue, it’s the mum’s fault...’

Margaret, a disabled mother who has three children with differing but severely disabling conditions, agrees. ‘I got my label first as an anxious mum and a neurotic parent who probably needed help and tablets...’ She resents the fact that instead of providing support, she was sent on ‘parenting courses’ which catered for ‘people on drugs, alcoholics, battered mums ... We were in a steady relationship, we had no family history or drink or drugs...’

8.1 Services

Poor services are not just a problem in their own right – they generate problems within the system as a whole. For example, if a school has failed to identify or address a child’s particular needs, their evidence to the Department for Work and Pensions will undermine that family’s chances of a successful application for DLA. The opposite is also the case. Where a school, or health visitor, or GP has informed themselves about the needs of the child, the family is more likely to get additional services, to hear about their benefit entitlement, be awarded DLA, and apply to the Family Fund.

Elisabeth, whose young son Mark is autistic, reports: ‘The pre-school lady has done wonders with him, she was working with (the special school). She was sent by social services – it was the best thing they did for me.’ They provided Mark with an educational psychologist and a speech therapist and put Elisabeth in touch with her local welfare rights advisor who has helped her to apply for DLA.

NHS

Although receiving a firm diagnosis can be a relief, it may put the family into a state of shock and crisis. There seems to be very little in the way of advice and support at this trigger point. Alison, who has four children, two of whom are on

the autistic spectrum, comments: ‘It has implications for the whole of their life, and the whole of your life, and an uncertain future and I think they should have somebody to give you counselling after something like that, but they don’t, they just give you a diagnosis and you’re sent on your merry way.’

Lack of financial support, counselling and appropriate services can push relationships to breaking point. Elisabeth, whose two-year-old son was recently diagnosed as being severely autistic observes ‘My husband and I are taking it so bad – we’ve not had counselling ... We are struggling to hold the family together...’

Although families are appreciative of the support they get from NHS practitioners, they may be forced to buy in private services because of long waiting lists, and sporadic, short term support. Although they view this additional private support as crucial to their child’s development, they fear they may be penalised. Jennifer comments: ‘...if I was to tell my NHS physio that we were getting a private physio she would stop coming...’

Schools

Families generally have very positive things to say about the educational system. Sometimes teachers compensate for inadequacies in the system elsewhere. Alyssa, who has not been allocated a social worker, explains that when she needs information and support she will turn to Gregory’s headteacher. However, families are concerned about the long term impact of shortcomings within some aspects of the educational system. Latoya feels that the failure of Thomas’s previous school to recognise and address his needs has had an adverse impact on his development. Thomas’s learning disabilities and complex needs were initially put down to bad behaviour. ‘They said he was naughty and they just wanted to exclude him.’ Although Latoya is very pleased with Thomas’s new school, she fears the damage has already been done. ‘For so long I’d been looking for help for him, nobody was guiding me in the right way, nobody said “We think your son has a problem and we’re going to refer him to somebody to look at him” – I think that’s why it’s got so bad now – it was left too long – from the age of four...’

Alison is worried about her son Jack who goes to the school where his older sister Becky’s needs were ignored, with disastrous results. (She ended up having a breakdown.) ‘They say “this is Jack” but he could be Becky in a few years time because he’s much more nervous...I found Becky with the curtain cord around her neck – and he’s going the same way...’ Mothers also feel angry when their knowledge and understanding of their child is ignored. Alison comments: ‘sometimes I know more than the (Special Educational Needs Co-ordinator)...’

Local authorities

Parents in this study who have struggled to get a statement for their child are highly critical of local education authorities. Alison comments: ‘...there are all these agencies, like the parent partnership, but they’re paid by the LEA who you’re fighting – (they’re) not on your side.. it seems like a personal crusade to deny you support...’

Welfare rights advisors who provided families for this study emphasise that although there are instances of good practice, these are often dependent on the good will of a particular individual. A welfare rights advisor reports that, without the personal support of the Director of Education, she would not have persuaded the local authority to put a DLA information leaflet into the pack issued to all children who receive a statement of special needs. She comments: ‘...all it takes is one individual clicking in with what you’re doing. It’s very much how they value the service...’

