

# Flexible Enough?

Employment patterns in  
families with disabled  
children

*A survey of over 900  
parents in the UK*

**contact** a family  
for families with disabled children

## **Flexible Enough?**

Employment patterns in families with disabled children

*A survey of over 900 parents in the UK*

*'Flexible hours should be the norm and not an exception. At my place of work, we have core hours between 10 am and 4pm outside of this we can do more or less as long as it balances out over the year' Finance officer*

**Contact a Family  
Final Report: February 2004**

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# Chapter 1 Introduction and Methodology

## 1.1 Introduction

There are half a million disabled children in the UK, the majority of whom live at home with their families. Each day, seventy five children are born or diagnosed with a disability. Contact a Family provides support, advice and information to families with disabled children across the UK. Each year our helpline and local information services support over 18,000 families, and a further million parents and professionals visit the website [www.cafamily.org.uk](http://www.cafamily.org.uk).

This report describes the findings of a two-month consultation exercise on the theme of flexible working in families where there are one or more disabled children. The work was funded by the Department for Trade and Industry. It was carried out by Contact a Family who also analysed the data and produced this report.

Contact a Family received 180 enquiries to its helpline specifically relating to employment problems between April and December 2003. In addition Contact a Family is a national partner in the 'Action for Carers and Employment' (ACE) project led by Carers UK and funded by the European Union Equal Programme. Our local project in Ealing office provides support, advice and training to parents in relation to returning to work as part of the ACE project. Contact a Family hears from many parents about the difficulties they face in obtaining care at home, accessing short breaks, getting information about their child's medical condition as well as the benefits and services that they can apply for. Previous research (Contact a Family 'No Time for Us' 2004) has indicated that 76% of parents experience stress or depression. There is a wealth of evidence that families with disabled children are more likely to experience poverty (e.g. DSS 'Households Below Average Incomes' 2001).

Parents with a disabled child already lead complicated lives and where they are trying to juggle paid employment with the care of their child, this complexity increases. This consultation exercise aimed to explore and understand some of this complex picture and look at the barriers to employment which families face.

## 1.2 Methodology

The consultation exercise incorporated three components:

- A postal survey
- A web-based survey
- A workshop for fathers

### **The postal survey**

A short questionnaire (see Appendix A) was sent to all 1700 subscribers to the Contact a Family West Midlands newsletter in January 2004. A total of 202 questionnaires were returned, giving a response rate of approximately 12%.

## **The web-based survey**

The Internet survey was essentially a shortened version of the postal survey. It was posted on the Contact a Family website from mid December 2003 to mid February 2004. This survey received 728 responses, and some respondents sent emails with additional stories or comments.

Together the two surveys therefore generated a total of 930 responses.

## **The workshop**

The workshop, which was held in Mold on 27<sup>th</sup> January 2004, involved eleven fathers and was facilitated by Contact a Family Wales.

### **1.3 The report**

In summary therefore, this report brings together the views and experiences of over 900 parents with a child with a disability.

Chapter 2 describes the key features of the families who responded to the two surveys, including the gender of the respondents, their ethnic origin, their current employment status, and the age of the disabled child. Chapter 3 describes the flexible working provisions which apply to families with disabled children and analyses the level of knowledge of the respondents about these provisions.

Chapter 4 outlines the parents' experience of flexible working. Chapter 5 looks at particular issues for fathers raised during the fathers' workshop in Wales.

Chapter 6 looks at the main problems families had in juggling working and caring. Chapter 7 gives parents' views of what could make things better for them.

Finally, the key findings, conclusions and policy implications and recommendations are presented in Chapter 8.

Throughout the report, the findings are illustrated with pie and bar charts. Quotes, comments and examples from the postal survey and the workshop, or from emails sent in by visitors to the web site, have also been incorporated in relevant sections throughout the report to illustrate the points under discussion

# Chapter 2 The Families in the Surveys

This chapter is based on both the postal and web-based surveys. It describes the key features of the families who responded to the two surveys, including the gender of the respondents, their ethnic origin, the current employment situation, and the age of the disabled child.

## 2.1 Gender of the respondents

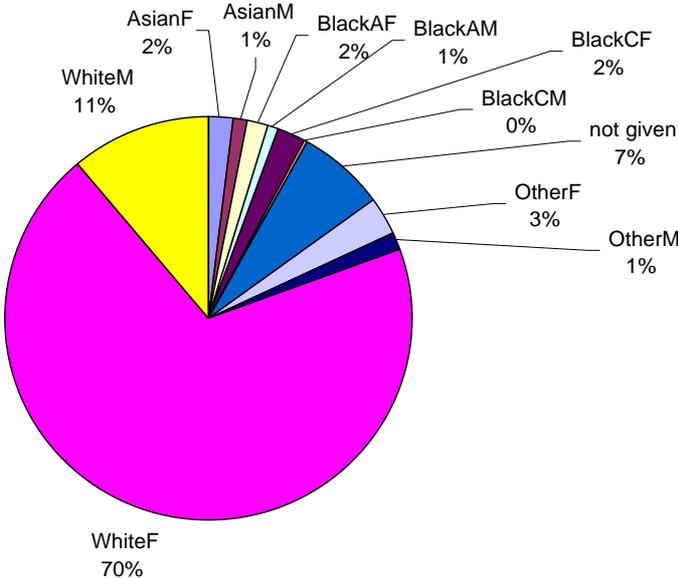
The vast majority of the respondents to the Internet survey identified themselves as female (568 = 78%). 109 (15%) identified themselves as male and 51 (7%) did not respond to this question. Women comprised the majority in all ethnic groups.

From the postal survey 85% of respondents were female and 13% male with 2% not answering this question.

## 2.2 Ethnic origin of the respondents

The majority (81%) of the Internet respondents described themselves as white (compared to the national population, in which 91% are white<sup>1</sup>). The remaining 19% were distributed amongst the other 4 categories (including 7% not given). Fig 1 illustrates the distribution by ethnicity and gender from the Internet survey.

Fig 1 Ethnic description



<sup>1</sup> Office of National Statistics (Feb 2003) Data from 2001 census

In the postal survey 85% of respondents were white, 12% described their origin as other than white, of which the largest subgroup were Asian (6%).

### 2.3 The current employment situation

Of the 728 respondents to the Internet survey

- 28% were working full time
- 26% were working part time
- 29% were not currently working outside the home
- 7% were self employed
- 10% did not answer the question.

As might be expected a greater proportion of the male respondents were working full time. 55% of the men were in full time employment as compared to only 25% of the women. Women were more likely to be employed part time (32%) than men (9%). Men were somewhat more likely to be self employed than women (11% as compared to 6%). There was a greater proportion of women who did not work outside the home (34%) than men (19%).

When looking at ethnicity, white men were most likely to be in full time employment (63%). However the situation is reversed for women. White women were the least likely to be in full time employment (24%) whereas Black Caribbean women had the highest rate of full time employment at 40%.

*Fig 2a –Employment patterns - men*

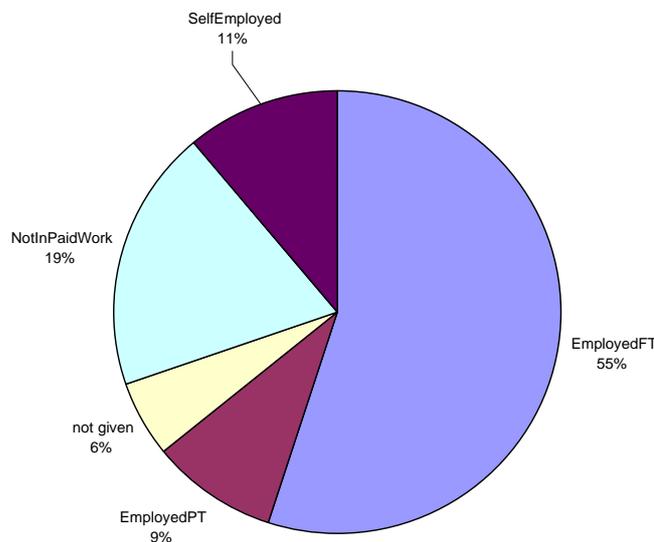
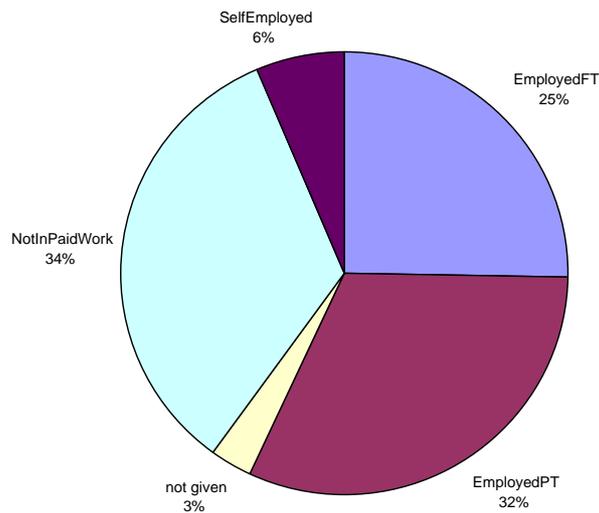


Fig 2b –Employment patterns –women



From the postal survey

- 28% of respondents were in full time employment
- 44% were working part time
- 5% were self employed
- 21% were not working outside the home
- 2% did not answer.

The postal survey further asked the respondents what type of work they did. The actual numbers in broad categories of employment are reported below.

Professionals	51
Office work	45
Social care work	19
Managers	14
Manual	14
Retail/catering	12

## 2.4 The age of the child

In the Internet survey

- 37% of the parents who responded had a disabled child aged under 6

- 34% were between 6-11
- 22% were aged 12-17
- 7% did not respond to this question.

In the postal survey

- 10% had a child under 6
- 48% a child 6-11 years
- 42% a child 12-17

Six postal respondents stated that they had more than one disabled child. The fact that the respondents to the postal survey tended to have older children may account for the pattern of working of these groups. Fewer were at home full time and more were working part time.

## Chapter 3 Levels of Knowledge about Employment Law Provisions

### 3.1 Introduction

The ability to work outside the home is important to many families with disabled children. A wage or salary helps them to meet the extra costs arising from having a disabled child. Employment can provide a break from caring, reduce isolation and develop the social contacts that work often brings. Being in employment can also bring status in society, a sense of self esteem and independence for parents.

Since April 2003, the Employment Act 2002 has increased parental rights at work. Parents with children under 6 or disabled children under 18 have the right to apply to their employer for flexible working arrangements. Employers have a statutory duty to consider such requests seriously, and will only be able to refuse when there is a clear business reason. However, it is not an automatic right since there will be circumstances where a business cannot accommodate the request. There are various requirements a parent needs to fulfil. They include:

- Having a child under six, or eighteen in the case of a disabled child
- Making the application no later than two weeks before their sixth, or eighteenth, birthday, as applicable
- Having worked for the employer for 26 weeks on the date the application is made
- Not being an agency worker, or member of the armed forces
- Not having made an application for flexible working in the past twelve months

In order to exercise this right the employee needs to make the initial written application to the employer. An employee can request a change to the hours they work, a change to the times they work, or to work from home. These changes would then be permanent.

