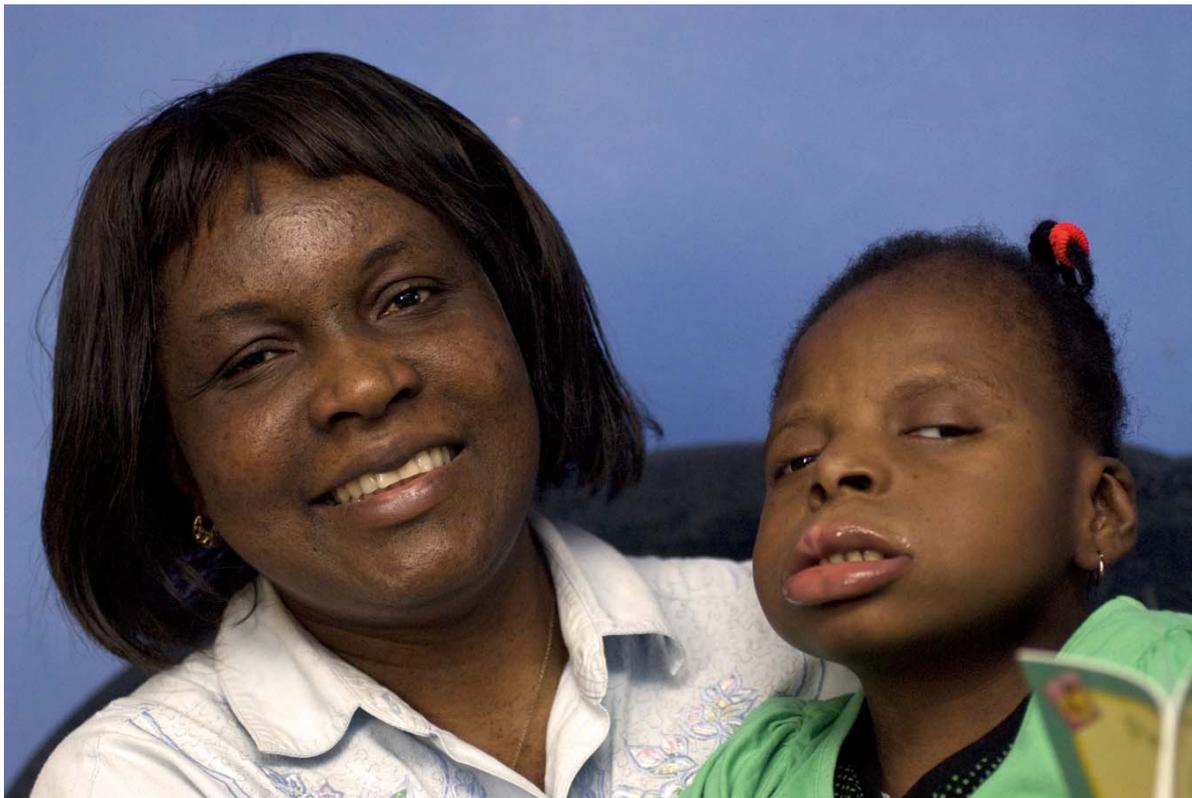


# Finding Flexibility: parents of disabled children and paid work



# **Finding Flexibility: parents of disabled children and paid work**

 a **working families** publication

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ISBN: 978-1-870878-40-1

## Key Findings

Working Families' survey of over a thousand families reveals a worrying pattern of unemployment and under-employment, with many parents being forced to decline promotion, accept lower skilled work, reduce hours of work or opt out of the labour market altogether in order to care for their disabled children. Furthermore the prospects of this group being able to return to the labour market are very poor. While finding suitable and affordable childcare is seen by parents as the main barrier to paid work, there are many other obstacles: taking time off to deal with hospital appointments and school emergencies; inflexible access to health, care and education services; the lack of part-time and flexible work options; the complexity of the benefit system and the lack of financial incentives to take on paid work; and the lack of focused services to support those who wish to return to work. Other research highlights the economic and social consequences of unemployment and under-employment with families of disabled children being at greater risk of experiencing poverty, poor housing, social isolation and family break up. Too often statutory services focus only on the needs of disabled children and fail to address the wider family context. Urgent action is required by the government, by service providers and by employers if the barriers to paid work are to be addressed and the families of disabled children are to escape the adverse economic and social consequences of unemployment and under-employment.

Working Families' survey of over a thousand parents of disabled children found that:

- 27% of respondents were not in paid work.
  - 82% of those not in work had given up in order to care for their disabled children
  - Over 50% of those not in work had given up at least six years ago making it very difficult to get back into the labour market.
  - 91% of those not in work would like to undertake paid work at some level.
  - Finding suitable childcare was regarded as the main barrier to paid work (83%).
  - Other barriers to paid work included paying for childcare, finding jobs with the right number of hours, finding jobs that could be worked on a flexible basis, and a lack of effective support to return to the labour market.
- 73% of respondents were in paid work.
  - Only 38% of those in employment worked for 30 hours or more.
  - 61% of those in work had changed or tried to change their pattern of work while 56% had changed or tried to reduce their hours, in order manage their caring responsibilities.
  - 64% of those in work had refrained from seeking promotion, declined promotion or accepted demotion in order to balance caring and paid work.
  - 65% of those in work said that finding suitable childcare was difficult or impossible.

This report sets out our findings in detail, considers these findings in the context of other evidence and highlights measures that could be taken by government, employers and service providers in order to remove barriers to paid work for parents and carers of disabled children.

## Recommendations

- Government, in association with local authorities, must address the gap in specialist childcare services for disabled children.
- Government should take the opportunity afforded by the introduction of Universal Credit, to compensate parents for the extra costs of childcare for disabled children.
- Government should consider the introduction of some form of *adjustment leave* to enable parents of disabled children to remain in work through a crisis period, for example, when a child is diagnosed as disabled.
- More employers should adopt flexible working policies that would enable parents to vary their hours and pattern of work, on a temporary basis, to deal with crises arising from caring responsibilities.
- Government should issue new guidance to schools with regard to emergencies in order that working parents are not required to attend schools unnecessarily.
- Health, care and education service providers should plan services in a manner that offers greater flexibility to working parents.
- The public sector should serve as an exemplar and advertise all jobs on a flexible basis, unless there are sound reasons why they cannot.
- Government should issue advice and guidance to employers on designing and advertising jobs on a flexible basis.
- Government should ensure that there are effective benefit advice services available on a local basis during the transition to Universal Credit.
- Improved training for Jobcentreplus and other agencies (social workers, health visitors, schools...) so that the presumption is that parents of disabled children CAN work, rather than they cannot.
- Targeted training, advice and job search support for parents wishing to return to work should be available.

