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& Speech Pathology

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**The Experiences of Working Parents of Disabled
Children: Family Case Studies**

Carolyn Kagan, Suzan Lewis and Patricia Heaton



**THE EXPERIENCES OF WORKING
PARENTS OF DISABLED CHILDREN:
FAMILY CASE STUDIES**

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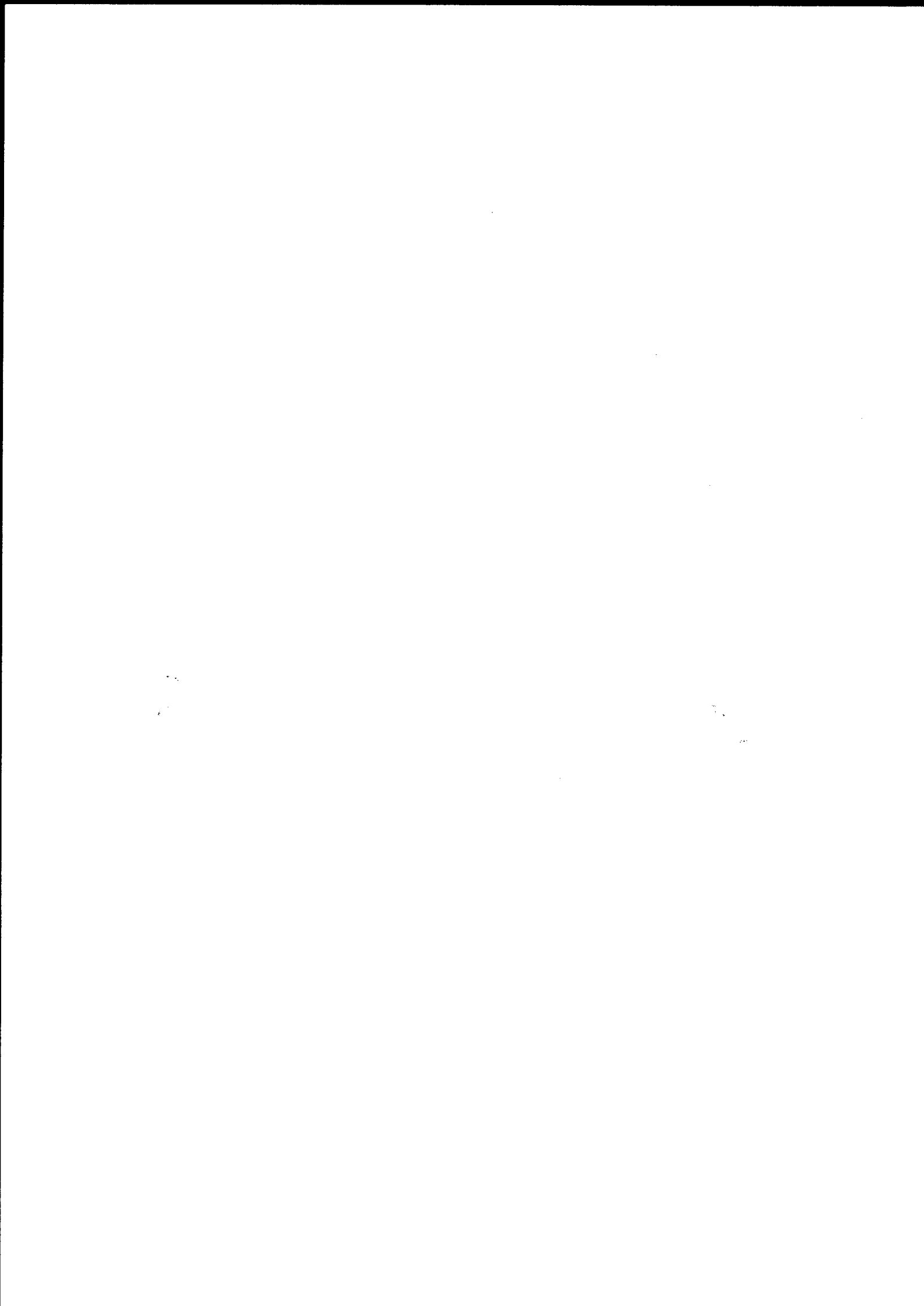
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1. The Phillips Family: In which a self-employed single mother has minimal informal support and has to struggle to get support from formal services



THE PHILLIPS FAMILY: IN WHICH A SELF EMPLOYED SINGLE MOTHER HAS MINIMAL INFORMAL SUPPORT AND HAS TO STRUGGLE TO GET SUPPORT FROM FORMAL SERVICES

Sharon is a divorced single mother with three teenaged daughters; Lisa aged 17 who has left home, 15 year old Helen who suffers from epilepsy and 13 year old Jenny. Sharon and her ex husband, Mike have been apart for nine years. Mike lives with his elderly mother, and sees his daughters only occasionally.