Once the employer has received the application they have 28 days to organise a meeting. This is an opportunity for both parties to discuss the desired work pattern and its impact and to consider any alternatives should the requested pattern of work prove difficult to implement. Within fourteen days of this meeting the employer must write to the employee either confirming the new work pattern and start date or providing an explanation as to why the request cannot be accommodated. If the employer feels more time is needed to take further action then the employee must be notified of this in writing within fourteen days of the meeting.

If the employee is unhappy with the decision they then have fourteen days to appeal.

There are also provisions in legislation which allow for Parental Leave - time off to care for children. Additionally, an employee can take unpaid time off to deal with an emergency relating to a dependant. This could be a parent, partner, child, or someone for whom an individual has sole care.

The surveys aimed to test out how aware parents were of the new rights to ask the employer for flexible working. Although we did not ask about parental leave or unpaid time off to deal with an emergency, many parents used the opportunity to give feedback on these provisions.

*'I am forever being told that the NHS is flexible and the DTI have set up the right to ask for flexible working, but I have not witnessed any flexibility, compassion or my personal rights. I feel that the ruling is still in favour of the employers as they will not allow me any carers leave if I know of a problem more than 24 hours in advance. This meant that when my daughter required an operation a few weeks ago, I had to take annual leave so that I could care for her' Nurse*

*'My husband works full time and because he has been there a number of years they allow him to take time off for emergencies, visits and meetings associated with our child. However, he always makes up the time or has it as holiday. He feels if he were to make special requests it could help them to decide that his services may no longer be required. They have him over a barrel.'*

In order to establish how much respondents knew about the law on flexible working, they were asked to indicate whether they thought the following four statements were true or false.

'The new rights to flexible working apply equally to mothers & fathers'. The correct answer is true.

'To use the new flexible working rights you have to have a child under 6'. The correct answer is false.

'The new flexible working rights apply if you have a disabled child up to 18'. The correct answer is true.

'If a parent asks, the employer has to let them work flexible hours'. The correct answer is false.

### **3.2 Application of the law equally to men and women**

On the Internet survey, we asked whether the new rights to flexible working apply equally to mothers & fathers.

- 52% gave the correct answer 'true'
- 38 % thought that the answer was false
- 10% did not answer

Men were slightly more likely (59%) to know the correct answer to this question than women. Awareness was highest amongst Asian men (66% of who gave the correct answer). Within the female respondents, white women were least likely to know the correct answer (53%).

On the postal survey –

- 54% gave the correct answer
- 33% the incorrect answer

- 13% did not answer.

Parents said

`Make it that more women know their rights' (office worker)

`Parents of special needs children should be able to work flexibly without being favoured less. The parent should not lose their job as a result. This should apply to both parents not just mother.' (part time public sector worker)

Fig 3a – the law applies equally to men and women – women’s responses

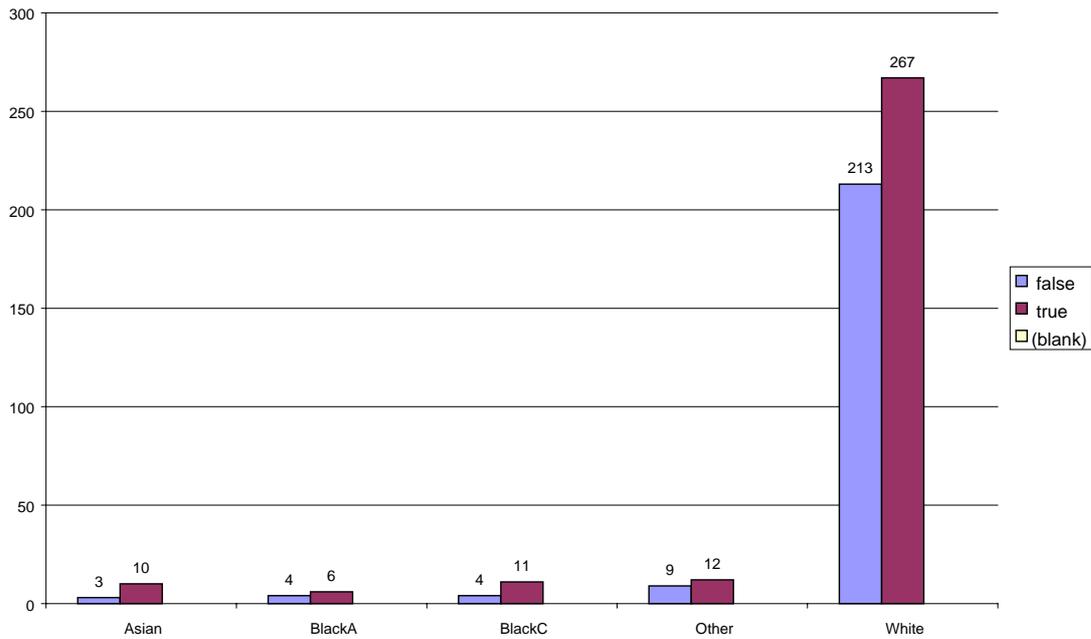
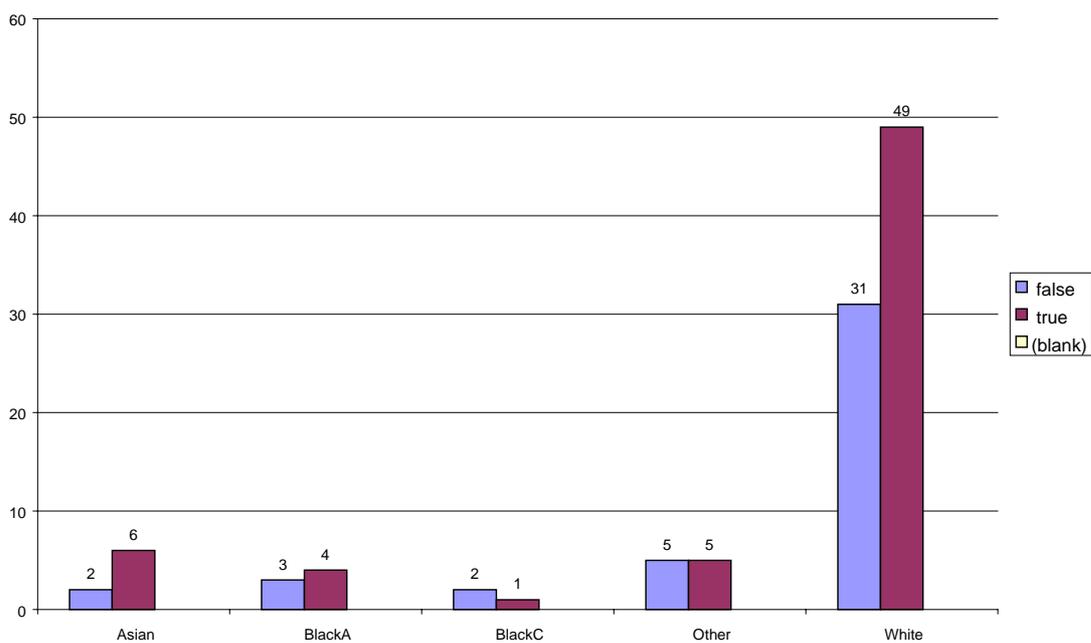


Fig 3b – the law applies equally to men and women – men’s responses



### 3.3 The law applies only if you have a child under 6

We asked Internet respondents to decide whether the statement 'To use the new flexible working rights you have to have a child under 6' was true or false.

- 49% gave the correct answer (false)
- 39% thought this statement was true
- 12% did not answer

Awareness levels were almost identical amongst men and women. However, there were significant variations between ethnic groups – with only 7% of Asian women knowing the correct answer compared with 86% of those who described their ethnic origin as 'other'.

In comparison, of the postal survey respondents –

- 51% gave the correct answer
- 33% were incorrect
- 16% did not answer.

Fig 4a the law applies if you have a child under 6 – women's responses

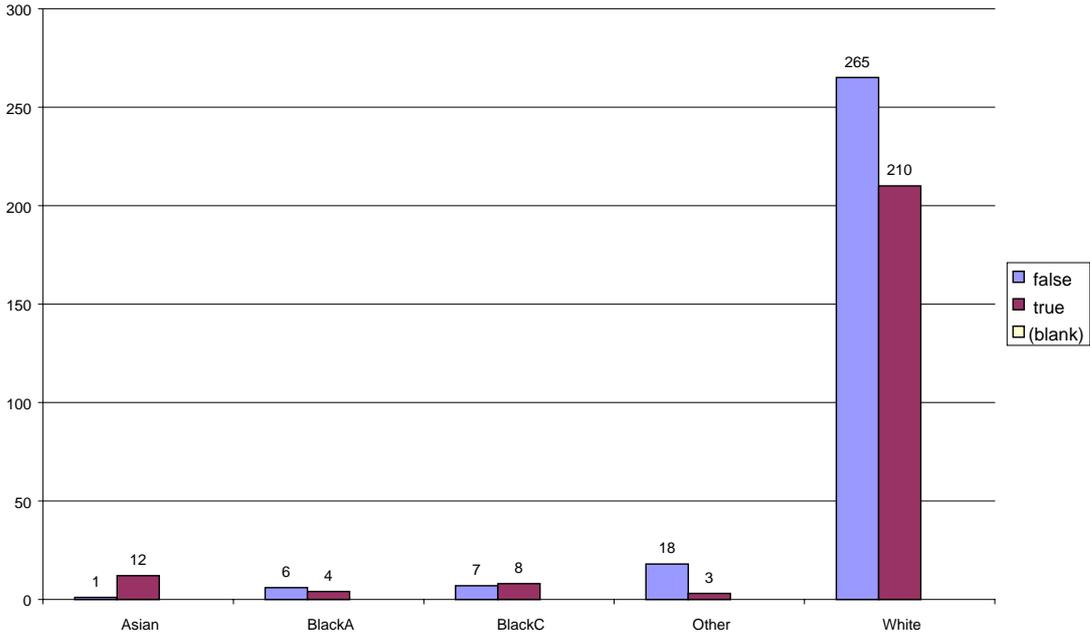
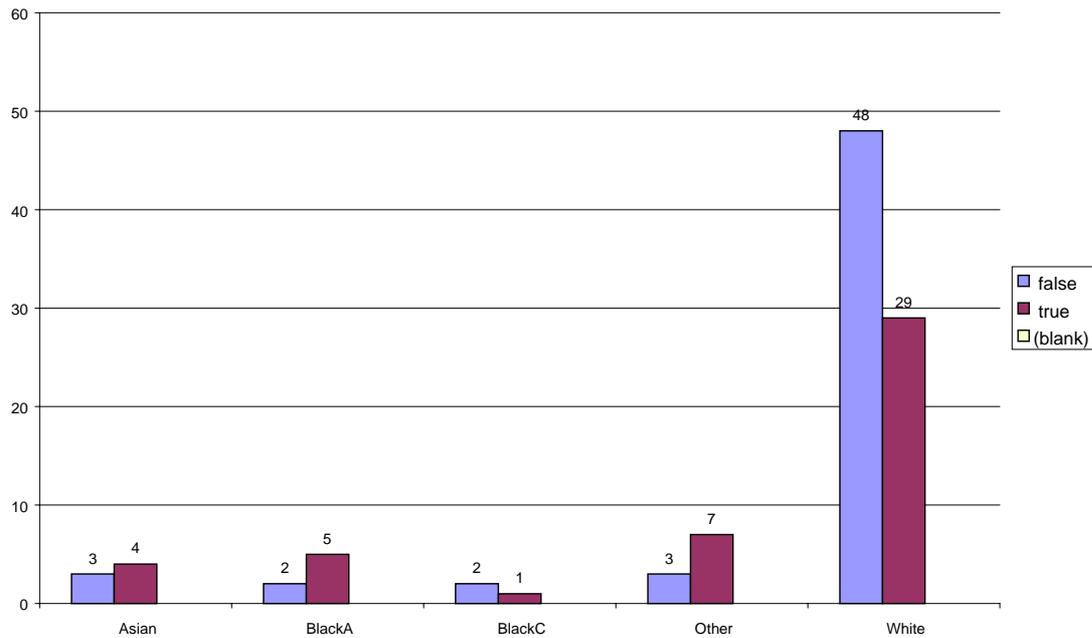


fig 4b – the law applies if you have a child under 6 – men's responses



### 3.4 The law applies if you have a disabled child up to age 18

The greatest numbers of correct answers were given in response to the question specifically about disabled children.