Child and adolescent mental health services (CAMHS)

Although CAHMS can be a valuable source of support, welfare rights advisors report that they sometimes seem to focus on how to improve a child’s behaviour, rather than addressing the specific needs of a family in crisis. Waiting lists are also a problem.

A welfare rights advisor reports: ‘I’d like to work more with CAHMS but it’s very difficult to get them to refer families ... they think parents will not seek improvement in children’s behaviour if they get financial awards – we’re talking about long term behaviour and serious difficulties ...’

Alison comments: ‘... CAMHS were saying the behaviour was affecting the learning...but it was the other way around, the learning difficulties were affecting the behaviour. Becky felt such a worthless person...’

Social services

Families report that they have little or no choice over the kind of support provided, or when it is made available. They feel that the emphasis is on supporting the child rather than the carer, and this can be divisive. Maggie comments: ‘I’m not actually the service user, my children are their clients. As a carer I express my views of how I need support but there’s just a rigid way of dealing with things...’

Parents fear that if they admit that they are finding it difficult to cope their children may be taken into care. Elisabeth comments: ‘I say to my husband I need to ask for help, but he says “They will take away my children” and I said asking for help doesn’t mean you can’t cope, it’s to help you cope.’

Alison also worries about asking for help. ‘People tell me “You should have a social worker” but I think no way, I mean I’m not saying all social workers are horrible but I think they might say “Oh your house is a mess, you’re not coping” and whisk Becky off again, and that’s what I’m trying to avoid ...’

Direct payments

Direct payments allow a person who has been assessed as needing services to receive cash to arrange and pay for services themselves. This is very welcome to families who experience difficulties with statutory support services.

Families believe that having direct payments will maximise choice and personal autonomy. Maggie believes they would certainly make her life easier. ‘...The direct payment scheme is giving more of a choice and I would feel I am in control of what I’m doing and getting support for myself, I’ve already tried the way of the social services and it didn’t work.’ She adds: ‘I would use direct payments for after-school support, half-terms, holidays.’

However, accessing direct payments is extremely difficult. In desperation, Maggie has recently appointed a solicitor to help her out. ‘I have been arguing for eight months ... they actually have to assess me under the Carers Assessment Act and then I’m told no they actually don’t have to do that, and I can’t make them do it if they won’t...I feel like I’m beating a dead horse.’

8.2 Discussion

Although the focus of this research was changes in family income, it soon became clear that it would be very difficult to assess the financial needs of families and the adequacy of benefits to address these, without considering the role played by statutory services. It seems that far from providing additional support to families in need, statutory services often seem to compound problems on a day-to-day basis. Differing priorities hinder ‘joined up thinking’. One of the starkest findings of this research is that families are forced to use benefit income, which is supposed to help with the extra costs associated with their disabled child’s particular needs, to pay for additional services. In effect, monies from the Department for Work and Pensions are being used to compensate for shortcomings within health, education, and social services.

9. Conclusions – social exclusion

Measures of social exclusion attempt to identify not only those who lack resources, but whose ‘non-participation’ arises in different ways. For example Burchardt et al argue that ‘an individual is socially excluded if he or she does not participate in key activities of the society in which he or she lives.’ (Hills et

al, 2002.) Families in this study report, time and again, that they feel excluded from many aspects of society, not just because of material deprivation, but also because of discrimination and ill-health.

However, gauging social exclusion for families with disabled children is complicated by family dynamics. Different members of the family have different experiences of exclusion. Sometimes the whole family is affected, sometimes it is just the parent-carer (usually the mother) or the disabled child. Fathers and non-disabled siblings may have different perceptions and experiences. Because this study was based only on interviews with mothers, their perceptions necessarily provide the focus.

Although social exclusion is difficult to quantify and measure, Tony Atkinson has identified three common elements (see Hills et al, 2002).

- ◆ Relativity (people can only be gauged relative to others in a given time and place).
- ◆ Agency (where people are excluded due to action of some agent).
- ◆ Dynamics (where exclusion may come about because of dim future prospects and not just current circumstances).

Does this framework provide a relevant context for this small study?