## Background

While estimates vary according to the criteria used, there is a very substantial number of families with disabled children in the UK. Langeman and Worrall (2005) put the figure at 700,000 while others use the 'Every Disabled Child Matters' campaign group's figures of 770,000 (EDCM 2011). Towers (2009) estimate that 85-98% of disabled children live at home with their families. As we shall argue later, Working Families believes that in about 500,000 cases the child's disability has a significant effect on a parent's ability to do paid work. It has been estimated that it costs three times as much to bring up a severely disabled child than a child without a disability (Dobson and Middleton 1998) and that at least 55% of families with a disabled child live in poverty (Langerman and Worrall 2005). In a great many cases, the child's care needs have a significant effect on a parent's ability to do paid work and this in turn is likely to be a key cause of family poverty.

Although paid work is seen by parents themselves, and other agencies, as a way out of poverty (Holzhausen and Pearlman 2000, Hirsch, Phung and Manful 2011), Contact A Family's 2010 survey of over a thousand parents of disabled children reported that 60% did not work (Bennett 2010). Towers reported over 30% of fathers of children with learning difficulties reducing their hours of work (Towers 2009). Towers also reported that fathers were on reduced income although they continued working, through demotion, loss of career opportunities and lack of pension provision (Towers 2009). The loss of Carer's Allowance when wages exceed £100 a week can make parents and carers cautious about taking on low paid and/or irregular work. Working Tax Credit calculations are complex, so parents can be unsure about how much they will be able to

claim if they move into work. In addition to financial reasons for seeking work, parents are also looking to work for personal fulfillment (Nelson and Youll 2002, Bennett 2010, Mearns and Swan 2000).

Some of the barriers to paid work that parents of disabled children encounter, including finding suitable childcare (Daycare Trust 2007), the cost of childcare (Bennett 2010), lack of flexibility such as for emergencies (Nelson and Youll 2010) have been commented on in previous studies. Parents also report discrimination from employers and expectations that they should not work by the professionals, such as social workers and health visitors (Mearns 2000), who inevitably become part of their lives.

Against this background, Working Families conducted a survey of parents of disabled children in spring 2012, to look at the interaction between their caring commitments and paid work.

## Working Families 2012 Survey

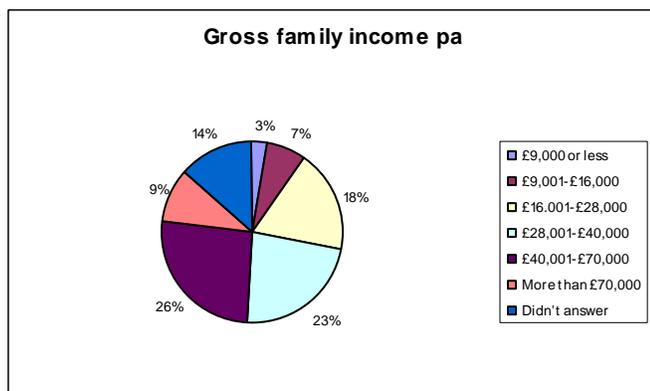
### Respondents in work

#### Key findings

- 89% were employed, 11% were self-employed
- 62% worked for employers with 100+ employees
- Less than half worked 30 hours a week or more
- 56% had reduced or tried to reduce their hours of work
- 61% had changed or tried to change their pattern of work
- 64% had refrained from seeking promotion, declined promotion or accepted demotion in order to manage care

There were 740 respondents who did paid work. Of the 738 in-work respondents who told us about their disabled children/young people, 18 had three or more, 92 had two and 628 had one disabled child/young person. A slightly lower proportion of those who were working, 87%, than of the entire cohort, were female. The regional and ethnic spread of the in-work group was very similar to that of the whole group. A slightly lower proportion, 4%, considered themselves disabled but a similar percentage, 6%, had a disabled partner. Some 19.2%, one percentage point more than for the whole cohort, described themselves as a carer for someone in addition to their disabled children.

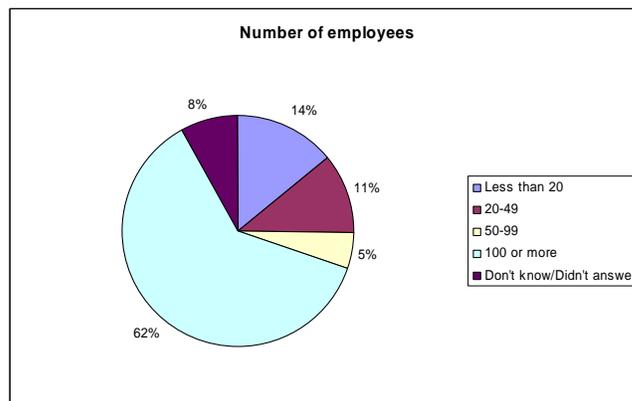
Most of the disabled children were at school: 71% of youngest/only children, 58% of second-to-youngest and 61% of third youngest. (Only 18 respondents had three or more disabled children/ young people.)



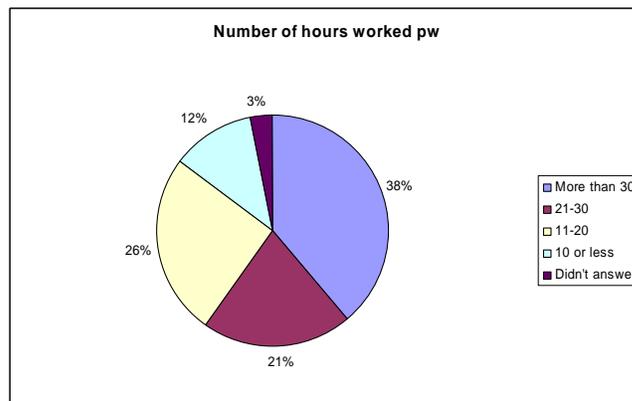
Interestingly, families where the respondent was in work only 3% were in households on £9,000 a year or less and 58% had a gross family income of more than £28,000 per annum, compared to 59% of the whole group.