- 64% of respondents correctly answered 'true' when asked whether the new rights applied to disabled children up to the age of 18.
- 24%, almost a quarter of respondents, were aware of this right.
- 12% did not answer.

An identical percentage of men and women knew the correct answer to this question. Over 70% of white men, Black Caribbean women and men and women who described their ethnic origin as other knew the correct answer. Under 50% of Asian men and women, Black Caribbean men and Black African men knew the correct answer.

This was also the question that most postal respondents answered correctly.

- 69% knew the correct answer
- 16% were incorrect
- 15% did not answer.

*Fig 5a the law applies if you have a disabled child under 18 – women's responses*

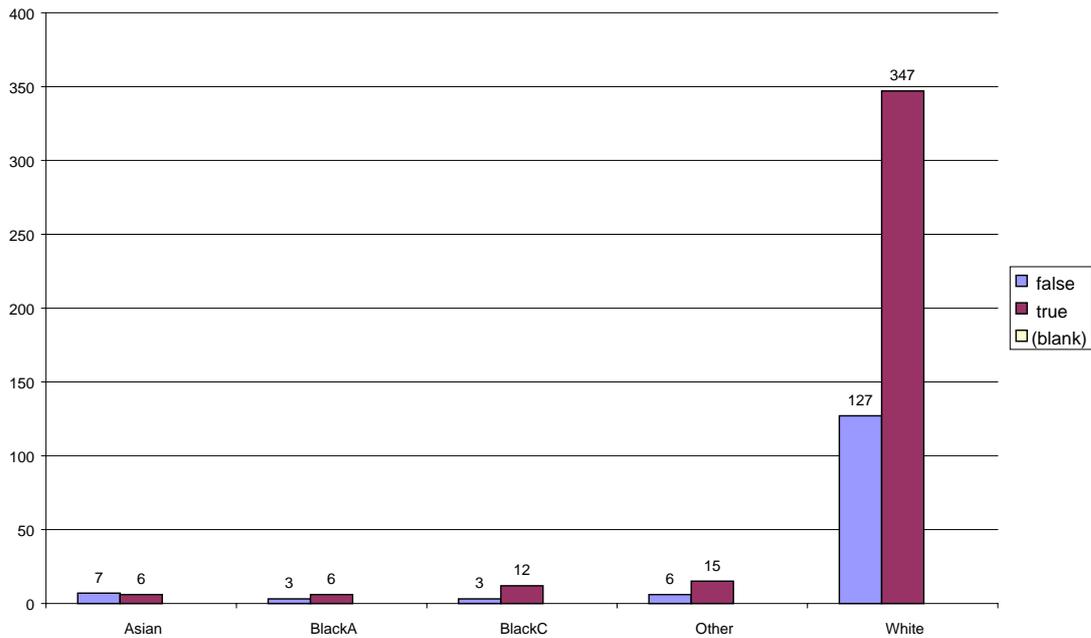
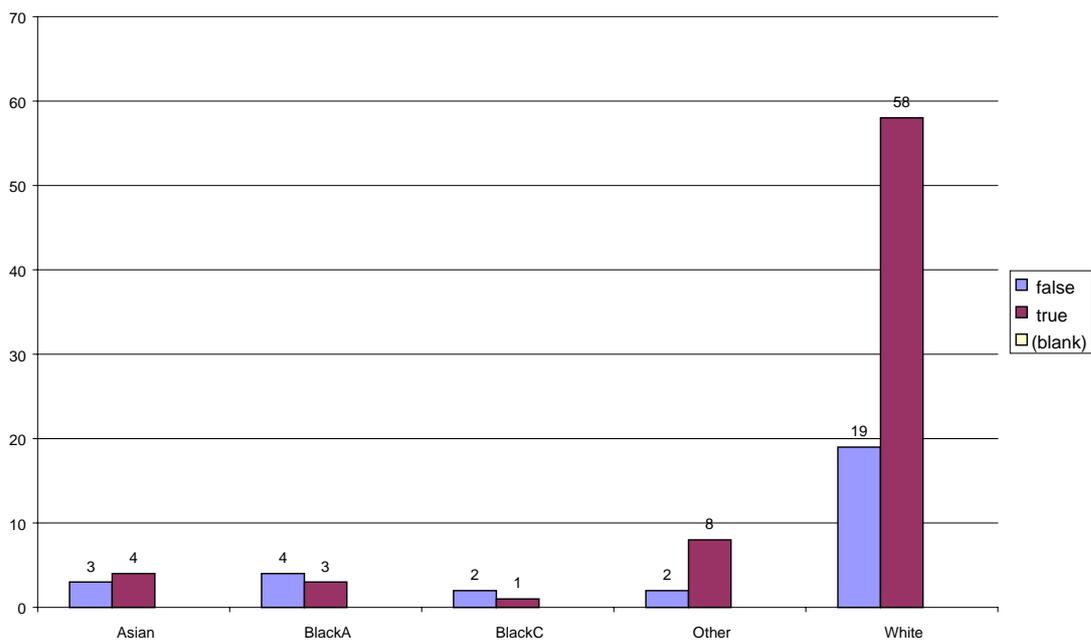


Fig 5b – the law applies if you have a disabled child up to 18 – men’s responses



### 3.5 The employer has to let the employee work flexibly

Finally respondents were asked if the employer has to let a parent work flexibly if asked.

- 53% of respondents correctly answered `false`.
- 35% thought that the employer did have to let parents work flexibly
- 12% did not answer.

Women were less likely to know the correct answer than men (56% compared to 62%). Awareness was lowest amongst Asian men and women (33% and 21% respectively). White men were most likely to have answered correctly (68%)

Postal survey respondents were asked the same question.

- 56% of postal survey respondents knew the correct answer
- 29% answered incorrectly
- 15% did not answer.

Several parents who did know that employers were not obliged to let employees work flexibly subsequently made comments that suggested they thought this should be changed. For example –

*‘Make employers make all jobs flexible to fit in with person’s life’ (care worker).*

*‘Insist that all large companies say above 80 staff are really family friendly and don’t just say so to make themselves look better.’*

*‘If there is a business reason for refusal the employer should be required to look at alternatives as a minor adjustment may be sufficient’*

*Fig 6a – the employer has to let you work flexibly if you ask – women’s responses*

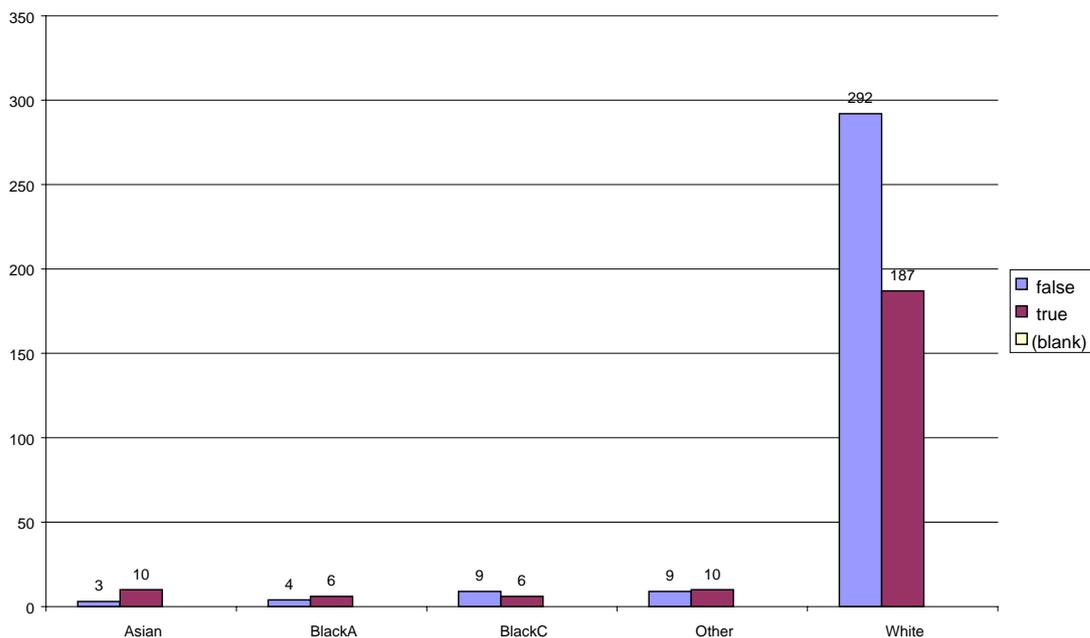
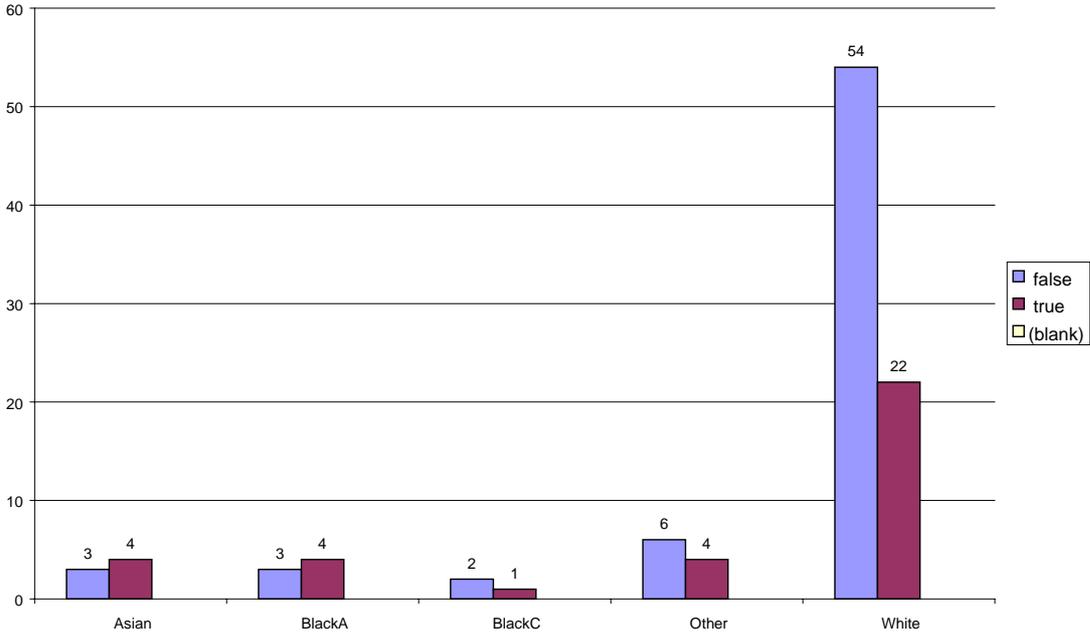


fig 6b – the employer has to let you work flexibly if you ask – men’s responses



### 3.6 Summary

The evidence clearly indicates that there was a considerable lack of awareness amongst parents of disabled children as to their new rights. Only about half of parents knew that the provisions applied equally to men and women; that it was not necessary to have a child under 6 to qualify or that employers did not have to agree to requests. Awareness was greatest that the provisions applied to disabled children up to age 18, but still about a third of parents answered incorrectly.