9.1 Relativity

Although families are reluctant to complain, they do think that their lives are rendered more difficult than other families because they are coping with extra costs on a lower income. Families feel that balancing the demands of caring for their child (or children) while battling for medical appointments, educational statements, statutory support services and welfare benefits puts them at a significant disadvantage relative to other families, and renders accessing paid employment more difficult. However, years of attrition may lower expectations.

Despite stark stories of material deprivation and social exclusion, a number of mothers consider themselves to be ‘lucky’ – because they ‘only have one’ disabled child, or because they have a partner who is in work. Families may feel ‘grateful’ because their child has lesser needs than other families, or because they receive DLA. Nevertheless, when they ponder their situation, they do feel they have a harder time than other families.

On the one hand, Alison, who has four children, two of whom are autistic, comments: ‘I mean... I do have a husband looming around, but not everybody is as lucky as me. I don’t think he’d see the kids go without ... but what’s it like struggling on your own?’ On the other hand she accepts that despite having a husband, life is very difficult. ‘And it’s weird because we’re living in poverty

really – it’s quite a struggle... I mean, I get all my clothes from the charity shop...’

Jennifer also has four children, two of whom are autistic. She emphasises that ‘our life’s good, we’re very, very lucky – we’re not a low-income family... we get a lot of clothes from friends.’ However, when she compares her life with people who are leading the life she led before, she concedes: ‘our lives are completely different – we don’t go to the theatre or the opera or any of the things we normally do – not that we go all the time, but maybe twice a year and splashed out – now we hardly ever do ... we haven’t been on holiday, I don’t buy clothes for myself or for the children.’ She reports: ‘My husband minds more than me – I don’t really mind not having Italian holidays because I’m so engaged with the children...’

Latoya, a lone parent with three children who is dependent upon income support and – at the time of the interview – was not receiving DLA or associated benefits, did feel that she was doing worse than other families, but hastened to point out that this was not because of her son’s condition, but due to her own ill-health. ‘I think other families have an easier time, not because of Thomas’s disability – I feel like I’m being held back because of my depression and my stresses – I feel I can’t get back on my feet.’

Sometimes families compare themselves with other families who have disabled children. Zoe, who is a close friend of Kathy’s, comments: ‘...I know Charlie needs helps because of ADHD, asthma, dyslexia – but I’d give anything for Adam to be like that, at least Charlie will have a job...’ On the other hand she observes: ‘My friend has a daughter who has problems, a bit like autism...she said “Zoe, I would rather have Adam with the Down’s than my girl with the autism because she’s a beautiful girl and she looks totally normal – at least with Adam you can see there’s a disability...”’

9.2 Agency

Powerlessness

Families in this study report that they are particularly disadvantaged by their dependency upon the unreliable and inadequate provision of external goods and services. They often feel powerless because their lives are dictated by the actions of a number of statutory agencies over which they have no control – including schools, local authorities, the NHS and the benefit system. They sometimes feel that decisions that affect their family are made by people – and systems – that may not have their best interests at heart. These range from a Government they feel undervalues their contribution to society because they are not in paid employment, to an unhelpful person on the DWP helpline. They report that their parenting skills are judged – and often found wanting – by

service providers and their integrity is questioned by a perennially suspicious benefit system.

Ironically, the more complex the system becomes, the more families are forced to rely upon specialist advice and support, which undermines feelings of autonomy and independence. And yet, despite an enormous and intrusive bureaucracy, families report that their children are still more likely than non-disabled children to be excluded from the statutory services they desperately need – such as play schemes and after-school clubs. The whole family is socially excluded because of prejudice in other services – such as transport and leisure facilities.

Taking action

Families with disabled children are more likely to have to move in quest of appropriate schools or housing, both of which are harder to locate. This may disrupt long term relationships for the whole family. Two families (Maggie's and Alyssa's) have recently moved to new housing association accommodation which has been adapted to their child's particular needs. Although they are delighted with their houses, there are no shops, parks, or schools within walking distance. Public transport is difficult to access. Alyssa has to take her non-disabled children backwards and forwards to their old school – a considerable daily journey. Anastacia has recently moved to Wales in quest of better services and to be near a high quality special school.