Most of those who did paid work, 89%, were employed, 11% being self-employed. Some people commented that they had taken up self-employment in order to have the flexibility they needed to look after their disabled child(ren).

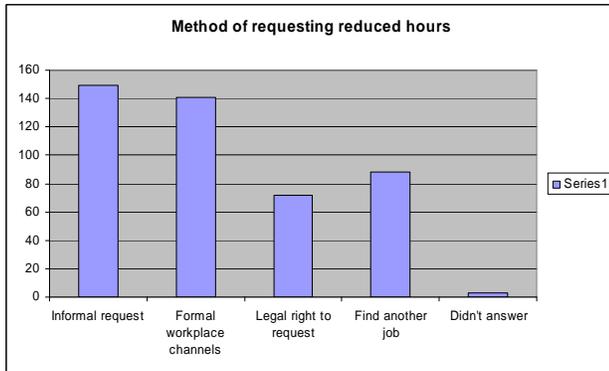
Of those who were employed, 64% worked for employers with 100 or more employees



Not even half of those in work did 30 or more hours a week and 12% did less than 10 hours a week.



Employed respondents were asked if they had reduced their hours or changed their way of working and, if so, the approach they had taken. Over half, 56%, had tried to reduce their hours. Few, 17%, had used their legal 'right to request flexible working'. Over 70% had either made informal requests or used their employer's formal channels and 21% had resorted to finding another job. Unfortunately, 11% did not get either the reduced hours they wanted or an acceptable compromise.



Even more people, 61%, had tried to change their way of working, for example to flexi-time or home working. The legal 'right to request flexible working' was used even less, 18%, over 80% instead using their employer's formal channels or making informal requests. However, again many, 18%, found other jobs. In this instance 13% did not get either the way of working they wanted or an acceptable compromise. Of course, the fact that so many people were able to make informal requests or used their employer's own channels may reflect the fact that the 'right to request flexible working' has been adopted as good practice by employers. It should be noted that respondents who were not in work commonly cited their inability to get a job with appropriate hours as the reason they were not doing paid work.

Many respondents made references to using much or all of their annual leave to deal with matters concerning their disabled children. Some employers make provision for carers and/or parents to access some additional days' leave if required. Since 1999 parents and others have had rights to unpaid leave in some circumstances. Our survey showed that 34% of respondents had made use of their right to 'Emergency Leave for Dependents' and 21% had taken 'Parental Leave'. A large proportion of respondents, 38%, had resorted to telling their employer that they were sick themselves in order to care for their disabled children. The survey did not ask

whether this was because legal entitlement to emergency or parental leave did not meet their needs; whether the parents were unaware of their rights; or whether it was for financial reasons. The fact that the need for time off for appointments was reported repeatedly suggests that existing legal entitlements are not meeting parents' needs.

*"I use my annual leave allowance and flexi-time provision to manage care. I receive no respite and find that there is now no provision that will allow me to continue working full-time once my daughter's residential college course ends."*

Nearly 64% of respondents had refrained from seeking a promotion, had declined a promotion or accepted a demotion because of their caring responsibilities. Many commented on working reduced hours, taking lesser paid jobs which were available term-time only or changing to self-employment because their caring commitments prevented them from being reliable employees.

These results show that parents value their jobs and the opportunity to work but most are unable to work many hours and because of their caring responsibilities they have compromised both on the number of hours they can work and on progression in their careers. Appropriate childcare is such a major barrier that most parents find that the only way they can combine paid work with their caring responsibilities is to organise work so that they do not need to find or pay for childcare. Flexible working legislation and culture have enabled many to do some work even if it is not the amount they would wish and is failing to make use of the parents' qualifications, experience and talents.

*"Even though I have a Master's degree from one of the top 20 universities in*

*the world, I have to take menial term-time jobs so as to avoid most holiday cover.”*

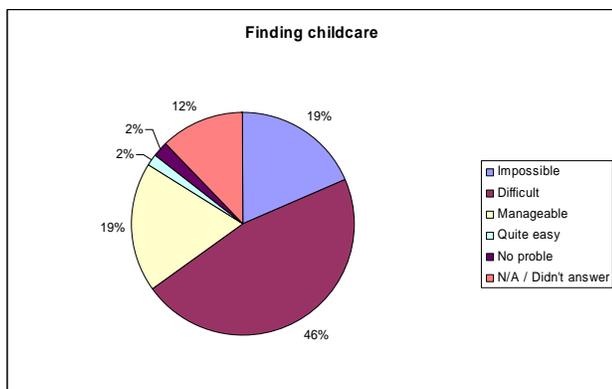
*“I managed to find a job in a school so I have no problems during school holidays, but I took a pay cut to do this.”*

*“I have found it impossible to have a contracted employment, because of the impossibility of getting school holidays off. I can work for an agency, or do casual work. I have been unable to progress in my career as a Registered Nurse...”*

### Childcare

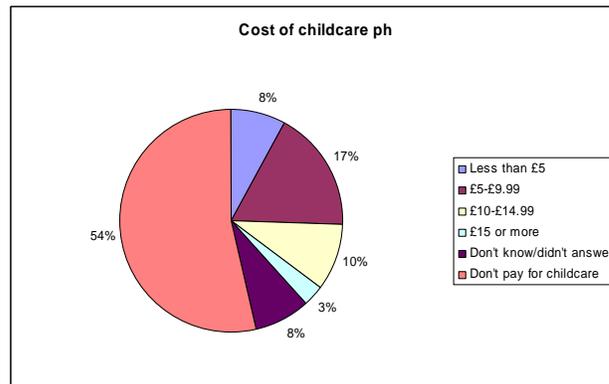
Respondents found sourcing appropriate care for their children difficult. Many people used open-ended questions to comment on the lack of availability of suitable childcare. Only 22% described finding childcare ‘no problem’, ‘quite easy’ or ‘manageable’. For a further 12% childcare was not applicable.

*“Holiday play scheme hopeless. Staff member referred to my child as deaf & dumb.”*



Respondents could also find childcare expensive, 13% paying £10 an hour or more. However, over half of respondents, 54%, did not pay for care at all. This group included those who used free care, presumably commonly provided by family members, those who used care paid for by direct payments and those who had

organised their working hours to fall completely within school hours.



Respondents felt there was a lack of understanding of their children/young people’s needs on the part of care providers and Local Authorities: in particular, the needs of those with high medical needs, on the autistic spectrum and older children/young people. Some aspects of the lack of suitable care, such as advance planning, would not be difficult to address.