# Chapter 4 Experience of flexible working

## 4.1 Experience of asking to work more flexibly

We asked Internet respondents whether, since April, they had asked their employer to let them work more flexibly. We gave examples, such as part time working, working regularly from home or changing their start or finish time.

- 19% said that they were self employed or not working so it did not apply
- 14% said that they already work flexibly and so have not needed to ask
- 5% had asked and been turned down by their employer
- 11% had asked and their employer had agreed as requested
- 3% had asked and their employer had agreed an alternative
- 32% had not asked
- 16% did not respond to this question

Fig 7a Women’s experience of flexible working

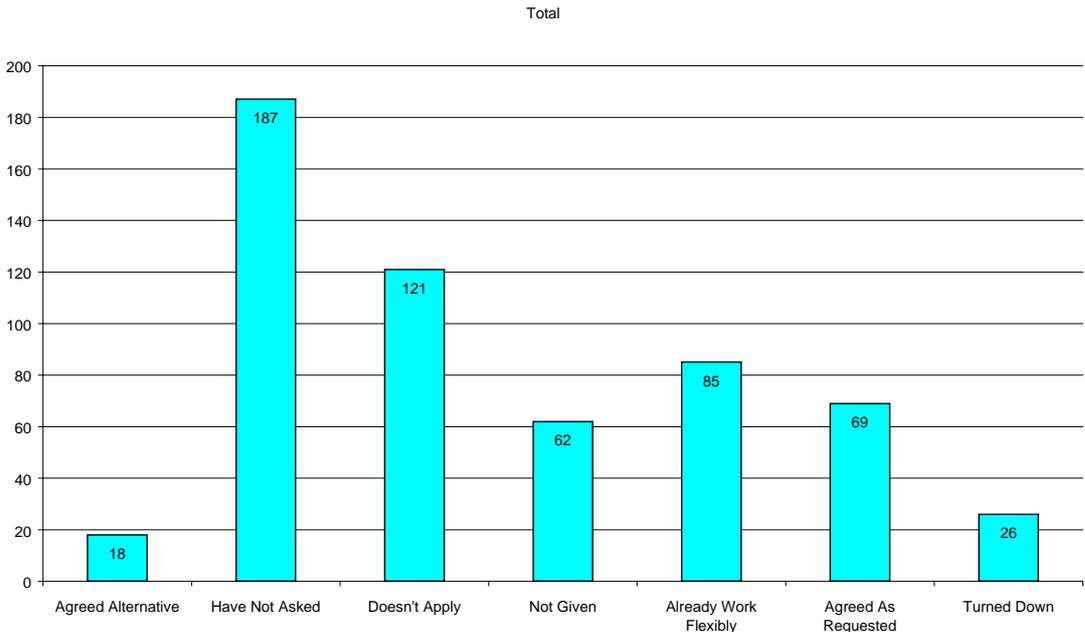
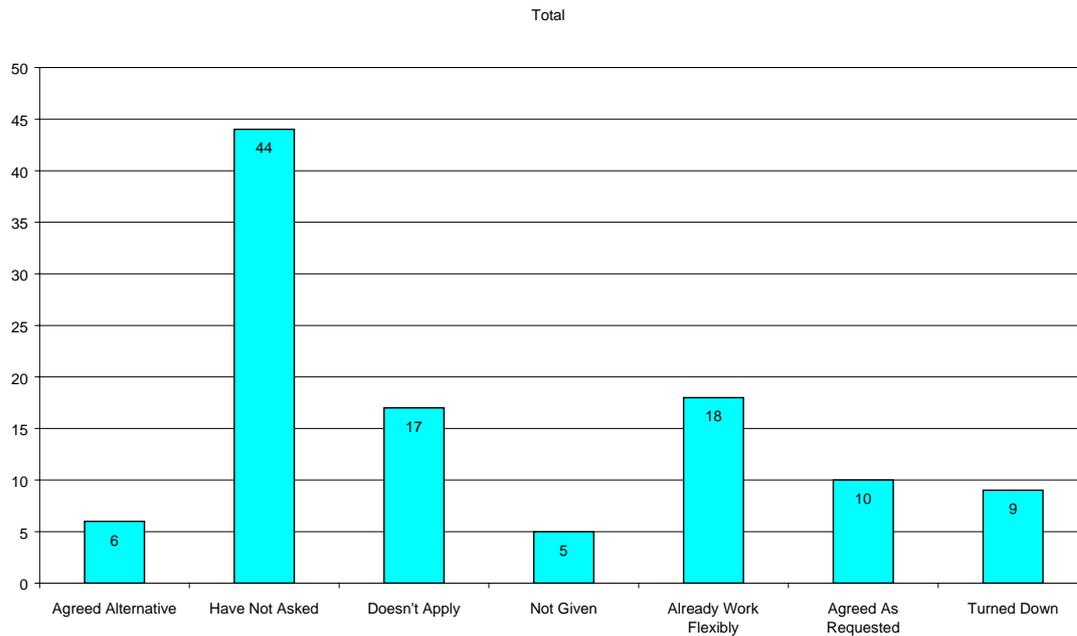


Fig 7b – Men’s experience of flexible working



When looking at the differences between men and women it was interesting to note that where the gender of the respondent was known, the percentage of men and women who said that they already work flexibly was identical at 16%. 40% of men had not asked to work flexibly compared to 33% of women. Men were slightly more likely to have asked and been refused by their employer (8% as compared to 5% of women). Asian women were more likely to have been refused than other women (18% of Asian women were refused compared to only 4% of white women) Women were somewhat more likely to have asked and have their employer agree than men (12% compared to 9% of men).

Of those who had asked their employer to work flexibly, respondents were asked whether they had made it clear that they were doing so officially (i.e. in writing and under the new law).

- 41% said that they had done so officially
- 59% had not.

In the postal survey of those who were working (150 out of 202)

- 37% (55 people) already work flexibly
- 5% asked but their employer did not agree
- 17% asked and their employer agreed
- 5% asked and their employer agreed an alternative
- 33% have not asked
- 3% did not respond

Postal survey respondents were also asked to indicate whether there is an Human Resources (HR) function at their workplace. Of the 55 people who already work flexibly, 33 have access to a Human Resources Officer at work, 16 do not and 6 were unsure.

## 4.2 Experience of employer refusal

Of those respondents to the postal survey whose employer refused (8 people)

- 1 put the request in writing and 7 did not
- 4 quoted the new law and 4 did not

We tried to ascertain what reasons the employer may have had for not agreeing to the request for flexible working. Those whose employers had refused were therefore asked to state the reasons given. These were:

- *not possible to be flexible (2 parents)*
- *"It didn't get that far as they put me off"*
- *"it wouldn't be fair on other workers"*
- *"flexible working is not suited to my status in the firm"*
- *time cover would be needed*
- *"do I want to keep my job?"*
- *would not fit in with shift patterns*

We then asked whether the respondent was considering doing anything about it. Answers were -

- *I went self-employed*
- *I resigned and am working my notice*
- *No (3 parents)*
- *Looking for another job (2 parents)*
- *May appeal*

Respondents had access to an HR Officer in 5 cases, not in 2 and one was unsure.

## 4.3 Experience of employer agreement in full

Of the 26 respondents to the postal survey who had requested to work flexibly and the employer agreed, we further asked whether they had put the request in writing. Ten had and sixteen had not.

We also asked whether the parent had quoted the law. Only one had – the remaining twenty five had not.

We then tried to clarify how the respondents thought that this had, or would in future, make a difference to their work/life balance.

Mothers made the following comments.

- *I will be able to work and also care for my son knowing that my employer will understand (office worker)*
- *I have to work around my life as a carer for my daughter - can carry on working – feel more supported since I put it in writing (midwife)*
- *It will allow me to spend time with my son and ease the burden on my husband; at present I work long hours and get bad tempered easily. (Recruitment consultant)*

- *My son has just started school full-time and by reducing my hours I will be able to be at home when he is dropped off by the taxi (Secretary)*
- *I now work term-time so can help in all the school holidays (Nursery nurse)*
- *It will enable me to have time with my family (Social worker)*
- *It will make life easier if my son has hospital/doctors appointments, I can take him without losing annual leave (office worker)*
- *Not very much – my employer does try to be flexible and is willing to swap shifts, time without pay, etc (optical assistant.)*
- *I have reduced my hours to mirror my daughter's school day (social worker)*
- *My employer asked me if I wanted my contract amended, I said yes and took two weeks unpaid leave in the summer; I hope to do the same this year but he suggested I might not be allowed this year! (training coordinator)*
- *I will lose financially due to the situation my special needs child is in and it has worried me that I will lose my job as a result (public sector)*
- *Don't feel so pressured in work; able to change hours at work (retail)*
- *I am home to see my daughter off to school and back except for one day (senior care worker)*
- *Quite a lot of difference because you don't feel guilty having time off work for child's appointments (company secretary)*
- *Makes me less stressed (nursery nurse)*
- *I am no longer worried about child care for school holidays (civil servant)*
- *It will mean that I don't have to give up work because of before and after school care (teacher.)*

#### Fathers

- *Without being able to utilise these flexible working arrangements my single parents household would not function – i.e. I could not maintain my mortgage etc. (office worker)*
- *Allow me to see more of my child – employer agreed to transfer me to a base nearer to home (fire fighter)*
- *Able to assist in routine appointments and have more say in school work (designer)*
- *I now have my office based at home and this has enabled me to continue to work full time, other wise I would have had to work part time (IT)*

Of these people, 15 said they had access to an HR Officer, 9 did not and one was unsure.