External and internalised discrimination

Families' sense of exclusion is compounded by a judgemental and critical public that they feel all too readily designates them as 'bad parents' because of the behaviour of their child. However, staying-in isn't necessarily the solution. Social exclusion can infiltrate the home. The attitude of others impacts upon the whole family. As Maggie points out, visiting or having friends over '...depends on the other parents, if they'll let their child come around.'

Alison observes that when her two non-disabled daughters are invited to other people's houses her heart sinks. 'I think "Oh, should I have them around?" but it's so difficult, especially with Becky, because she tends to shout at them and she can be quite frightening... and, you know, the house is a complete and utter mess, it's embarrassing to have people around ... and I think "Oh, how humiliating."'

The ability to engage with friends and family is severely circumscribed by having a child with severe disabilities or behavioural problems. Relatives may be unwilling or unable to help out with 'difficult' children, or they may not live nearby. A number of families report that because their extended families live in

other countries, they feel isolated and lonely. Three of the mothers report that friends and family were either in their country of origin (and that their low incomes were further depleted by sending money back home to help them out) or that relatives in this country were widely dispersed. Establishing friendships with others who have the same cultural identity within a constrained community (which is often limited to people living in the same block of flats) is clearly very difficult, and may compound an underlying sense of isolation.

Despite parents' best efforts, building up social relationships generally may be rendered much more difficult by the presence of a disabled child. Kathy observes 'I'd have their kids three times, they'd have Charlie once.'

Long term friendships may be put under stress. Jennifer recalls that one friend finds her sons, who are on the autistic spectrum, difficult to cope with. 'The reality is ... she has a habit of saying something, but her face shows what she's thinking. She'd look at John and her face would be completely horrified like he was some sort of monster – and there's nothing you can do about that – you can't say to somebody – "Change your face – he's very sweet really..."'

In a culture of blame and criticism, it is hardly surprising that families sometimes feel guilty about their child's needs. Jennifer explains: '... you feel so defensive about everything from genes to you name it, David's very defensive... every time anybody criticises John he takes it as a criticism of him ...'

9.3 Participation

Social

Mothers report that older children are excluded from everyday social interactions, such as shopping, or going to McDonalds, not just because they can't afford them but due to prejudice, or because their child can't go out on their own, or their child worries about being 'different'. Kathy worries about her teenage son Charlie. 'As he's got older he's sort of drifting... a child Charlie's age should be out and about and going to Brent Cross, but he doesn't ...' Unlike other parents with teenagers, however, Kathy is loath to leave him on his own at home. 'He says "I'm not going out" so I pop out locally but I'm a bit wary of leaving him...'

A number of families report that their children attend special schools. Although they welcome this provision, their children are usually picked up and taken some distance from the family home and returned after school. This renders it difficult for both parent and child to forge local friendships. Mothers miss out on social interaction that often takes place at the school gates.

Mothers with older children also miss out. Sharing problems with the parents of other teenagers often isn't an option. This is partly because they may not meet up with other parents, and partly because their children's experiences are so very different. Unlike other mothers, they are loath to complain about their child's behaviour and unable to dream about their future. Alison recalls: 'Somebody told me they'd gone away for the weekend and their teenager daughter had had a party and wrecked the house, and I thought to myself, I wish Becky would do something like that, you know, something normal that other teenagers do...' She adds: 'You see other kids around in McDonalds or in a café and you think, "that will never be my daughter" – and I think it gets worse at they get older, and when they have Asperger's they know they don't fit in and that's where the mental problems start...'

Production

Meanwhile, families with disabled children are overwhelmingly excluded from the labour market, due to lack of appropriate support or inflexible employment patterns. All the mothers report on the difficulties of combining employment and caring. While a number of mothers do – or would like – to participate in voluntary work, such work is impeded by lack of support (for example, access to the childcare tax credit). Studying and training is rendered more difficult because of problems with childcare. Although families feel that they are contributing to society, they feel marginalised by a society in which status derives from employment and income.

Political

Parents who do not have time for themselves as individuals, let alone as a family, are clearly less able to engage in local or national decision making. Furthermore, their experiences of unresponsive and inappropriate services may generate an angry and cynical view of political processes. A welfare rights advisor reports that, although she has been asked by the local authority to encourage families with disabled children to participate in decision-making meetings, they are reluctant to do so, partly because their participation is unpaid, and partly because of an innate suspicion that their views will not make a difference.