*“...specialised childcare is very difficult to find, if you do find a reputable agency offering this service it is usually very expensive.”*

*“Childcare appears to be aimed at young children, to find suitable care that does not stigmatize the young person or make them feel babied is just not achievable.”*

*“My daughter is 22 with no learning difficulties but needs constant supervision. There is no suitable care for her (as far as I am aware). My daughter would, understandably, feel embarrassed and humiliated being looked after by a 'babysitter'.”*

*“...my son has complex health needs. He needs specialist support. The local authority will have to step in to arrange childcare/respice.”*

*“I use my annual leave and parental leave to cover school holidays.”*

*“We only use trusted friends and family as we don't have any faith in other forms of childcare being suitable for our son who has an autism spectrum disorder. He does not cope with change well, so needs to be with people that he is familiar with.”*

*“I can't plan my leave until I know what holiday schemes my son can get booked on. This means that other staff often get their requests in first and I am left with a limited choice. I am not sure how I will get through this summer...”*

*“I am forced to be self-employed so I can manage the childcare problems.”*

*“... the job had to be flexible therefore picked weekend work, or evening or nightshift... had so many jobs [because] if they did not fit around my responsibilities I would leave. I am now self-employed.”*

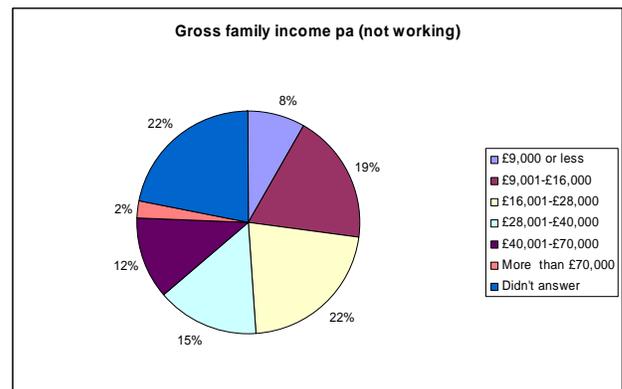
## Respondents not in work

### Key findings

- 82% had given up work because of their caring responsibilities
- 91% wanted to do paid work
- Term-time or school hours work would enable them to work
- Finding and paying for suitable childcare was a major barrier
- Parents could not access effective back-to-work support and they had little faith in the statutory services available.

Not surprisingly, a slightly higher proportion of those not currently working, 92%, were female. The total number of people in the non-working subgroup was 272. Over 8% of

non-working respondents were in households on £9,000 per annum or less and 27% had more than £28,000 a year, compared to 3% and 58% of the in-work cohort. Nearly 10% of this group considered themselves disabled and 71% lived with a spouse or partner. In the non-working subgroup, of those who had spouses/partners, in 8% of cases their partner did not work either, but this represented only 15 individuals.



The ethnic make up of the non-working subgroup was similar to that of the whole group.

As with the working subgroup, about three quarters of the non-working subgroup's children were either under school age or still at school.

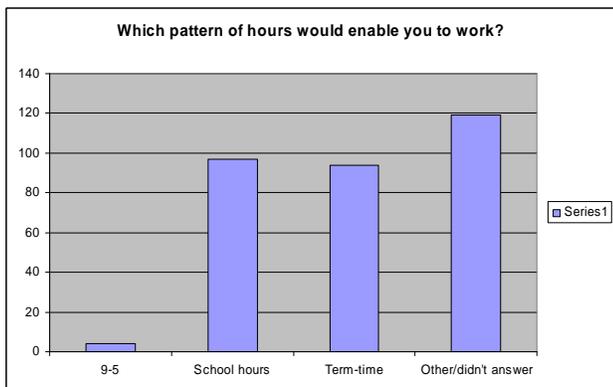
The nature and spread of impairments reported by the non-working subgroup was very similar to the other groups. About half their young people had learning disabilities. A slightly higher proportion, about 60%, were on the autistic spectrum.

### Barriers to work

Unsurprisingly, a vast majority, 82.4%, of those who were not doing paid work said they had given up work because of their caring responsibilities.

Respondents overwhelmingly reported a desire to do paid work, 91%. There was wide agreement about the barriers to

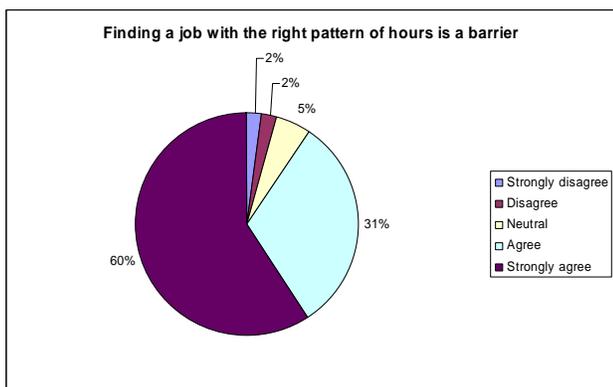
returning to/taking up work being the difficulties in finding jobs that fitted with the constraints on the respondents' availability and finding and paying for suitable childcare/care. Opinion was very equally divided about whether lack of confidence and of skills constituted a barrier for individuals.



*"...being back at work helps you meet other adults and forget your own problems."*

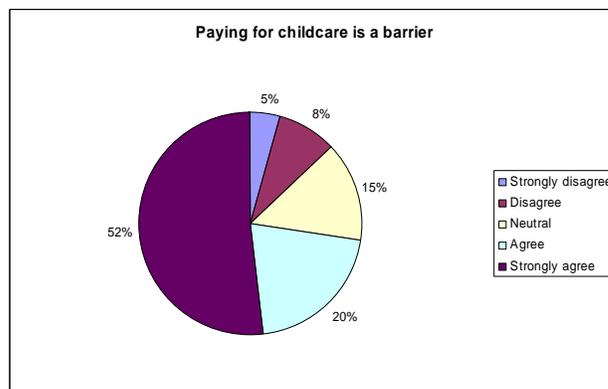
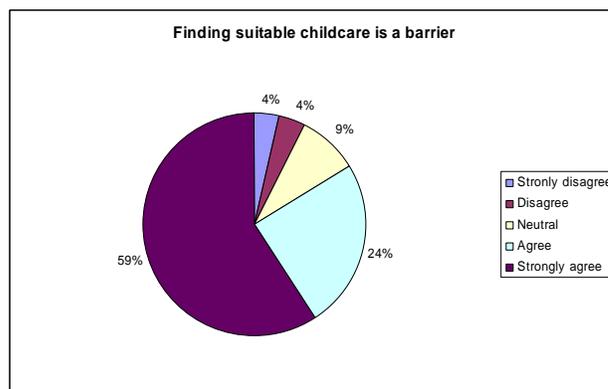
*"[My] child is tube fed, finding expert childcare is hard."*

*"My daughter has epilepsy, which isn't controlled. Employers don't want to employ someone who has to take time off for appointments or when their child is poorly."*



Overwhelmingly, those seeking to return to work said that term-time or school hours jobs would enable them to work. Other barriers to work commonly cited were children's appointments, children's

precarious health, being called to school, carers' own health issues and effects on benefits/tax credits.