#### **4.4 Experience of those whose employers had agreed an alternative**

Seven postal survey respondents' employers had agreed to an alternative solution other than that originally proposed by the parent. We asked whether they had had put the request in writing. Four had and three had not. One had quoted the law but six had not.

We also asked them what difference it had made or would make to their lives.

Mothers told us:

- *Less stressed, able to take my child to appointments (manager)*

- *Less stress (NHS)*
- *I have been given time to attend strategy reviews for my daughter instead of having to use annual leave (social worker)*
- *I am now working from home during school holidays or on an occasional basis; this means that I do not use all my annual leave on childcare and can save five days (by working at home) to take my other child on holiday (office worker)*

One father told us:

- *Decrease stress when I need to take time off for appointments or periods of illness (e.g. physiotherapist). It will hopefully allow me to attend meetings and appointments with my son rather than relying on my wife. It will also hopefully allow me to be at home during difficult periods (paramedic)*

Of these respondents 5 had access to an HR Officer and two were unsure

#### **4.5 Experience of those who had not asked to work flexibly**

We then asked those who were employed but had NOT asked to work flexibly why they had not done so. They were asked to tick as many reasons as applied to their situation.

The following responses were given to the Internet survey

- 24% would like to work less hours but could not afford to earn less
- 17% said that had not asked because they do not know enough about their rights.
- 17% said they did not need or want to work more flexibly
- 16% did not think that their employer would let them work more flexibly
- 14% were worried about the effect on their career or chance of promotion
- 11% said they were worried about how their work colleagues would react

Fig 8a Why women do not ask to work flexibly

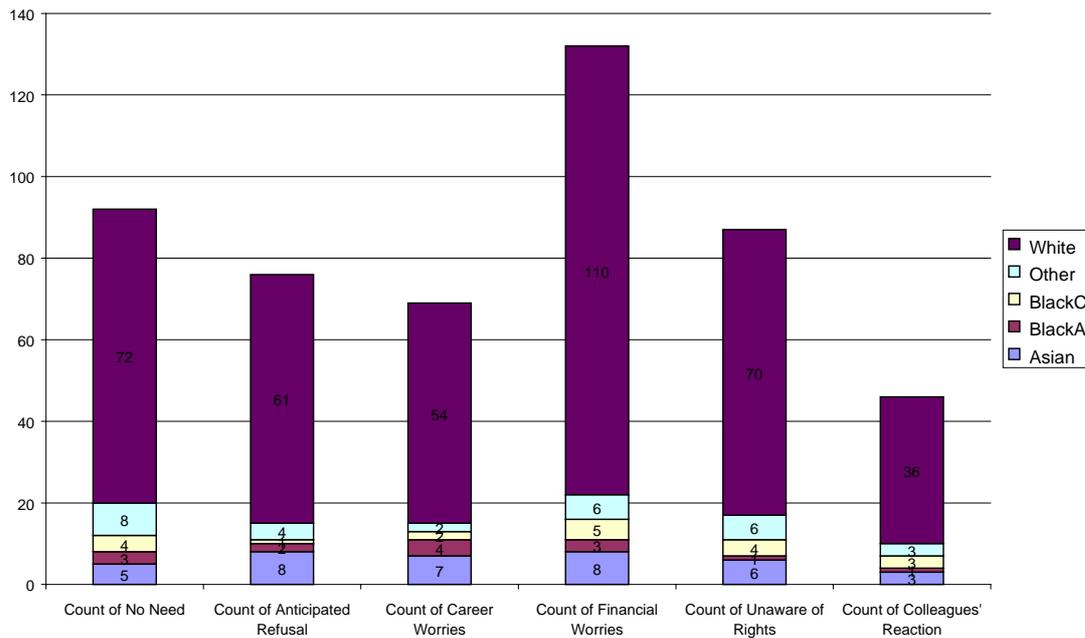
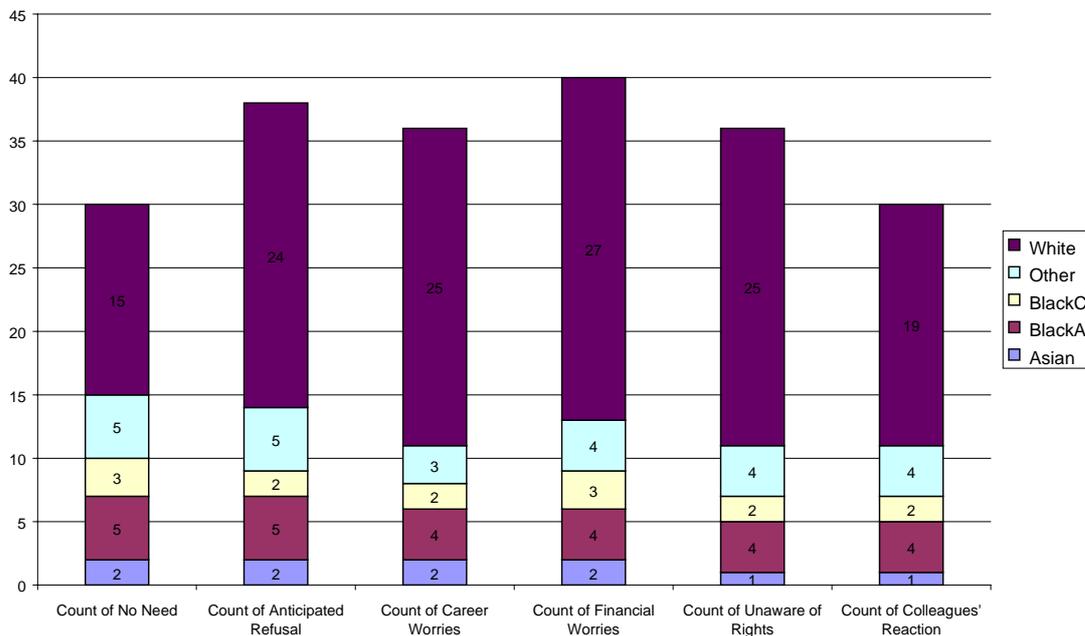


Fig 8b Why men don't ask to work flexibly



28% of men said that they did not need or want to work more flexibly but only 16% of women. In all cases respondents from ethnic minority communities were more likely to say that they did not want or need to work more flexibly. In some cases the differences were marked. All of the Caribbean males said that they did not want or need to work more flexibly as did 71% of black African males. This compares to 19% of white males.

Caribbean and African males were also most likely to believe that their employer would not let them work more flexibly (66 and 71% respectively, compared to 30% of white males). Overall, 35% of men believed that their employer would not let them work flexibly compared to 13% of women. Asian women were the most likely of the women to believe that their employers would not let them work flexibly (with some justification as they were also objectively more likely to be refused). 57% of Asian women believed their employers would not let them work flexibly compared to 12% of white women).

The effect on careers was more of a concern for men (33%) than women (12%) Black Caribbean and African men and Asian women were significantly more worried about their career or chance of promotion than other groups. All groups worried about the loss of income more than any other factor. This was more of a concern for men (37%) than for women (23%). Those most concerned about the issue of loss of income were Black Caribbean and African men and Asian women.

15% of women and 33% said that they felt they had not requested flexible working because they did not know enough about their rights. Given the level of misinformation that clearly abounds as shown by the answers to the true/false question, it is perhaps surprising that such a low percentage said they were unaware of their rights. It appears that more believe that they know their rights than is actually the case.

The issue of how colleagues would react was the least often cited reason for not asking to work flexibly. However, this was significantly more of a concern for men (28% of whom said it was an issue) than for women (8%). This may be due to stereotypical assumptions about respective gender roles and caring responsibilities.

We asked the postal respondents the same question about why they had not asked to work more flexibly. There were 50 people who had not made such a request.

- 58% would like to work less hours but could not afford to earn less
- 40% said that had not asked because they do not know enough about their rights.
- 36% did not think that their employer would let them work more flexibly
- 28% said they did not need or want to work more flexibly
- 26% were worried about the effect on their career or chance of promotion
- 18% said they were worried about how their work colleagues would react

As in the Internet survey, financial constraints are the top concern and attitude of colleagues is far less so.

The postal respondents were also asked to give us any other reasons why they had not asked to work flexibly. Their responses are reported in full below

- *My line manager would not agree and make life difficult for me – however, his superior would probably agree (office work)*
- *They don't understand what's its like to have a disabled child*
- *Nature of teaching is inflexible*
- *Would not agree because I am a lone worker*
- *Job involves telephoning during restricted hours*

- *My employer has already had me disciplined for taking my son to hospital appointments; I was on a two written warnings for a year (F/T nursery nurse)*
- *Job specification is for mornings only*
- *It is unacceptable as I work at a small local preschool*
- *Unable to because of nature of work (security officer)*

Of these people, 25 had access to an HR Officer, 14 did not and 11 were unsure.

#### **4.6 Knowledge of current employer's flexible working arrangements**

We asked the Internet respondents whether their employer currently has any flexible working arrangements.

- 30% said yes
- 18% said no
- 17% did not know
- 35% left this question unanswered.

Proportions of men and women were similar in all categories. Asian women were least likely to report that their workplace offered flexibility, with 36% saying that their workplace did not offer flexible arrangements.

#### **4.7 Applying for jobs if there are no flexible working provisions**

We asked the postal survey respondents only whether they had ever not applied for or turned down a job offer because the employer was not able to offer flexible working. Of 202 respondents 72 of them (38%) had turned down a job or not applied because there was no flexible working. 50% had not and the remainder did not respond.

As one parent said:

*'Flexible hours should be offered before job taken up' (manager)*

#### **4.8 Summary**

Only about 16% of parents surveyed are currently working flexibly. 40% of men and 38% of women had not asked to work flexibly, for a variety of reasons including financial implications, not needing or wanting to, not knowing enough about rights and worries about what their employer or colleagues would say.

The benefits of flexible working in terms of reduced stress were apparent from the comments made.

## Chapter 5 The Experience of Fathers

### 5.1 Introduction

Throughout the report, we have attempted to compare and contrast the relative experience of men and women. As part of this research Contact a Family Wales agreed to undertake a qualitative piece of research with a small number of fathers in order to gain a more in depth understanding of men's views and experiences. To this end, a workshop for fathers on employment issues was held on 27<sup>th</sup> January 2004 in Mold. Fathers attending other workshops in Wales from Autumn 2003 onwards were also asked to contribute their experiences.

The Mold workshop was facilitated by Keith Bowen and Jill Bartlett of Contact a Family Wales. In total, 11 fathers attended from 3 different counties

Current employment Status	Full time	4
	Part time	2
	Self employed	2
	Not in paid work	3
Type of work	Postman, primary deputy head teacher, Local Authority parks officer, charity worker(unpaid), shopkeeper, carpenter, aircraft fitter, development officer (learning disability charity), community church administrator	
Age of (disabled) child	Under 6	2
	6-11 years	4
	12-17 years	5
Ethnic background	All white	

### 5.2 Awareness and use of the legislation

There was a low level of awareness amongst the 11 fathers about the current legislation, for parents generally and specifically in regards to disabled children. All but two of them said that they knew very little about the current legislation; they were aware that there had been some recent changes but did not know how these changes may or may not be relevant to them as a parent of a disabled child.