Sharon runs her own property management business. At one time her business was very successful. It provided an income to support her three daughters and the flexibility to provide the care that Helen needs. However the business has declined in recent years. Her income is now low, irregular and insecure, varying from week to week. They receive disability living allowance and mobility allowance, although not at the higher rate. They also receive family credit which Sharon says she could not manage without.

Mike also used to have his own business until he recently became bankrupt. He now has a job but although he gives the girls pocket money he has never contributed to their maintenance.

The need to work

Sharon is struggling to manage to run a business single handedly in order to support her children financially and to provide care for her sick daughter. She feels that her need to be flexible to care for Helen's unpredictable needs precludes other possibilities.

Sharon: I can't work for anybody else, nobody would give me the time off that I need. I just have to keep going, no matter how little I get out of it.

Sharon finds the struggle to be economic provider and carer so difficult that she can understand why others in her position would give up and rely solely on benefits.

Sharon: If Helen's ill she might just sleep all day... but you can't leave her

by herself, just in case, and its at those times when you need the help to be able to work, and you know I can honestly say that I can understand how people just throw the towel in. So, I might just as well sit at home and let the state keep me because what's the point?

Nevertheless she is reluctant to give up her business and the hope for the future which it represents. Like other mothers with disabled children, she feels that work is important for her psychological well being.

Sharon: it gives me a little bit (of income) and I've still got the chance of pulling back....other than that I would just sit at home and vegetate..... its not just earning money, its giving me some space of my own, and it gives me something to concentrate on , and while I'm at work I'm busy doing what I'm doing. I'm not wallowing in self pity... it keeps you sane.

Her youngest daughter, Jenny, also recognises that her mother needs to work for more than just financial reasons;

Jenny: I would prefer (mother to be at home more), but not always, because she'd get fed up of it.

Nevertheless, having to manage the business single handedly as well as the family care without support is daunting. Sharon sees no alternatives however.

Sharon: I thought what the hell am I going to do. I cannot run the office on my own and go the bank and do the viewings .. I thought , well I am just going to have to find a way because I just can't do anything else.

What makes it difficult to work and care?

The unpredictability of Helen's illness makes it difficult for Sharon to run her business

without some support from others. Helen's fits were controlled by medication until she was ten, but it has not been possible to control them in the last 5 years. Her fits are currently frequent and unpredictable. Sometimes Helen has fits all night and is not well enough to go to school the next day. It is difficult for Sharon to work on those days. Helen also often has fits at school, and Sharon is called away from her business to take her home.

Helen is sometimes violent, so Sharon cannot leave one of her sisters to supervise her while she is at work.

Sharon: I daren't leave Helen alone with her because she'd just hit her and punch her and kick her

When Helen is hospitalised this creates additional problems for Sharon coping single handedly, although she feels that just a little support would help.

Sharon: Its more difficult for me her being in hospital than it is her being at home, because I've got the business and the other children and the home,um I just need somebody to help me for half an hour, that's all I need.

Self employment provides some flexibility, but business is vulnerable to the vagaries of the market and economic context and does not provide a secure regular income. A number of factors have contributed to the decline in Sharon's business

Sharon: Three, four years ago I had two offices and nine full time staff, and two subcontractors that I kept in work every day of the week just doing repairs and then...rents dropped, councils changed the procedures, this that and the other, and the business slowly went down until I'd closed one office and then I kept making more and more cutbacks, until I ended up with one office and just me and one girl.

She has had to let her last employee go and that has restricted her ability to work flexibly.

Sharon: Now that I've made her redundant its very difficult..I have to lock the office

if I have to go out and do viewings, leave the answering machine on. If Helen's ill I've got to try and find somebody, anybody that will actually come and stay here with us.

Moreover, she recognises that while self employment provides flexibility, her frequent absences from work to care for Helen have contributed to the decline in the business, creating conflict between her various demands.

Sharon: I wonder how much business I lost by not being there, ...its where do you draw the line? I need to feed them and to clothe them, but I also need to look after them.

Sharon: I'd just have to stay at home and lock the office, and then what happens is, in that kind of a business, people start seeing your office closed and locked...you lose business because clients start worrying and thinking well...what's going on.