Respondents felt there was a lack of understanding from employers amounting to discrimination against carers.

*"Tricky if don't have flexibility built into working arrangements."*

*"What happens when your child is in hospital? My daughter has spent four months twice as an inpatient. It was planned hospital admission and the lack of flexibility of my boss that eventually made me give up work."*

It is interesting to note that those who wanted to work felt that term-time and school hours work would enable them to work and that this is what, in fact, many of the in-work group had achieved. Both groups believed that finding and paying for childcare which was suitable for their children was very difficult to achieve.

*"...[lack of] competent, conscientious, adept and appropriately trained care workers."*

*"...discrimination - people don't understand the responsibilities of caring and disability."*

*"Lots of hospital appointments so no employer would want me."*

*"...affects tax credits."*

*"Loss of Carers' Allowances if pay exceeds DWP rules."*

*"...child's erratic school attendance."*

Only 94 of the 242 respondents who said they would like to work, 38.8%, had sought help from Jobcentreplus and 68.1% had sought help from a voluntary or commercial organisation. Although a few people cited help from a Job Centre or, in more instances, from a voluntary organisation, many respondents used the opportunity afforded by an open-ended question to comment on their experience of the lack of help or understanding offered by Jobcentreplus or that they had not considered them even worth approaching.

*"No support at all from Jobcentreplus."*

*"They don't help. They just print off a list of low paid jobs without reflecting my qualifications or skills. When I ask why, they tell me I should look at these jobs 'for now'. But my son's situation won't change, so there is no 'for now' for me."*

*"No help and didn't understand my limits and restrictions."*

*"None. I had a bad experience with Jobcentreplus several years ago and do not think they are interested, motivated or capable of providing an appropriate service for me."*

*"The Jobcentreplus paid for some shoes and a pair of trousers and top so I looked smart when I started back*

*working. The adviser arranged my childcare fees through her computer for me...she inputted the wrong amounts."*

*"...never approached them."*

*"Zero help. I had to battle it myself all the way. In fact, most professionals/agencies told me that single parents in my situation just don't work. I refused to accept that."*

*"I have had support from [local carers' organisation]."*

## Conclusions

This section of our report considers the survey findings in the context of other research and addresses a number of key questions.

- How many families face the challenge of combining caring and paid work?
- What are the economic and social consequences of unemployment and under-employment for these families?
- What are the principal barriers to combining caring and paid work and how might these be overcome?

As we have already noted, it is often asserted that there are 770,000 disabled children and young people in the UK. This estimate is derived from the Prime Minister's Strategy Unit report 'Improving the life chances of disabled people' (2005) but it reflects 'the widest survey definition' and the report contrasts the estimated number of 11 million disabled people with the three million in receipt of disability benefits. Since we are specifically concerned about families where the nature and severity of a child's disability is likely to impact on paid work, it is necessary to

refine the figure of 770,000. Based on a statistical analysis of the 2001 Census for England and Wales, Carers UK (2006) found that 462,000 families had at least one child with 'a long term illness, health condition or disability'. Hence it is reasonable to assume that around half a million families with disabled children, in the UK, are likely to face the challenge of combining caring with paid work. Our survey found that 73% of respondents and 87% of spouses/partners were in some level of paid work with 77% of all respondents having a spouse/partner. Of the respondents in paid work, only 38% worked 30 hours or more while 38% worked 20 hours or less. However, this almost certainly reflects the fact that 65% of our respondents considered themselves to be the main carer. By contrast, 89% of spouses did paid work, of which 87% worked 30 hours or more. Emerson and Hatton (2002), in an analysis of government figures, found that families of disabled children were 2.5 times more likely to have no parent working for more than 16 hours, while Langeman and Worrell (2005) found that only 16% of mothers of disabled children were in paid work compared to 61% of mothers of non-disabled children and only 38% of families with disabled children had two parents in paid work compared to 55% of families in general. Our more positive findings suggest that the real challenge is for those who consider themselves to be the main carer.

Nevertheless, there is a pattern of unemployment and under-employment that is not a matter of choice but is seen by parents of disabled children as a matter of necessity, arising from their need to care for their disabled children. Of those not in work, in our survey, 91% reported a desire to do paid work at some level while over half, 56%, of those in work had tried to reduce their hours in order to manage their caring responsibilities. Of those not in work 82%

reported that they had given up work due to their caring responsibilities. Finding and paying for suitable childcare were seen as the principal barriers to paid work but, as we shall see, this pattern of unemployment and under-employment is also driven by a number of other factors.

## **Economic and Social Consequences**

With the exception of limited questions relating to family income and benefits received, our survey did not set out to gather data on the economic and social circumstances in which families live so it is necessary to consider other research. From talking directly to families, it is clear that family life is often organised around the daily care needs of a disabled child and the routines necessary to meet those needs. Caring for a disabled child is not simply one aspect of family life but an overarching consideration which can impact on all aspects of family life and on all members of the family. In some instances impacts are both consequential and cumulative. Unemployment and under-employment lead to low income, low income to poverty and poverty to social isolation. In a disproportionate number of cases unemployment, poverty and social isolation lead to family break up.