Of the two fathers who did know more, the first had received an official leaflet with his wage packet and the second had heard via a colleague who was planning to make use of the new arrangements himself. Both these fathers worked for a local authority, the first in a planning department and the second as a deputy head teacher.

In their questionnaire responses the fathers did report a higher level of awareness than they declared in the workshop itself, although their answers contained a high level of inaccuracy. This indicates that even where there was some knowledge of the

current legislation, fathers did not have access to the information most relevant to their situation.

### **5.3 Where fathers look for information**

When asked where they would look for information about their rights to parental leave and flexible working if they needed to, the fathers gave a variety of responses, (in this order)

- Citizens Advice Bureau
- Trade union
- Employers' occupational health department
- Employers' Human Resources department
- Internet
- Local library
- Disability organisations, such as Contact a Family, Sense, the Downs Syndrome Association etc.
- Local parents' groups
- General practitioner
- Social worker/Community Nurse (although access to these professionals was varied)

One father said that he certainly wouldn't ask at the Job Centre as they had been particularly unhelpful on other related issues.

### **5.4 Father's views of employer awareness**

The fathers felt that their employers currently had a similarly low level of awareness of the new legislation on parental leave and flexible working. It was felt that this would apply to the new arrangements for all parents but in particular for those with disabled children.

*"If they (the employer) had anything to do with special needs they would know, otherwise why should they?"*

The size of employer seemed to make a difference, as it was felt that larger companies and organisations were more likely to have Human Resources departments and official policies on these matters, as one father commented:

*"Local Authorities seem to be in the know"*

One father from a previous workshop, who worked for a major supermarket chain, had been able to make use of the company's policy on flexible working when his disabled daughter was born, overriding a manager who was not initially helpful.

However the assumption that larger employers will be better informed was not always the case, as another father from a workshop in South Wales, who worked as a fireman had experienced considerable problems when his line manager had

refused to acknowledge that there was any new legislation despite being given the DTi leaflet.

It was felt that whilst having a limited knowledge initially, medium to small sized businesses may be more able to respond flexibly to individual requests as they arose.

One father who worked for a community church project had been able to develop very flexible work arrangements with his employer which fitted his need to balance the care of his disabled child and other family commitments.

One small employer was in the process of finding out more about the new legislation since an employee was now taking paternity leave following the birth of his non-disabled child. The father had been given information about his new rights when he attended ante-natal classes with his partner.

There was a feeling that many employers were not keeping up to date due to information overload.

*“There’s so much legislation flying about – who takes the time to read it all anyway”*

*“There’s too much paper work for employers anyway”*

## **5.5 Fathers views of employer’s understanding of the reality of having a disabled child**

A number of fathers were concerned that the new legislation could work against parents of disabled children, saying that if an employer had read the legislation and knew they had a disabled child they might not employ them.

*“Don’t employ him if he’s got a disabled child - too much hassle - too much time off”*

The fathers said that most employers have a very limited understanding of having a disabled child, although there was considerable variation depending on the relationship with their immediate boss.

*“If you talk to an employer about respite they wouldn’t even know what the word meant – if you had a disabled child you would and you’d know how much it was needed and how little there is of it available”*

*“A good employer is great they can really help –if they let you leave work easily, at the drop of a hat. But there is a responsibility on both to make things work. I can go home but take work with me but there is an obligation to get it done but this is o.k. as I have lee way to come and go as long the work gets done. I know without asking that I could go home if needed. I realise this is probably an exception to the rule.”*

*“There’s no understanding of having a disabled child – but what did we know before we were in this situation”*

## **5.6 Opportunities and barriers to flexible working**

All of the fathers said that they had had to make changes to or compromises in their career due to balancing the needs of their disabled child. These ranged from taking annual leave to attend hospital appointments, changing from full to part time working, passing up opportunities for promotion and training to leaving paid employment entirely.

*“I couldn’t work overtime due to commitments at home”*

*“When I was a psychiatric nurse I turned down 18 months training because I knew I would need to take time out to look after my family and I couldn’t commit to this”*

*“I didn’t go for my boss’ job (promotion) because I couldn’t give them the commitment that they wanted”*

Most had made informal arrangements with their employers if possible although there was one father who had recently made a formal application to reduce responsibilities from being a deputy head in a primary school to a class teacher. He had not referred to the new legislation in his initial request.

Informal arrangements were seen to have their drawbacks though, in particular as the fathers then felt guilty about asking their employers for further help.

*“One concession was that I was allowed to take half days when others weren’t, therefore I used them all up on annual leave and didn’t feel I could ask for more as it was already a favour to take half days. I always felt under pressure or obliged to people and always took annual leave for hospital appointments – I didn’t have a holiday for three years.”*

All the fathers saw benefits to flexible working and access to parental leave in supporting them balance the needs of their family and disabled children with work. Examples such as hospital appointments, meetings, respite/child care arrangements breaking down at short notice and medical emergencies were all cited.

None of the fathers had made use of the new opportunities under the current legislation at this point, although as outlined earlier, most had little knowledge of their rights. The main barriers to asking for more flexible working were:

- Loss of earnings – if reduced hours were agreed
- The nature of employment – rigid shift patterns in certain jobs e.g. the catering and engineering industries

*“As a chef, no one would get dinner that night”*

- Possible adverse affects on career
- Lack of knowledge of employment rights
- The corporate climate

*“It’s all about “how will this affect profit margins?”*

- Being self employed – which did offer a certain flexibility but there was little in the new arrangements if time off needed to be taken in an emergency

*“Being self employed... I own a shop. I just have to close, there is no option”*

*“If you are self employed it’s very difficult, who do you ask? You either get the work done or get a bad reputation for not finishing a job and you don’t get asked back”*

- The attitude of colleagues – some fathers were cautious not to be seen to be getting preferential treatment.

*“I over compensated then by feeling I had to work extra”*

*“You feel you can’t dump your problems on your colleagues. You have to try to leave issues behind as you walk in the door”*

*“Don’t say too much – play it down - you wait to ask for something until you really need it. Nobody wants to hear you go on about it – so you’re unable to ask for help”*

*“Some colleagues are very supportive”*

- “Flexible working” not flexible enough – rather than making ongoing arrangements to change or reduce hours, most wanted greater flexibility on a day to day basis to be able to attend appointments, leave early, take work home to be able to fit work around the needs of their disabled child.

It was clear the fathers of disabled children along with their partners were still taking the lead in finding their own solutions to “work life balance” issues. Even where there was a supportive employer, it was left to the employee to come up with the ideas. Employers were not being proactive in helping families find arrangements which would suit them.

*“My local authority took the attitude – you tell me what you want and then we’ll try and sort something out – I wanted some ideas from them about what I could do, as I wasn’t sure then exactly what I wanted”*

## 5.7 Balancing work and caring with partner

Parents have to reach a balance between maintaining themselves in paid work and caring. 50% of the fathers' partners were also working. This is a higher percentage than usual amongst parents of disabled children. However, most of those were in part time work and had chosen employment which fitted with their caring role.

*"My partner got a job as a school escort which fits in with school hours"*

*"She got a job as a one to one support (to be able to still look after our child)"*

In most of the relationships, one parent (usually the father) took on the main breadwinner role and the other became the primary carer.

*"There is a lot of pressure on families at an early stage - in most families these days both parents need to work – this is just not an option for most of us"*

*"As a postman I get out early but I finish early to be able to help out"*

The fathers felt that they were trying to maintain their caring responsibilities, support their partners as well as keeping down their paid employment.

*"When I come in from work although I've been working all day, she needs a break from caring and then I have to start another job as a carer to try to give my partner a bit of a break"*

*"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 employer if I could come off night shifts after asking to go on them, it felt like no win situation"*

Three of the fathers had reached the decision that it would be better to give up paid employment and take on caring for their disabled children full time.

*"We had used up all our savings, the doctor suggested I stopped work 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"*

## 5.8 Fathers' views of how employers could help

The fathers felt that employers could help them in a number of ways

- Provide information on entitlements – there was one positive example where one father had received a leaflet with his wage packet

*"Information is needed at the appropriate moment, in the right time and right place and then you'll read it"*

*"Put on information on reception at the work place or on the notice board"*

- Be more pro active in finding flexible work arrangements – at the moment parents were having to find their own solutions to present to employers. Employers could take more of a lead in offering flexible work arrangements rather than leave it to their employees to ask.

*“Communicate with your staff, find out how things are and show more understanding”*

*“If an employer does a good job of caring for an employee with a disabled child it’s a feather in their cap, they can be seen to be doing the right thing”*

- Take work life balance issues seriously

*“I have a good employer who asks at least once a week how my family is? Not just the child with a disability but all of us and seems interested”*

*“If an employer has faith in their employee this goes a long way and means the work gets done”*

## **5.9 Fathers’ views of what the DTI could do to help**

- Advertise entitlements more widely

*“Full page adverts in newspapers they do it for other things, why not this?”*

- Distribute information through other government agencies

*“Send out information with benefits forms, DLA etc. and tax forms ”*

- Educate employers about the issues of having a disabled child

## **5.10 Main problems faced by parents with a disabled child who want to work**

- Lack of alternative care to look after disabled child resulting in one parent having to remain at home. This is a problem which is particularly acute during summer holidays
- Getting time off for the many hospital visits
- The ability to drop work at short notice if the child is ill or needs emergency treatment
- Lack of understanding amongst employers of the extra commitment and stress faced by parents and limited awareness that the demands do not lessen with time

## **5.11 Summary**

Amongst the 11 fathers there was a low level of knowledge about the current legislation and their entitlements as employees – both generally as parents but specifically as parents of disabled children. This highlighted a need for government departments, employers, unions and the voluntary sector to be more active in making sure that information reaches parents at the right time.

Whilst all the fathers had made changes in their working lives due to balancing the care needs of their disabled child, almost all of these had been at their own instigation and were usually on an informal basis. Employers were still not taking an active role in helping their employees develop flexible working arrangements.

Knowledge amongst employers of the needs of parents with disabled children is still poor and support at work depended very much on the relationship between parents and their immediate supervisor.

For the 11 fathers the main barriers to flexible working were; knowing about their entitlements in the first place, worries about loss of earnings/career prospects and the need for flexible arrangements to reflect the unpredictability of caring not just reducing work hours.

## Chapter 6      The Main Problem

The postal survey asked parents 'what is the main problem faced by parents with a disabled child who want to work?'

Parents of disabled children tend to work against all the odds even with the support of sympathetic employers. They expressed these in a variety of ways but almost all comments boiled down to the same few problems.

- Lack of child care that is suitable for disabled children in holidays and after school. 102 parents (50%) cited this as a major issue
- Time needed for hospital and school appointments and reviews. This was mentioned by 60 parents (30%)
- Lack of understanding and flexibility by employers of the reality of parents' responsibilities and pressures caring for a disabled child. This was an issue for 29 parents (14%).
- Linked to this, the unpredictable nature of many disabled children who develop illnesses and crises overnight. 14 parents (7%) mentioned this.
- 8 people mentioned financial problems, particularly concern over loss of benefits

The remaining comments all relate to: exhaustion, lack of sleep, employers' and colleagues attitudes and lack of knowledge about rights and entitlements.

