

Policy briefing Poverty and families with disabled children in Wales



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contact a family **Wales**

for families with disabled children

incorporating

The Lady Hoare Trust

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Contact a Family Wales welcomes the Welsh Assembly Government's current focus on child poverty, A Fair Future For Our Children (2005) and fully supports the work of the End Child Poverty Network Cymru.

Disabled children and their families are at particular risk of suffering the consequences of poverty, which is reflected in the fact that each year financial worries attract the largest number of enquiries to the Contact a Family Wales office and our UK free phone Helpline.

This briefing is a summary of the issues highlighted by recent research into the experiences of families with disabled children. All parent quotes are from Contact a Family research.

FINANCIAL CONSEQUENCES / GREATER RISKS

Families of disabled children are significantly more likely to be living in poverty -

55% of families with disabled children live in, or at, the margins of poverty

HM Treasury (2004) Child Poverty Review

73.3% of families with disabled children have an income below the UK mean income

21.8% of families with disabled children have an income below 50% of the UK mean income

Wooley, M (2004) How do they manage? Income and expenditure of families with severely disabled children. York: Family Fund

Families with disabled children are four times more likely to owe in excess of £10,000 than the average UK household (15.7% as compared to 4%)

Harrison, J & Wooley, M (2004) Debt and Disability: The impact of debt on families with disabled children. York: Contact a Family & Family Fund

Families with disabled children have costs up to three times higher than other families, including; travel and other costs relating to hospital appointments and admissions, bedding or laundry equipment, extra or replacement furniture, heating and specialised equipment and adaptations.

Dobson, B & Middleton, S (1998) Paying to Care: The costs of childhood disability. York YPS

Dobson, Middleton & Beardsworth (2001) The Impact of childhood disability on family life. York: YPS

Wooley, M (2004) How do they manage? : Income and expenditure of families with severely disabled children. York: Family Fund

Over half of households with disabled children lack some of life's basic necessities because they can't afford them.

Gordon et al (2000) Disabled Children in Britain

Minority ethnic families are less likely to claim benefits, are refused more often when they do

and are routinely given lower rates than white families.

Chamba 'On the Edge' (1999)

Children from lower income households are more likely to report long standing illness or disability and mental health issues, reflecting a two-way relationship between low income and disability.

Improving the Life Chances of Disabled People (2005) The Prime Minister's Strategy Unit

ACCESS TO WORK

Parents of disabled children face significant barriers to accessing paid employment -

Mothers of disabled children are much less likely to be able to work than other mothers, only 3% work full time (compared to 22% of others) and only 13% work part-time (compared to 39% of others).

Child Poverty Review, HM Treasury 2004

There are significant challenges to combining work and caring – including the availability of appropriate childcare, taking time off for appointments and hospital admissions, financial problems in the benefit system and lack of understanding from employers.

Harrison, J & Shelley, P (2004) Flexible Enough? Contact a Family. Kagan, C Lewis, S Heaton, P (1998) Combining work and care: working parents of disabled children. Seddon, D (2001) Supporting parent carers in paid employment Bangor

"We had used up all our savings. The doctor suggested I stopped working as we'd be better off financially. We could then both look after our twins, one each. My boss also told me I was better off not working"

Despite recent changes in legislation which recognise the extra needs of parents of disabled children, parents are often unaware of their rights to parental leave and flexible working.

Harrison, J & Shelley, P (2004) Flexible Enough? Contact a Family

"I tried to work nights so I could be there in the day to support my wife but then I got no sleep either and ended up having to ask my employer if I could come off night shifts having asked to go on them. It felt like a no win situation"



ACCESS TO CHILDCARE

Childcare is a particular problem for families with disabled children -

Childcare for disabled children is expensive and difficult to find. Despite the recent expansion in childcare provision, there is still very limited choice for parents of disabled children. Parents describe difficulties in finding information about suitable childcare in their area, as well as problems finding childcare staff with relevant experience and training in caring for their disabled children.

Childcare costs for parents of disabled children Contact a Family 2004

'We have a 17 year old with a rare disorder. She is physically too old for childcare yet mentally not old enough to be by herself in the summer holidays, or go to activities for adults. This is a large challenge and pretty frustrating. Even when she is at school, we have to fit work and meetings around bus pick up and delivery times.'