EDCM (2007) highlights the 'cost of care' and the 'income penalty' as two factors which make the families of disabled children more likely to sink into poverty. Citing studies by Dobson and Middleton (1998), EDCM estimates that it costs three times as much to bring up a disabled child compared to a non-disabled child. While the benefit system, for example, Disability Living Allowance, recognises that there are additional costs, it is argued that it does not recognise 'the true costs' of disability. While costs are higher, the pattern of

unemployment and under-employment amongst the parents of disabled children imposes an 'income penalty' which leads to a further imbalance between costs and income and thus greater vulnerability to poverty. Emerson and Hatton (2002) found that families with disabled children were almost one and a half times more likely to live in poverty. In its analysis of the impact of current austerity measures, the Family and Parenting Institute (2012), estimates that 'relative child poverty' will increase by 400,000 between 2010/11 and 2015/16 and 'actual child poverty' by 500,000. It also argues that 'tax and benefit changes introduced in 2011 on average weaken the incentive for those with children to undertake paid work'. In a survey of 2,300 families with disabled children, Contact A Family (2012) found that families are increasingly going without essential items including 17% going without food and 21% going without heating. In addition, 29% of families had taken out loans, almost 40% of which were used for food and heating. Moreover, 21% of families have been threatened with court action for failing to keep up with loan repayments.

Financial pressures inevitably lead to other difficulties for families of disabled children. Emerson and Hatton (2002) found that families with disabled children were more than twice as likely as other families to be local authority or housing association tenants, not to be home owners, to live in accommodation that could not be kept warm enough in winter and to live in neighbourhoods which they found very unsatisfactory. In a survey of over a thousand families of disabled children, Contact A Family (2011) found that 65% of respondents felt isolated most or all of the time while 72% experienced mental ill health including anxiety, depression and breakdown. Over half of these families attributed their feelings of isolation to lack of support from statutory agencies, lack of

time and money to do things that other families could do and to discrimination and stigma. In their analysis of the 2001 census, Carers UK (2006) found that 34% of families with disabled children were single parent families compared to 25% of families with non-disabled children.

While the interrelationship between the factors impacting on family life for families with disabled children is complex, there is clear evidence of a pattern of unemployment and under-employment which is contributing to financial pressures and that these in turn impact on the quality of life. Tackling the barriers to paid work will not remove all of the challenges facing families of disabled children but it has the potential to make an important contribution.

## **Barriers to Paid Work**

### **Childcare**

Our survey confirms the findings of other research, in that for parents of disabled children, access to suitable and affordable childcare is the overriding barrier to taking up and/or maintaining paid work. However, there are many other factors which contribute to the pattern of unemployment and under-employment: lack of support at the point of diagnosis or crisis when parents may need space to acknowledge their child's disability and put in place practical measures to enable them to combine their caring responsibilities with paid work; difficulties in taking leave to deal with hospital appointments and school emergencies; inflexible access to health, care and education services; the lack of part-time jobs and flexible work options; the complexity and inflexibility of the benefits system which mean that work may not pay; and the lack of training and support for those wanting to return to the labour market.

We have already noted that 82% of those not working had given up work in order to care for their disabled child. When asked about returning to work, 83% agreed or strongly agreed that finding suitable childcare was a major barrier while 72% agreed or strongly agreed that paying for suitable childcare was a major barrier. Of those in work 65% said that finding suitable childcare was difficult or impossible while 64% had declined promotion or accepted demotion in order to balance work commitments with caring. Only 38% worked 30 hours or more while 56% had reduced or tried to reduce their hours and 61% had changed or tried to change their pattern of work in order to accommodate caring responsibilities.

A Family Fund Survey (EDCM 2011) notes that the national average cost for childcare was approximately £3.50-£4.50 per hour while respondents to the survey were paying up to £12 or £14 per hour. The report also cites Department of Education research into affordability pilots in which it was found that parents were paying up to £20 per hour for disabled children. It is therefore not surprising that parents choose to give up work or reduce hours in order to care for their disabled children. Over half of our working respondents, 54%, did not use childcare services while only 24% of the Family Fund survey respondents accessed these services.

While the Children Act 2006 required local authorities to ensure that sufficient childcare is available for children up to the age of 14 (17 for disabled children), in 2010 almost half of all local authorities reported insufficient childcare for disabled children, 49%, and insufficient childcare for older children, 47%, (EDCM 2011). Action is required to address both the accessibility and affordability of childcare. From our direct work with families and local authorities we are aware of a limited

number of examples where local authorities are taking action to grow and coordinate the supply of childcare for disabled children. At least one local authority centrally funds a post charged with encouraging and training providers to meet the needs of disabled children and with serving as a broker between parents and providers. This model is typical of the models established under the DCATCH (Disabled Children's Access to Childcare) pilots, the funding for which was discontinued in March 2011. Pressure on local authority finances has effectively meant that this provision was lost but positive action of this kind is essential to stimulate the childcare market and ensure that local authorities can satisfy their requirement to ensure a sufficient supply. With regard to affordability, EDCM (2011) suggests that this could be addressed through changes to the Working Tax Credit system. Given the current and ongoing changes to the benefits system an alternative approach may be more appropriate. As a matter of principle, however, if the government is genuinely committed to making work pay, it would be perfectly possible to conceive of mechanisms to compensate parents for the additional costs of childcare for disabled children.

*"I am really worried about how I will manage to work when the children are too old for school. They cannot be at home unsupervised, I need to work to afford to keep our home..."*

*"There is a total lack of suitable childcare across the country for parents of disabled children and there is a massive workforce out there who want to work. It is not rocket science."*

### **Recommendations**

- Government, in association with local authorities, must address the gap in

specialist childcare services for disabled children.

- Government should take the opportunity afforded by the introduction of Universal Credit, to compensate parents for the extra costs of childcare for disabled children.

### **Flexible Working**

When a child is born with a disability or diagnosed as disabled at a later stage, it is perfectly natural for parents to think that one or other of them should give up work to become the main carer. Indeed many parents report that health, care and education professionals clearly expect that they should do so. In many cases a parent will give up paid work in the expectation of returning at a later date. However, getting back into the labour market, especially after a long period of unemployment, can be extremely difficult. In addition to an inevitable CV gap, out of date skills and lack of confidence may come into play. Despite the fact that 91% of our non-working respondents expressed a desire to return to work, over 50% had been out of work for at least six years. While some big employers offer various forms of 'carers' leave' or short term flexible working, there is no legal entitlement to what might be described as 'adjustment' or 'crisis' leave. For many parents the ability to work reduced and flexible hours for two to three months may be sufficient to enable them to put care arrangements in place and to determine a realistic long term pattern of paid work for themselves. The 'all or nothing' scenario results in too many parents being forced into long term unemployment with all of its attendant economic and social implications. Current flexible working regulations do not address the problem since a successful application results in permanent contractual changes.