Sharon has not been able to rely on Mike very much to enable her to work and care. She says that Mike, was unable to take the strain of Helen's illness, first turning first to drink and then leaving the family home, when Helen was six years old. At first he had little contact with Sharon and his daughters, but more recently he has started to take the girls out and sometimes, to help care for Helen in emergencies so that Sharon can work. Sharon is grateful for any practical help that he gives her and does not press for more or for financial support.

Sharon: I decided that while we were arguing about him giving me maintenance I wasn't getting any help with the children, so I've never had a penny off him, because I'd much rather it be friendly between us, so not to create more problems,

.. the father takes them out, so I don't fight with him over maintenance, because I think, well if he takes them out I don't have to, but then he gets the quality time.

Sharon does not expect Mike to learn how to manage Helen's illness and makes excuses for

his inability to cope.

Sharon: to be honest with you he gets frightened. You see he doesn't see as much of Helen as I do, and he took her to the zoo.. the other week. Now if I'd have been with Helen I'd have just brought her home and put her to bed., but to be fair to him he didn't know... he just panicked..

..that's not a fault, that's him being over cautious because he doesn't know.. He's not as familiar with her illness and the minute she does anything he panics.

Although Mike sometimes helps out on his days off he is reluctant to ask for time off work as he has not been in the job for long, and is conscious of the insecurity of jobs in the current climate. He does take holiday days, for example, to accompany Helen and Sharon to the David Lewis epilepsy centre, but this is only possible for appointments that are planned in advance. Sharon feels that Mike's employers are unsympathetic about personal situations, and she is reluctant to contact him at work, even in a crisis. Despite the fact that his income does not contribute to the family upkeep, she does not feel she can disturb him at work.

Sharon: I know sometimes if I need to ring him at work, um sometimes they seem ok, but if I had to ring him more than three times at work, he would be in deep trouble for keeping having personal phone calls.

Sharon has no support from extended family. Both her parents are dead, her mother having died in an epileptic fit. Mike's mother is ill herself which makes it difficult for him to look after Helen.

Sharon: His mum's very poorly and she can't cope with Helen. A couple of months ago he started having her overnight and at weekends, to give me a bit of a break, but his mum's very cantankerous and doesn't agree that she should be there.

Mike's mother and also his sister believe that Helen's care is not Mike's responsibility. Mike did take Helen to stay at his sister's on one occasion;

Sharon: after about a week his sister said she shouldn't be here, she should be with her mother.

Sharon can no longer afford to pay for someone to help to care for Helen while she is at work. The lack of any informal support, creates many crisis situations. The family therefore has considerable need for formal supports and services, but these are often difficult to find.

Sharon says that she has had to struggle and fight for any formal help. She feels that this has resulted in much unnecessary suffering for Helen. She also talks of "reaching breaking point", becoming "out of control" and of "flipping" herself. She says that it was only when she reached a stage where her own coping resources were exhausted that some help became available and she was put in touch with services such as the British Epilepsy Association and the David Lewis Centre, which could give her some support.

Sharon: Its taken us four years to get this far, and Helen's had to be constantly ill, constantly off school, have I don't know what degree burns, but I know we were going back to the doctor's every other day, for about eleven weeks with this burn for dressing, broken arms, broken legs, concussion before we could even get an appointment, and I had to be put in a hospital ward because I was out of control, and I had to get, Helen had to be that ill and we had to get to that pitch before.... we could get there.

As she appears to be coping, nobody asks her what she needed or offered help or support. She feels she is expected to continue to cope.

Sharon: I need to feed them and I need to clothe them, but I also need to look after them... and there doesn't seem to be a middle ground where somebody says well fair comment you want to go to work, we will help you look after your child,

It has been a particular struggle to get any information about Helen's illness, which might help Sharon to anticipate problems, or seek appropriate supports.

Sharon: because they knew my mum was epileptic . . . maybe they thought I should know..... nobody took me to one side and said look you're coping very well, and you're doing very well, and its nice that she's doing so well, but this could happen, and this is what you should do if this happened, and this is where you go for help, financial, whatever, care workers whatever

Lack of information extends to information that it is acceptable, and not neurotic, to ask for help.

Sharon: I wasn't aware that the British Epilepsy Association, ok you go in the hospital and there's things pinned on the wall. Well you try not be neurotic. If the people at the hospital would have said to me you should join because of this and this, then maybe before I got to breaking point.....

She also feels that information about benefits which could make life easier have been withheld.

Sharon: Nobody tells you what help you can have, and its the Social Security ploy. They don't tell you that you can claim these benefits, because they don't really want you to have them if the truth be known...