Parents report that problems with childcare make it difficult to balance work and caring, often leading to a reduction in working hours or leaving work all together.

Contact a Family Web survey (2002)

There are very few specialist nurseries, childminders with accessible premises and appropriate training and expertise to look after children with complex needs.

Joseph Rowntree Foundation (1998) Combining Work and Care

"Finding appropriate care is almost impossible, even though she is a pleasant easy going child. Her medical needs are just too complex and many people have been unwilling to watch her due to fear of what might happen, as illness comes on suddenly and seriously."

"I am really struggling with this issue now. I need to work to help to support my family but my son needs me to be at home. I want to finish my degree as well but guilt is taking over."



ACCESS TO WIDER SUPPORT SERVICES

Social activities - disabled children are still excluded from many play, sport, leisure and arts activities.

Shelley, P (2002) Everybody Here? Contact a Family

"My son needs a companion to support him in mainstream activities"

Housing - three quarters of families with a disabled child live in an unsuitable home. *Oldman & Beresford (2002) Housing Matters The Policy Press, Oldman & Beresford (1998) Homes Unfit for Children York: JRF*

Social services – the Audit Commission Report (2004) – Services for Disabled Children covering England and Wales found:

- A lottery of provision, dependent on where people live and on how hard they can push for services;
- too little being provided too late, with long waits for information, equipment and treatment;
- a maze of services that frustrates and confuses families.

The Audit Commission Report (2004) – Services for Disabled Children. Contact a Family Wales (2003) The Children's NSF – Wales Disabled Child Module Report

"There needs to be more respite and greater flexibility, respite is given on the Local Authority's terms, not on a flexible basis in consultation with parents."

Health - Travelling to and from hospital can place a considerable financial burden on families with disabled children.

Contact a Family Wales (2003) The Children's NSF – Wales Disabled Child Module Report. Davies M, (2004) Parking At Hospital Sites - AWCH and Contact a Family Wales Survey

'I live in West Wales where there is no neurology service for children. My daughter has uncontrollable epilepsy and we travel to Great Ormond Street Hospital in London frequently. I would like to see changes that incorporate assistance with costs for families travelling outside their Health Authority area.'

55% of families with disabled children live in, or at, the margins of poverty.

HM Treasury (2004) Child Poverty Review

RECOMMENDATIONS

Contact a Family Wales welcomes the Welsh Assembly Government's current focus on child poverty, A Fair Future For Our Children (2005) and the recognition it gives to the extra needs of families with disabled children.

The Fair Future For Our Children Implementation Plan must now explicitly address the specific needs of families with disabled children in Wales to achieve the aims set by the Strategy.

Income poverty

The Welsh Assembly Government should continue to work with the UK government to :-

- ☞ **Increase in the amounts allowable for childcare to parents of disabled children through the Tax Credits system.**
- ☞ **Urgently review the levels of financial support available to families of disabled children who need to travel long distances to frequent hospital appointments and admissions.**
- ☞ **Review the regulations which prevent those on carers allowance studying full time, which is a particular barrier to mothers of disabled children accessing re-training for employment.**
- ☞ **Look at extending flexible working rights to enable parent carers to request flexible working from when they begin a new job.**

Access to childcare

- ☞ **Increase funding to child minders and other childcare staff to develop their skills and experience in caring for disabled children, to ensure a substantial increase in the availability of all types of childcare provision for disabled children across Wales.**
- ☞ **Ensure that all extended school activities are accessible to disabled children.**

Work with employers to improve work/life balance and ensure equality

- ☞ **The Welsh Assembly Government needs to work with employers, trade unions and the Citizens Advice Bureau to promote awareness and uptake of the extra entitlements to parental leave and flexible working available to parents of disabled children.**

Local Authority drive to encourage full benefit take-up

- ☞ **Any benefit take-up campaign must specifically target families with disabled children.**

Debt advice

- ☞ **Any review of the provision of money advice services should consider the role voluntary organisations in the field can play in reaching families with disabled children. As well as considering increasing the provision of home visiting and out- reach services to access families of disabled children.**

Contact a Family Wales - February 2006

Contact a Family is the only UK-wide charity providing advice, information and support to parents of all disabled children – no matter what their health condition.



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