Employers should be encouraged to design and offer jobs on a flexible basis, and the public sector could serve as an exemplar in this regard. An additional approach could be to establish some form of 'adjustment leave' with funding provided using a model similar to statutory sick or maternity pay.

*"In my remit of work all local employers know my family difficulties and as such I am not a first choice despite my excellent skills (and they are excellent). I am a highly experienced lawyer and am criticised and penalised by the legal fraternity [for trying to combine work and caring]."*

*"...have been carer for eight years – who will look at my CV with such a gap?"*

### **Recommendations**

- Government should consider the introduction of some form of *adjustment leave* to enable parents of disabled children to remain in work through crisis period, for example, when a child is diagnosed as disabled.
- More employers should adopt flexible working policies that would enable parents to vary their hours and pattern of work, on a temporary basis, to deal with crises arising from caring responsibilities.

### **Leave Arrangements**

Taking time off for hospital appointments or to deal with school emergencies is another barrier frequently raised by parents. 21% of our working cohort had used 'parental leave' while 34% had used 'emergency leave for dependents' and 38% had told their employer that they were ill themselves when in fact they were caring for their disabled child. From our direct work with parent groups, it is clear that many parents

are not aware of their entitlement with regard to parental leave but others are no doubt put off by the financial implications. Some employers offer a limited number of paid days of 'carers' leave'. Parents also express frustration about the frequency with which schools tend to ring and demand that the parent comes immediately to the school to deal with an issue or to take the child home. Clearly there is a need for better guidance as to what schools can be expected to manage and in what circumstances schools can require parents to attend an 'emergency'.

*"My employer (or more precisely, my immediate boss) is very understanding when I need to take time off."*

The issue of taking leave for hospital appointments and school emergencies is compounded by the inflexibility of the services to which parents require access for their child or themselves. In most cases appointment times are non-negotiable and no allowance is made for working parents. This confirms the tendency for health, care and education professionals to assume that at least one parent of a disabled child will not be in paid work. Hence it is as much of a cultural as a practical problem and it could be addressed by improved planning and a customer-focused approach to service delivery.

### **Recommendations**

- Government should issue new guidance to schools with regard to emergencies in order that working parents are not unnecessarily required to attend schools.
- Health, care and education service providers should plan services in a manner that offers greater flexibility to working parents.

### **Part-time work and Flexible Recruitment**

It is interesting to note that 62% of our working cohort worked less than 30 hours while 94% of those not working, but expressing a desire to do so, wanted to work for less than 30 hours with 72% wanting to work 20 hours or less. With regard to the pattern of work, 80% of the non-working cohort favoured school hours and 72% term-time working. Hence there is clearly a strong demand for both part-time working and flexible work patterns amongst parents of disabled children.

In this survey, 81% of non-working parents agreed or strongly agreed that finding a job with the right hours would be a barrier to returning to work while 91% agreed or strongly agreed that finding a job with the right pattern of work would be a barrier. The pattern of work was also the principal concern for the working cohort with 61% having changed or tried to change the pattern compared to 56% having changed or tried to change their number of hours. However, the vast majority of jobs are advertised on a full-time basis and on a traditional fixed pattern. This can only reflect the fact that the full-time fixed pattern model is readily understood since there is no logical reason why the vast majority of jobs should happen to require 35-40 hours undertaken in a particular way. For those established in work, the flexible working regulations provide an opportunity to seek amendments to both the number of hours and the pattern in which they are worked. However, this flexibility is not available to people seeking work. In addition, parents frequently express concern about explaining to employers that they have caring responsibilities since they fear that it will prejudice an application or their future prospects. Clearly there is a need to encourage employers to be open to recruitment on a more flexible basis.

*“Tend to work extra hours on lead up to long summer holidays [so] I can be off with my daughter.”*

### **Recommendations**

- The public sector should serve as an exemplar and advertise all jobs on a flexible basis, unless there are sound reasons why they cannot.
- Government should issue advice and guidance to employers on designing and advertising jobs on a flexible basis.

### **Will work pay?**

While the government is in principle committed to making work pay, for many parents of disabled children this may not be the case, in part due to the loss of benefits and in part due to the extra costs of childcare. As already noted, 64% of our working cohort had declined promotion or accepted demotion in order to balance caring and paid work. Many parents also report that the only work they can secure that is compatible with caring, is low paid part-time jobs. Perhaps it is inevitable that the benefits system is complex given that it must allow for a whole range of circumstances, but this complexity leads to concerns on the part of parents about taking on paid work or changing hours in case it impacts negatively on family income. A further concern is that changing the number of hours worked on a regular basis interrupts the flow of benefits and leads to further complexity. In some local authority areas there is access to skilled benefits advice, provided by statutory services or local charities, but in others provision is patchy. If parents are to consider returning to work or changing their pattern of work it is essential that they have access to high quality advice. If work is to pay, then a

much wider range of jobs must be made available on a part-time and flexible basis.

*“I would need to get a very well paid job to make up for the benefits I would lose.”*

### **Recommendation**

- Government should ensure that there are effective benefit advice services available on a local basis during the transition to Universal Credit.

### **Return to Work Support**

Despite the fact that 91% of our non-working cohort expressed a desire to return to work, only 38% had sought assistance from either Jobcentreplus or voluntary or commercial agencies. From the responses to an open-ended question, it is clear that many parents have little or no faith in the support available. However, the lack of effective support to return to work is not only a matter of quality but of service organisation. Jobcentreplus is primarily geared to supporting those who are in receipt of Job Seekers' Allowance and thus registered for work. Parents of disabled children considering a return to work will be reluctant to risk their existing benefit packages by registering for work. Even where help is offered, the constraints imposed by caring responsibilities will inevitably restrict the options available to parents of disabled children. As we have already noted, 52% of parents expressing a desire to return to work had been out of the labour market for at least six years. Hence it is likely that they would benefit from retraining, together with a systematic programme of job-seeking skills. In some areas local charities provide return-to-work services but provision is limited so this area of need should be addressed systematically through statutory support services.

## Recommendations

- Improved training for Jobcentreplus and other agencies (social workers, health visitors, schools...) so that the presumption is that parents of disabled children CAN work, rather than they cannot.
- Targeted training, advice and job search support for parents wishing to return to work.