9.4 Dynamics

Families with disabled children not only experience lower incomes than families who are able to access paid employment, but – as this study highlights – they are particularly susceptible to a fluctuating income in the short term, and financial insecurity in the long term. This generates enormous ongoing strain on parents, and has an impact upon their ambitions for both themselves and their children.

Disabled children – ambitions

Although the families who participated in this study are fiercely defensive of their disabled children, they are concerned that they will never be financially independent, may never form relationships, and worry about who will care for them when they are no longer around.

Nicole reports that her son Alexander, who has ADHD, worries about his own future. ‘His view of life is very sad, he says “I’ll never get married”, “I won’t have a job” ... he is aware of his differences.’

A number of families mention diagnosis as a trigger point, where their map of the world is revised and their hopes and dreams are smashed. Elisabeth observes: ‘They give you this diagnosis, you have to find out what it’s all about, the implications, your shattered dreams. You’re left to cope, you have to cope – you go into mourning – for ever, for ever – now I have to ask God for a long life to look after this child – it’s a life sentence – but then you die very unhappy because you worry, what’s going to happen to my son – and I look at my other one, and I wonder, will he change like Mark...?’

Alison agrees. ‘When I got the diagnosis ... it was like a big weight taken off my shoulder because I’d been tracking around for six years trying to find the answer, and then after that wears off there’s a period of mourning almost when you think “Oh my God, what’s going to happen to them in life?”’

However, Caroline is determined to be positive about Sam’s prospects. ‘Thinking about the future – he’s a very competent little boy who has very clear ideas. How he will cope at school I just don’t know, but longer term he will be all right, he will need support from me, but I don’t think it’s more than the support I would give any child...’

Non-disabled children – ambitions

Because families have to concentrate their energy – and often their resources – on their disabled children, they fear that their non-disabled children miss out now, and will continue to do so. Jennifer notes ‘I think the other siblings have a rough deal – I think it’s hard to quantify that. There’s a huge difference in the way you treat them. When they’re older you can explain it, but at the moment, John is allowed a piece of cake and Andrew isn’t... They’re just expected to cope.’

Mothers – ambitions

Mothers’ ambitions for the future are constrained by having to give up work, often for years, and their long term caring responsibilities. While some mothers just want to stay at home and care for their children, others nurture hopes of

studying, of getting a job, of things getting better. Some mothers fear that things will never change. In order to cope they dare not anticipate anything, they take each day as it comes.

Latoya points out that the difficulties of living on a low income are compounded by loneliness and the belief that things will never get better. 'I've been indoors for so long – I've been in this house for so long, and I don't see how things are going to get any better – I want to study, I want to do something.'

9.5 Discussion

Can measures of social exclusion be applied to the families who participated in this study? This chapter has established that Atkinson's framework for social exclusion is particularly appropriate for these families, who fare worse than other families because low income is compounded by difficulties accessing employment (relativity), they are disproportionately reliant upon external services over which they have little power (agency), and feel the whole family confronts an uncertain future (dynamics). It highlights the close connection between disability, low income and social exclusion.

A drop in income forces families into debt and heightens anxiety and feelings of powerlessness. Anxiety and ill-health undermine parents' ability to go on ordinary outings or engage socially with friends, let alone access paid employment. The link with material deprivation is clear. Coping on incomes that are clearly too low to live on saps both stamina and confidence and exacerbates health problems. An increase in income can bring about significantly greater levels of inclusion for all the family. Additional financial support reduces stress levels, enhances self-esteem, and may enable parent-carers to pursue their studies and/or seek out paid employment.

However, this chapter also suggests that families with disabled children are susceptible to social exclusion for a variety of reasons that are not directly linked to material deprivation. Socially, families often cite discrimination as a reason for not engaging in activities that other families on a similar income might be able to enjoy. The inaccessibility of public transport, an often hostile and judgemental public, and poor services are just three factors that keep families and their children at home.