What parents said:

### **6.1 Problems with childcare, respite, after school clubs or care in holidays (102 parents)**

*'Not having child care available during school holidays and particularly after 4pm when she returns home from school'*

*'Appropriate reasonably priced child care'*

*'I find it difficult to get childcare that meets the needs of a disabled child including before and after school childcare that can cater for my 3 children's different special needs. There is none available'*

*'There are very few childminders for older kids (mine is now 16) or who will take children with disabilities. My childminder is wonderful but when I asked social services for a list there were only 2 prepared to take on an older child with a disability.'*

*'Specialised and economically viable child care'*

*'Not enough experienced childminders/play schemes to look after a child with disabilities and to be flexible with hours'*

*'No after school cover because school cannot accept child without carer; we cannot access mainstream play schemes or holiday clubs; registered childminders reluctant'*

*to take on my disabled child so have to use unregistered minder and therefore unable to claim child care tax credit.'*

*'Once they are 11 no one seems to care, not enough centres for them to attend, not enough transport facilities. No-one cares enough!'*

*'Child care – a problem for all working parents but so much more if your child has difficulties over and above those of the majority of children.'*

## **6.2 Taking time off work for hospital/school appointments (60 parents)**

*'The amount of appointments needed to be attended during the week..'*

*'A crisis can arise at little or no notice which can result in not turning up at work or leaving without warning. Hospital and therapy appointments are also always within working hours.'*

*'Amount of time needed off when child is ill, this can take up all of my annual leave entitlement'*

*'Time to go for hospital appointments, visits school or be at home when needed'*

*'Time off for various hospital appointments – my son is epileptic and I need time off while he recovers.'*

*Requesting time off (sometimes at short notice) for the many hospital appointments, physiotherapy appointments, etc.*

*'My main problem is having to take time away from work (when my employer has already agreed to my part-time hours) to occasionally care for my 14 year old son. My managers think that I am abusing the system and support they give, leaving me feel guilty about everything.'*

*'So many hospital appointments and operations and some illness to cover. Sometimes the problem is sheer exhaustion and stress'*

*'If the consultant has his clinic Monday am, that's when you go, not Thursday pm coz it suits your boss.'*

*'Although I am always given the time off to attend appointments, I feel that I don't like to let my employer and school children down'*

## **6.3 No understanding/prejudice from employer (29 parents)**

*'Lack of REAL understanding that emergencies happen all the time without warning. Employers put pressure on you to cope always and do not allow for 'down' days*

*'Employers don't understand the pressures and anxiety parents face'*

*'I worry about consistency i.e. the employer understanding that the employee may require some flexibility – that it's a two way process. Stigma!'*

*'Not having an understanding or sympathetic boss – hence my now working self-employed with hours to suit me.'*

*'A lack of flexibility by employers. A feeling that you are asking to be treated differently from your colleagues and that you cannot do your job as well as other employees. '*

*'Employers regard you as a hindrance to the company – I have known a person who was harassed by hr manager for ask g for flexible working.'*

#### **6.4 Unpredictability of child's needs (14 parents)**

*'The anxiety of never knowing when your child is going to need you'*

*'Things are unpredictable and therefore you can have consistent periods and then sometimes can be more vulnerable. I also have a disabled partner and this only adds to my difficulties'*

*'The fact that you can't guarantee the stability of your home life to free you up to go out to work; your child's needs will vary from day to day so you need the flexibility to give priority to your child and work when you are able to'.*

#### **6.5 Finances (8 parents)**

*'If you work you are not eligible for a Carers Allowance. You are in a no win situation'*

*'Time lost with children vs. need for money'*

*'Having to go out to work to earn money to pay bills, live and give your child a good quality of life.'*

#### **6.6 General**

*'Nobody really understanding the constant concerns, unpredictable problems, extra time planning, chasing, phone calls, strain on family, siblings..'*

*'Attitudes from people in general who don't think that you should work but should stay at home to look after the child. I even had this attitude from the disability department in social services'*

*'I've had plenty of interviews, never get a job. Employers don't want people who may have to lose time from work, even if you are willing to make the time up'*

*'My husband has had a heart attack'*

## Chapter 7

## What could make things better?

We asked parents in the postal survey what they would like the government to do make the law on flexible employment better for them.

### 7.1 Knowledge about rights

a) 28 people (23%) want more publicity for parents.  
Of these 25, put this at their first choice.

- *Firstly you need to get the information out to us parents so that we can take up the options available to us*
- *Crystal clear information about your rights and entitlements*
- *An agency to highlight rights to employers and employees*
- *More information for parents so we know what the law means and how it can affect us*
- *An aggressive advertising campaign so that everyone knows about it*

b) 18 people (15%) want publicity about the law aimed at employers

- *Drum home what we are entitled to and quote the law. There are so many laws and employers do not have time to peruse through clauses and sections of relevant laws*
- *Make employers aware of the law as most are only dimly aware if at all.*
- *Make it clear to employers that the law applies to all jobs (within reason)*

c) 18 people (15%) indicated their ignorance of the law, either by asking for a law on flexible working or by saying that they do not know what their rights are.

- *If it did become law you wouldn't feel so guilty about having time off or get fired for it*

d) 6 people think that employers need to be trained and aware of the needs of disabled children and their parents.

### 7.2 Improving the way the law operates

Many respondents had views on this with 68 people (55%) making suggestions. These broke down into the following main headings:

- Proactive employers
- Paid time off for hospital and other appointments
- School holidays
- Compulsion

a) Being proactive

9 people said that employers should be proactive in offering flexible working by

- *Offer flexible working at interview stage*
- *Employers should display rights in pay slips, on staff notice boards etc.*
- *Make it easier to ask*
- *Encourage employers to write the new flexible law into all job contracts*
- *Make it easier to apply - employer offer flexible working rather than waiting for employee to apply for it*

#### b) Paid time off

22 (18%) people want the right to have paid time off when they have to take their child to hospital, school and other appointments. They saw this as a special leave entitlement above their normal allowance.

- *Time off if child needs you at home or in hospital, no questions asked, full pay.*
- *Special leave for carers to cover educational issues, health appointments and important meetings including support groups which are often held in the day*
- *I would like time off for regular appointments and I would like to be paid for it.*
- *Include "special leave" days in the leave allowance of parents who have disabled children*

#### c) School holidays

10 people (8%) want the right to take time off in the school holidays

2 people want the right to work from home, especially in school holidays.

Other ideas were

- *Banking hours (3 people)*
- *Career break scheme (1 person)*
- *Flexible rights should cover 24 hour period*
- *Exemption from weekend working for parent carers*
- *All employers should be compelled to offer job shares and flexi-time*
- *The right for parents to cover their child's departure to and arrival home from school*

#### d) Compulsion

19 people (15%) expressed views in various ways about enforcing the law where employers do not comply. Examples were:

- *Employers must listen to parents' requests (4 people)*
- *They must be made to build flexible work around the child's needs not the employer's needs (2 people)*
- *Against the law to penalise people's promotion or pensions if they work flexibly (6 people)*
- *Make it against the law to discriminate against carers*
- *An external body to act as arbitrator in difficult situations and quickly*
- *Insist that all large companies with over 80 staff are family friendly*
- *Ensure that flexible working applies to all jobs no matter how long worked in job*
- *Compensating companies, without bureaucracy, for the extra allowances they make for parents carers*
- *Ensure when requesting leave it is always granted*

- *All out of school hours working including Saturdays and Sundays should be flexible/optional*

### **7.3 Child care**

25 people (20%) said that there should be more help with child care. This was a second option for several people.

- *Provide a good database of experienced child carers*
- *Encourage larger employers to have/help fund on site child care facilities*
- *If people want to be childminders they should have training on looking after older children and those with disabilities. Crèche facilities should also provide for this*
- *Government do more (financially) to encourage childminders to take on a child with a disability*

### **7.4 Finances**

13 people (11%) mentioned finances.

- *Families on low rate of DLA should be able to get more support via child tax credits*
- *Allow parents to access WFTC and pursue proper careers not just low paid jobs*
- *More help for single parents*
- *Make it possible to claim child care tax credit even when registering unregistered child minders*
- *Give more financial assistance with child care*
- *Reduce hours from 16 to 4 to qualify for benefit*
- *Better pension provision and allowances for carers who cannot work*
- *Pay parents of under fives to stay at home (2 people)*
- *Put up minimum wage to decent amount (2 people)*
- *Better hourly pay*
- *Make the working week a max of 40 hours*
- *Provide child care vouchers for parents of disabled children*
- *Government should look more at role of carer, better pension provision and better allowances. I would work more hours but I would lose my ICA and pay my own tax and NI which is ridiculous. That is what the government should look at – tax, ICA and pensions (Management consultant.)*

## Chapter 8 Conclusions and Recommendations

### 8.1 Key findings

Contact a Family was asked to test out parents' awareness and use of the legislation introduced in April 2003 which gives parents a right to request their employers to allow a more flexible working pattern.

#### a) Awareness

Awareness is not high overall. In the Internet survey:

52% of parents knew that the law applied equally to men and women.

49% of parents knew that it did not only apply if you had a child under 6

64% knew that it applied if there was a disabled child aged up to 18

53% knew that an employer did not have to grant flexible working arrangements

In the postal survey the percentages ticking the correct answer were:

54% on equality between men and women

51% on the law applying if you have a child under 6

69% on the disabled child being aged up to 18

56% on the obligations of the employer

Fathers at the Wales workshop were no more aware of their rights.

In all of these cases, these are respondents most likely to be aware of their rights. We know that at least 728 of them have access to the Internet, a major source of government information. The remainder are on the mailing list of Contact a Family West Midlands office or in touch with our Wales office. Yet there is still a high degree of ignorance about the law. Overall, men were somewhat more likely to know their rights than women.

#### b) Use

Despite these respondents all being parents of at least one disabled child, only 14% of our Internet respondents were working flexibly. In 19% of cases they were self employed or not working and therefore it did not apply. But almost a third (32%) could have asked to work flexibly but had not asked. 14% had asked and their employer had agreed as requested or an alternative. Only 5% had asked and been refused.

Postal survey respondents were somewhat more likely to be working flexibly – but still only 27% of the total sample were in flexible employment (37% of the employees). 33% of the employees could have asked but had not.

A variety of factors stop people asking. Most often, it is that they could not afford to earn less (24%). 17% said that they did not need or want to work more flexibly and the same percentage said they did not know enough about their rights. 16% thought that they would be refused. 14% were worried about their career or promotion chances. 11% were worried about colleagues' reaction.

Only 30% of the Internet respondents thought that their employer had some kind of flexible employment provisions.

38% of postal respondents had not applied for, or turned down a job because it did not offer flexibility.