## Survey Design and Respondents

Working Families' 2012 Survey was available to complete online and paper versions were available on request. Where it was promoted online, a link was provided. Working Families received 66 paper responses. The survey was promoted to Working Families' Waving *not* drowning network of parents of disabled children who work or wish to work and interested professionals through the Waving *not* drowning newsletter and monthly e-bulletin, and through organisations concerned with disabled children and their families, such as Parent Forums. Enquirers were encouraged to promote it through their newsletters and contacts. Online and paper versions of the survey were piloted and revised in the light of parents' comments both about the clarity of the questions and assumptions which appeared to underlie them.

The survey was designed to elicit the circumstances of parents who were already combining paid work and caring and to ask if those who were not doing paid work would like to do so, if not now, in the future. Respondents were asked about the nature of the barriers to paid work and the limitations their caring responsibilities imposed on them even when they were in work. The results illustrate the successful work-life balance some parents have achieved and the aspirations of others,

highlighting changes which could be made in the workplace, in services provided and attitudes to caring which could help parents of disabled children/ young people achieve what, for them, is a satisfactory work-life balance.

The survey included open-ended questions for parents and carers' comments as well as multi-choice questions.

It is the intention of Working Families to conduct future surveys to see if the situation for parents of disabled children who wish to work has changed.

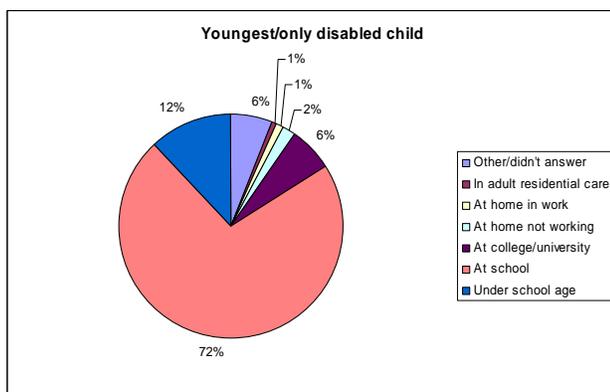
The survey was of families with disabled children/young people under 25 in their family. Those respondents whose youngest disabled child or young person was not under 25 were disqualified. The cut off point of 25 was chosen because by that age most young disabled people can no longer access services for children and/or young people. The definition of 'disabled' was left to the respondents. Respondents were specifically told that 'family' included any children/young people in residential school or adult residential accommodation. There were 1,014 qualified respondents but only 1,008 told us about their disabled children. Of these 158 had two disabled children in their family and 27 had three or more.

Most of the respondents, 88%, were female. Although not truly representative of the regional distribution of the population, there were responses from all areas of the UK, except for the Channel Islands and the Isle of Man, with 88.2% describing themselves as 'white English, Scottish, Welsh, Northern Irish or British' and the others were from a wide variety of other ethnic backgrounds. Nearly 77% of respondents had a spouse or partner of the opposite sex. There were four responses from people in same-sex partnerships. Less than 6% defined themselves as disabled

and the same percentage had a disabled partner. Just over 18% described themselves as a carer for someone other than their disabled children.

Most respondents had only one disabled child. Of those that had more than one, the survey only asked parents about their three youngest disabled children.

Nearly three quarters of the youngest/ only disabled children, 72%, were over five but still at school. A further 12% were under five. Seven were in adult residential care.

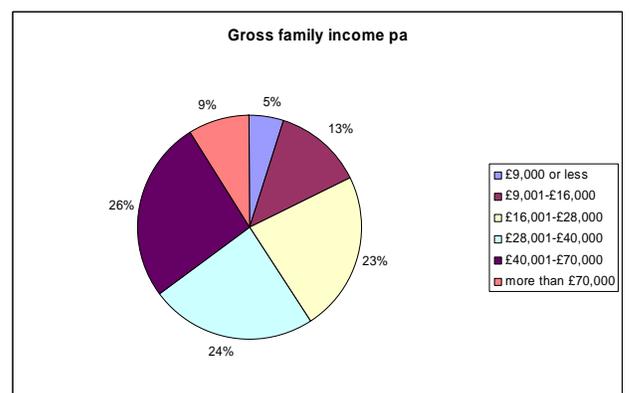
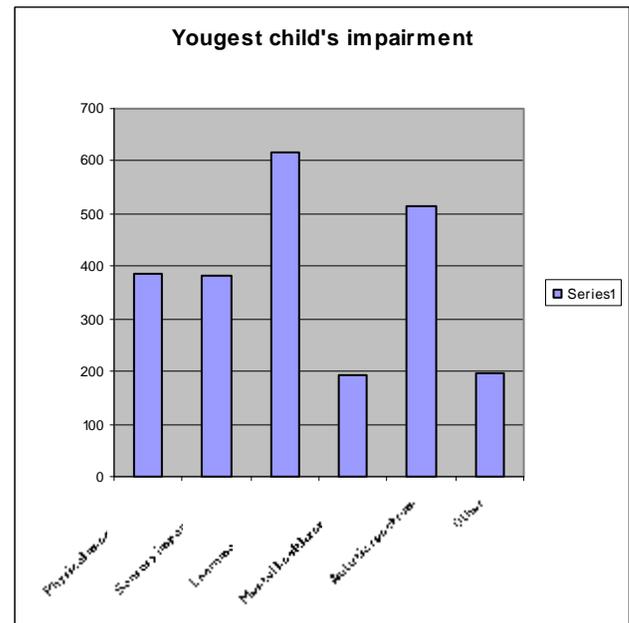


Of the 158 second-to-youngest children, over half, 65.2%, were at school or under five and 18.4% were at college or university. None were in adult residential care.

There were only 27 cases where information was supplied about a family's third youngest disabled child/ young person. Of these, it was also the case that about three quarters, 74.1%, were at school or still under five, but there were only three examples of third youngest children under five. None were in adult residential care.

When asked about their children/young people's impairments, respondents had the opportunity of selecting as many categories as were appropriate. Learning disabilities were cited by about half the parents as was the autistic spectrum. It is perhaps surprising to see as many as 20% of the

children/young people using mental health services. Under the category 'other' ADHD and epilepsy were mentioned a number of times, but most people who selected this option used it to give the medical name for the child/young person's impairment.



Just over 73% of respondents did paid work. Respondents were asked about their total family income, including benefits. More than 60% were in households with annual incomes in excess of £28,000 (an average two parent family income) and 5% had less than £9,000 per annum.

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