Findings and recommendations – a summary

The benefit system

The Government recognises that disability is both a cause and a consequence of poverty. It has introduced a number of significant improvements to disability benefits for children in order to avoid them being sucked into an often intractable cycle of disability, social exclusion and poverty. When the system works, additional financial support does make a real difference to families' lives. A rise in income reduces stress levels, and enables families and their children to be more active participants in society.

If Government initiatives on the reduction of child poverty are to be successful, it is clearly important that families with disabled children access the benefits to which they are entitled. However, flaws within the system prevent families accessing benefits, and actively undermine policy initiatives to reduce high levels of poverty amongst disabled children. Caring for one – or sometimes two or more – disabled children without adequate support exacts a huge financial and social toll on parent-carer's (and indeed their disabled and non-disabled children's) physical and psychological well-being.

Families whose child is awarded DLA report that it is frequently downrated or removed, resulting in fluctuating incomes. Families are perplexed when their child's DLA award changes, but their child's care needs (and their costs) have not. Far from providing financial security for families, the current system renders families with disabled children extremely vulnerable to high levels of poverty and social exclusion. The provision of reliable, long term financial support is essential if 'security for those who cannot work' is to become a reality.

Additional disability-related costs sap income whether or not a family is receiving their full benefit entitlement, and yet families who are most vulnerable to poverty are the least likely to apply for DLA (Chamba et al, 1999). Although an award of DLA is clearly enormously helpful, for low-income families who have been struggling for some years with disability-related costs without additional financial support, it may do little more than pay off debts. As a consequence, DLA may simply bring family finances up to income support levels, which the Government acknowledges are not sufficient to cover the extra costs of disability (hence the introduction of additional disabled child and carer's premiums within income support). Although DLA is back-dated to the date of the original application, there is no acknowledgement that low-income families, who may have struggled for many years without extra financial support, need to 'catch up' financially before DLA can effectively meet extra costs.

Families highlight a number of specific issues that must be addressed if the Government's hopes of eradicating child poverty are to be realised:

- ◆ Failure to receive DLA and associated benefits renders low-income families with disabled children vulnerable to high levels of poverty and social exclusion. Maximising take-up is a priority. Given the shortcomings of information and advice emanating from the DWP, improving take-up requires a well-financed local authority and independent advice sector which can provide long term advice and support with applications, appeals and reapplications.
- ◆ Publicising information about benefit entitlement in schools, as part of a local authority take up strategy, would be an effective way of alerting parents to their child's potential entitlements, and would ensure that the educational establishment is better informed about disability benefits.
- ◆ A number of families who receive DLA for their child do not realise that they are entitled to carer's allowance and/or disabled child and carer's premium within income support. They therefore miss out on crucial forms of additional support. Currently people are expected to make separate applications for benefits such as carer's allowance or to know they need to notify the DWP so that additional premiums within income support can be paid. There is no reason why an award of DLA should not trigger these payments automatically.
- ◆ There are serious concerns about the quality of decision making – particularly with regard to 'invisible' and/or fluctuating conditions such as ADHD. Although the Disability and Carers Service is piloting two training modules for decision makers on ADHD and children's mental health services, it remains to be seen whether these will improve the quality and consistency of awards. Meanwhile, the increase in the number of short term awards made for DLA has widened the scope for conflicting and contradictory decisions.
- ◆ DLA and associated benefits' reliability as a financial 'safety net' needs to be improved. A DLA run-on (for example, for three months, or until the person has lodged an appeal) would protect those families whose child's DLA has been subjected to an inappropriate decision from an overnight loss of income, and would provide financial breathing space for families whose child's needs have changed.
- ◆ The ability of DLA to meet extra costs needs to be reviewed in the light of woefully inadequate income support levels and families' starting point income-wise.
- ◆ The sudden loss of carer's allowance and disabled child and carer's premiums within income support can be devastating. An extension of entitlement to carer's allowance/carers' premium and the disabled child elements in child tax credit, housing benefit and council tax benefit for up

to three months or until an appeal has been lodged would prevent sudden drops in income. (Although the transfer of financial support for children from income support to tax credits may prevent sudden drops of income, the loss of DLA will remain a problem.)