## **8.2 Conclusions, Policy implications and recommendations**

It is important to acknowledge that some parents have benefited greatly from the new legislation. Those parents who have successfully applied to work more flexibly appear to have accrued significant benefits as a result. They report that they are less *'worried'* *'pressured'* or *'stressed'*

However, the survey results demonstrate that there are significant problems relating to the law on flexible working which could be ameliorated by government action.

### **Awareness**

The first is the need to increase awareness of the legislation. Parents of disabled children, even the better informed, simply do not know about their entitlements.

*'I don't know enough about my rights'*

*'Give me a leaflet!'*

*'You need to get the information out to us parents so that we can take up the options available to us'*

*'I myself have never heard about more flexible working hours'*

Several respondents made suggestions about more joined up government – for example putting leaflets about flexible working in with decision notices about claims for Disability Living Allowance for disabled children, or with Inland Revenue tax returns. This would be an excellent and well targeted way to reach many families with disabled children.

Employers should provide information proactively through pay slips, staff magazines, and notice boards and need to be encouraged by government to do this. Parents also thought that employers needed more information themselves and expressed some sympathy for employers not being able to keep up with legislative change. Government could supply small information summaries to go out with payslips – perhaps credit card sized, with a phone number for further information. One parent suggested;

*'Provide employers with some sort of incentive for those offering and implementing flexible hours'*

Employers also need to be informed better and understand the business case for allowing flexibility. It was outside of the remit of this report to develop and provide the business case for granting flexibility. However, if employers were made more aware

of the business case for allowing their employees to work flexibly, that could increase the likelihood that they would agree to such requests. If employees could see that their employer was likely to agree, this in turn would encourage them to ask.

Where employers do offer flexible working, it is very important to encourage them to state this in their recruitment advertising. This is because a large number of parents had not applied for jobs because they felt (rightly or wrongly) that the employer did not offer flexibility. It is also important that employers approach employees and proactively discuss how they can help them if they have disabled children. Several parents suggested that these matters should be the subject of workplace discussion, or should be raised in supervision. An employer who actively offers help to work flexibly would have been welcomed by many employees.

There was a considerable amount of suspicion about the consequences of asking to work more flexibly might be. As one respondent put it:

*'There are more ways of getting you out of a job, within the law, than there are to skin a cat'*

The survey demonstrates that a real difficulty is persuading employees to ask for flexible working. If they do ask, employees are more likely to be granted at least some concessions than refused (especially if they are a white woman). We need to disseminate the results of this survey widely to boost parents' confidence in putting the case to their employers.

Contact a Family, and the voluntary sector more widely, also bears a responsibility to inform parents about their rights. This could be done through providing information about employment rights in local and national newsletters, on websites and by giving specific talks and running workshops locally. But a government sponsored campaign with press and TV advertising; both on mainstream and minority ethnic interest channels would reach more families and show a real commitment to parents. One possibility is to combine such a campaign it would be possible to combine with the Tax Credits publicity drive. For example, promoting the message and advertise that reducing your hours might lead to greater entitlement to tax credits. This would be an alternative to leaving work altogether.

## **Legislative change**

In the longer term, many parents would be keen to see an extension of the legislation and an increase in the amount of protection that it offers them. Rather as American legislation protects those who are 'associated' with disabled people, several parents spoke of their desire for changes such as –

*'Less discrimination towards carers, this would probably have to be enforced in law'*

*'Make it against the law to discriminate against people who have sick/disabled children'*

*'To ensure that people who need to work flexibly are not prejudiced against in promotion opportunities'*

Other parents made remarks about the length of the working week:

*'Make the working week max 40 hours'* (building site manager)

Not allowing 'opt outs' of the working time directive might help in this regard.

Other parents suggest that:

*'A compulsory percentage of jobs should be job shares and all jobs flexible and negotiable on hours.'*

*'parents do not want a permanent change [to their contract], also limiting it to one application per year puts people off, applying makes it difficult to reapply'*

38% of parents had not applied for a job or turned down an offer because of lack of flexibility. Several parents made comments about this:

*'Employers should offer this [flexibility] at interview stage'*

*'Ensure flexibility applies to all parents no matter how long worked in job'*

Parents support the need to increase to parental rights. For example, flexible working applied to all employees regardless of length of service and indeed at interview stage. There would be great support for a right to work flexibly, rather than simply a right to ask. This might also allay many fears about the consequences of making a request:

*'If it did become law you wouldn't feel so guilty about having to take time off and you wouldn't get fired for it'*

There was also a strong feeling from the parents we surveyed that there should be paid leave to take children to appointments. One possibility would be to offer paid carers leave, available at short notice. DTI need to consider the business implications of this proposal and whether this leave should be funded out of general taxation. However, we believe that it would be cheaper to support parents to remain in work rather than pay for them to remain on out-of-work benefits in the longer term.

There are other factors which parents raised with us which it will not solely be the responsibility of the DTI to tackle.

## **Finance**

It is well established that poverty impacts more greatly on families with disabled children than other groups and that they have lower incomes and higher expenses. There are financial barriers to flexible working which are very real for parents.

In part, this reflects a lack of knowledge of the benefits system and the increased income now possible through the tax credits system for low income families.

It also reflects current rates of Disability Living Allowance which are simply not high enough to meet disability related expenditure.

As full time employees cannot receive any assistance with mortgage costs through benefits, an employee must earn enough to cover their mortgage and outgoings. Only those with very low incomes can claim Income Support to help with these costs. A middle way, offering assistance with mortgage costs to those who work more than part time hours, but earn less than enough to fully support themselves, should be considered. Several suggestions were made

*'Put up minimum wage to decent amount'*

*'Provide financial assistance for specialist childcare'*

*I would work more hours but then I would lose my ICA....That is what the government should look at'*

*'Government could help me financially to be at home'*

## **Childcare**

Lack of suitable childcare options for disabled children, especially after school and in the school holidays is a major problem. Unless this is comprehensively tackled, many parents will simply not be able to work. In an economy regulated by supply and demand, we need to provide financial incentives for child care workers to take on disabled children. One way to do this is to increase the amounts available for disabled children's childcare costs in tax credits. At present these allowances are the same as for non disabled children. One parent suggested:

*'Child care tax credits to be claimed for unregistered as well as registered childminders'* (administrator)

*'Pay babysitters who are known to us'*

However, it is also important to encourage training and support for childminders and the development of alternative care such as out of school clubs which fully include disabled children.

*'Government could do more to encourage childminders to take on a child with a disability'*

*'If people want to be childminders, they should have training to look after order children and those with disabilities. Crèche facilities at work should also have provision for this: mine does not take kids over 11'* (nurse)

*'I would like to be a more adaptable employee but I do not have any child care at the drop of a hat'*

## **Patient choice**

A patient centred NHS (and indeed other services becoming more responsive to user choice and need) should co-ordinate hospital and other appointments to take place on the same day, so that the amount of time needed for routine check ups and assessments is minimised.

## **8.3 Final word**

Parents face the same problems that any other employees face. Someone needs to stay home and wait for an engineer to repair their gas central heating which has broken down, someone may need to wait in for a delivery or the childminder is ill etc. However, in trying to balance work and family life, there are a whole range of problems facing parents with a disabled child which do not affect other employees. Outside work, families face a whole series of barriers and hurdles to be overcome. Many tell us that their whole life feels like one endless battle.

*“There is added stress when you have to fight for your rights, if services were easy to get we wouldn’t have to type out loads of letters, fill in forms. Try doing this and keeping a full time job going, I feel I have to stay at home to fight for our rights”*

Any government assistance to ensure that the workplace does not become another battlefield would be warmly welcomed by the parents responding to our survey

### Employment Survey

In April 2003 the Government brought in new employment rights to help parents who are trying to balance their work and home life. How much do you know about these rights and have you tried to use them? The Government has asked us to find out the views of parents of disabled children. If you have a disabled child under 18, can you spare a few moments to tell us what you think? *(If more than one person is employed please choose one person to answer the survey, or photocopy it if you would both like to respond)*

1) **What sex are you?** *(tick one)*

Male  Female

2) **How old is your child?** *(tick one)*

Under 6  6 - 11 yrs  12 -17 yrs

3) **How would you describe yourself?** *(tick one)*

White  Asian  Black African   
Black Caribbean  Other *(please specify)*.....

4) a) **What sort of work do you usually do (e.g. builder, office worker, manager)?**

b) **Are you currently ..?** *(tick one)*

Employed full time  Employed part time  Self employed  Not in paid work

5) **Do you think the following statements are true or false?** *(tick true or false for each)*

The new rights to flexible working apply equally to mothers & fathers true  false   
To use the new flexible working right you have to have a child under 6 true  false   
The new flexible working right applies if you have a disabled child up to 18 true  false   
If a parent asks, the employer has to let them work flexible hours true  false

*(If you are self employed or not working, you can now go to question 11. If you are an employee please go to question 6)*

6) **Since April, have you asked your employer to let you work more flexibly (e.g. work part time, or from home regularly, change your start or finish time?)** *(tick one)*

I already work flexibly and have not needed to ask  *go to question 10*  
I have asked but my employer did not agree  *go to question 7*  
I have asked and my employer agreed as I requested  *go to question 8*  
I have asked and my employer agreed an alternative  *go to question 8*  
I have not asked my employer  *go to question 9*

7) a) **Did you put your request for more flexible working to your employer in writing?**

yes  no

b) **When applying, did you make it clear it was a request under the new law?**

yes  no

c) **What reason did your employer give for refusing you?**

d) **Are you considering doing anything to try and meet your requirement for more flexible working?** eg. look for another job, appeal against your employer's decision?

..... *(now go to question 10)*

8) a) **Did you put your request for more flexible working to your employer in writing?**

yes  no

b) **When applying, did you make it clear it was a request under the new law?**

yes  no

c) **How do you think your new flexible working arrangements have made or will make a difference to your life?**

.....

..... now go to question 10

9) **There are lots of reasons why people don't ask to work flexibly. Which, if any, of these reasons would apply to you? (tick as many or few as apply)**

- I do not need/want to work more flexibly
- I do not think that my employer would let me
- I am worried about the effect on my career/chance of promotion if I asked
- I would like to work less hours but I could not afford to earn less money
- I have not asked because I don't know enough about my rights
- I am worried about how my work colleagues would react if I asked
- Other (please tell us why) .....

.....

10) **Does the place where you work have a Personnel Officer/Human Resources officer?**

(tick one)

Yes  No  Not sure

11) **Have you ever not applied for a job, or turned down a job offer, because the employer was not able to offer flexible working? (tick one)**

Yes  No

12) **What, if anything, would you like the government to do to make the law on flexible employment better for YOU (Please put what you think is most important as number 1, the next most important as number 2. If you need more space, you can attach another sheet)**

1)	
2)	

13) **What would you say is the main problem faced by parents with a disabled child who want to work?**

.....

.....

Thank you for taking the time to fill in this survey. Please send it back to **Contact a Family, Freepost LON8801, London EC1B 1EE** by 13<sup>th</sup> February 2004. No stamp is needed.

If you would like to know more about employment rights or financial help for parents returning to work look at our website [www.cafamily.org.uk](http://www.cafamily.org.uk) or call our freephone helpline 0808 808 3555.