- ◆ Families who choose to care for their disabled children themselves should be adequately supported in financial terms – for example, by a significant increase in carer’s allowance – and by the provision of appropriate and affordable support services. Any parent-carer who cares for more than one disabled person (children and/or adults) should receive additional financial support whether they are lone parents, or part of a couple.
- ◆ Childcare tax credit is rarely accessed by families with disabled children because they are unlikely to be in paid employment. The provision of specialist, high quality childcare for disabled children, irrespective of their parents’ work status, would reduce stress levels, improve parental health and acknowledge the important role full time carers play. It would enhance the quality of life for disabled children and would render the long term prospect of employment for their parents more realistic.

Employment

Families with disabled children report that employment remains a difficult and unreliable route out of poverty. The main barriers to employment are inflexible employers, expensive childcare, worries about losing benefit, and the fact that parents are often advised to give up their jobs by professionals who represent their children’s needs. Families raise a number of issues that have implications for the Government’s ‘welfare to work’ policy:

- ◆ Parents are grateful for additional financial support (such as income support and DLA), but they feel marginalised by the ‘welfare to work’ focus of New Labour’s strategy which seems to stigmatise them because they are financially reliant upon benefits that are designed to help them cope.
- ◆ Some mothers express the desire to use the expertise and knowledge they have acquired caring for their child to develop their careers. However, there is very little support (for example, with childcare) if they wish to undertake voluntary work, attend lectures, or study at home.
- ◆ Some parents want to care for their disabled children themselves. Reducing benefit does not constitute an inducement for such parents to access employment, it merely renders life significantly worse for parent and child.
- ◆ Some mothers (particularly those with two or more disabled children) report that they would rather have their partners at home helping to care for the children than have them out at work all day, even if this means living on a lower income. When their partner shares caring

responsibilities, mothers report an improvement in family relationships and a reduction in stress levels, which improves outcomes for all the family. However, fathers worry that even a short gap in employment due to caring responsibilities will be viewed as unacceptable by prospective employers. Differing priorities may contribute to stress and breakdown of relationships.

- ◆ Improving financial support for carers would enhance the status of people who choose or have to give up employment to care for their disabled children, and may improve their long term chances of accessing employment.

Services

Families' reliance upon statutory services renders them particularly susceptible to unreliable and inadequate provision. Much more needs to be done to ensure that 'seamless' and holistic services are adapted to the needs of disabled children and their family. Differing priorities and a culture of blame hinder 'joined up thinking'. Poor services result in families being forced to use benefit income, which is supposed to help with the extra costs associated with their disabled child's particular needs, to pay for additional services.

Social exclusion

Individual members of the families experience social exclusion in different ways. Little is known about the perceptions of social exclusion amongst disabled children themselves, their non-disabled siblings, and their fathers. Further research is essential.

References

- Adelman, L. Middleton, S. and Ashworth, K. (2003) *Britain's Poorest Children: Severe and persistent poverty and social exclusion* (Save the Children supported by Joseph Rowntree Foundation)
- Acheson Report (1998) *The Independent Inquiry into Inequalities in Health* Chaired by Sir Donald Acheson (The Stationery Office)
- Audit Commission (2003) *Services for disabled children: A review of services for disabled children and their families* (Audit Commission)
- Asghar, Z. and Burchardt, T. (2003) *Comparing incomes when needs differ: Equivalisation for the extra costs of disability* (CASEpaper 64)
- Barnardo's (2002) *Still missing out? Ending poverty and social exclusion: messages to government from families with disabled children* (Barnardo's).
- Beresford, B. (1994) *Positively parents: caring for a severely disabled child* (Joseph Rowntree Foundation), Social Policy Research Unit (SPRU), University of York.
- Beresford, B. (1995) *Expert opinions: a national survey of parents caring for a severely disabled child*, (SPRU, The Policy Press and Community Care).
- Beresford, B. Sloper, P. Baldwin, S. Newman, T. (1996) *What works in services for families with a disabled child?* (Barnardo's)
- Burchardt, T. (2003) *Being and Becoming: Social exclusion and the onset of disability* (CASEreport 21)
- Chamba, R. Adham, W. Hirst, M. Lawton, D. Beresford, B. (1999) *On the edge: Minority ethnic families caring for a severely disabled child* (Policy Press).
- Child Poverty Action Group (CPAG) (2004) *Ending child poverty by 2020: The first five years* (CPAG).
- Contact a Family and Family Fund (2004) *Debt and Disability: The impact of debt on families with disabled children* (Contact a Family and Family Fund)
- Craig, G. Dornan, P. Bradshaw, J. Garbutt, R. Mumtaz, S. Syed, A. and Ward, A. (2003) *Underwriting citizenship for older people: The impact of additional benefit income for older people* (University of Hull, Social Research Paper No, 9)
- Dalley, G. (ed) (1991) *Disability and Social Policy* (Policy Studies Institute)

- Disability Alliance (2005) *Hard working families: caring for two or more disabled children* (Disability Alliance)
- Dobson, B. and Middleton, S. (1998) *Paying to care: The cost of childhood disability* (York Publishing Services (YPS) for Joseph Rowntree Foundation)
- Dobson, B. Middleton, S. and Braithwaite, I. (2001) *The impact of childhood disability on family life*, (York Publishing Services (YPS) for Joseph Rowntree Foundation)
- DSS (1998) *First findings from the disability follow-up to the FRS* (Research summary No. 5) (DSS, unpublished)
- DWP, (2001) *Families and children 2001: Living standards and the children* (DWP Report 190)
- DWP, (2002) *Research in the DWP 2000-01* (Social Research Branch, DWP)
- DWP (2004) *Families and children in Britain: Findings from the 2002 Families and Children Study* (FACS) (DWP, Research Report 206)
- End Child Poverty and Council for Disabled Children, (2003) *Disabled children, their families and child poverty* (End Child Poverty and Council for Disabled Children)
- Family Fund (2004) *Income and Expenditure of Families with a Severely Disabled Child* (Family Fund)
- Gordon, D. Adelman, L. Ashworth, K. Bradshaw, J. Levitas, R. Middleton, S. Pantazis, C. Patsios, D. Payne, S. Townsend, P. and Williams, J. (1999) *Poverty and social exclusion in Britain* (JRF, York Publishing Services)
- Gordon, D. (2000) *Disabled children in Britain: A reanalysis of the OPCS disability survey* (The Stationery Office)
- Hills, J. Le Grand, J. and Piachaud, D. (2002) *Understanding Social Exclusion* (Oxford University Press)
- HM Treasury (2004) *Child Poverty Review* (HM Treasury)
- Jenkins, S. and Rigg, J. (2003) *Disability and disadvantage: Selection, onset and duration effects* (CASEpaper 74)
- Meyers, M. Brady, H. Seto, E. (2000) *Expensive children in poor families: The intersection of childhood disabilities and welfare* (Public Policy Institute of California)
- Middleton, S. Ashton-Brooks, K. Cox, L. Dobson, B. with Reith, L. (2004) *Disabled people's cost of living: more than you would think?* (published by the Policy Press for the Joseph Rowntree Foundation (JRF))
- Pahl, J. (1989) *Money and Marriage* (Macmillan Education).

- Prime Minister's Strategy Unit (June 2004) *Improving the Life Chances of Disabled People* (Disability Project – Analytic Report – Early Years, Strategy Unit)
- Prime Minister's Strategy Unit (January 2005) *Improving the Life Chances of Disabled People - Final Report* (Strategy Unit, DWP, Department of Health, Department for Education and Skills, Office of the Deputy Prime Minister)
- Roberts, H. (2000) *What works in reducing inequalities in child health* (Barnardo's, for JRF)
- Roberts, K. Lawton, D. (1999) *Reaching its target? Disability living allowance for children* (Social Policy Report No. 9, Social Policy Research Unit, University of York)
- Sefton, T. and Rigg, J. (2004) *Income Dynamics and the Life Cycle* (CASEpaper 81)
- Social Exclusion Unit (2004) *Tackling Social Exclusion: taking stock and looking to the future – Emerging Findings* (Social Exclusion Unit, Office of the Deputy Prime Minister)
- Walker, R. (ed) (1999) *Ending Child Poverty* (Policy Press, Bristol)