She is grateful that the woman from the family Fund provided information about what she considers to be;

things that the DSS wouldn't tell me and the social services didn't tell me and other people wouldn't tell me.

However, Sharon is reluctant to ask for help, particularly financial support, and feels that only desperation would lead her to do so.

Sharon: I had a spell where I've never had to ask for money from anybody, and I didn't like asking so I would never have told anybody that I was struggling financially, only when I flipped and then it all comes pouring out.

Sharon's low expectations of support from Mike and reluctance to ask for formal, particularly financial support can be understood within an ideological context which emphasizes self reliance and maternal responsibility for caring. She feels that she will lose her self respect if she has to ask for financial help.

Sharon: (When the business was successful) we had more income, so we could have holidays and we could do this that and the other... because I could afford to pay for it, and I didn't have to beg for it, that's the difference. No I didn't feel that I was begging people for charity so that made me feel better about myself.

She says that if it had been made clear to her from the start that benefits were an entitlement of the child, regardless of parents' ability to pay, she would feel more comfortable about claiming them.

The prevailing gender ideology of maternal responsibility for childcare, and the acceptability of fathers' lesser involvement in family care also makes it difficult for Sharon to work. Despite Sharon's total financial responsibility for the family, she still feels guilty about having to leave Helen when she is unwell, in order to run her business.

Sharon: If Iknew that if Helen took ill.. somebody would be here...I could go to work with a clear conscience.

Sharon is conscious of the expectation that she should be at home with her sick daughter, which is based on the assumption that mothers are not also economic providers, and feels particularly guilty and driven to deceit when lack of support forces her to make difficult choices.

Sharon: there have been times when I have had Helen, not when I thought she was

going to fit, but say like the day after when I know she's going to sleep and I've gone to work and kept ringing home to see if she was ok and nipped home at lunch time and said to Helen, don't answer the phone, because if school rings up and finds out that you're on your own I'm in trouble.....

Interviewer: If you didn't go to work you don't earn anything do you?

Sharon: Well that's right, and then there would be no food on the table, or I'd be in queer street.

WHAT MAKES IT EASIER?

Being self employed does give Sharon some flexibility and control. For example she can start work late after taking the girls to school and can leave work if Helen is ill, without needing permission from an employer.

In the past, when Sharon's business was successful being able to employ someone to help both in the office and at home helped.

Sharon:... when I did have someone in the office that was great because if ever Helen was ill I just didn't go to work and she (the assistant) would ring me at home if she had a problem.

She was able to support the family financially and pay for help with childcare and this improved the quality of life for the whole family .

Sharon: I could afford to pay someone to come in and help me at home, and to be honest with you the quality of life for me and the children was better.....I had a life away from the illness. I could put more effort into the business and make it work, so we had more income, so we could have holidays..I had the help because I could afford to pay for it, that's the difference. No, I didn't feel that I was begging people

for charity, so that made me feel better about myself.

Another thing that used to help was having a nurse at Helen's school. This meant that Sharon was not called away from work whenever Helen was unwell at school. This is no longer available.

Sharon: ..school....used to have resident nurse,not resident,I mean she was there all the time, and with the cut backs they now haven't got one, so just the receptionist is a first aid officer Now when the nurse was there full time if Helen had a fit at school and it was a mild one, she'd put her to bed in the sick bay, leave her for an hour and then send her back to lessons. That doesn't happen any more. Helen's only got to complain of a headache and they're on the phone can you come and get her....they're frightened of her and I can't blame the school,but when the nurse was there all the time she'd put her in the sick bay and she wouldn't even ring me.

Now that she can no longer afford to pay for childcare or help at work she is grateful for the occasional support provided by Mike, who sometimes looks after Helen or takes the girls out. She also has a friend who will sometimes sit with Helen when she is ill to enable her to go to work, although this friend is not always available.

Benefits are very important in enabling Sharon to sustain her way of life. Family credit provides an incentive to continue to try to make a success of her business.

Interviewer; Would you be worse off? Financially maybe? (relying on benefits alone)

Sharon: Financially probably,because family credit is more than income support, so it does give me a little bit of flexibility. Not a lot, but it gives me a little bit and I've still got the chance of pulling back.

The family's most positive experiences of support have been from the Family Fund and the David Lewis Centre. Sharon was referred to the Family Fund by a hospital social worker

at a time when she was quite desperate

Sharon: This was as I say when I had flipped in the hospital... they have like a social worker in the hospital who came to see me...and she said about the Family Fund that would step in where nobody else did, and she sent this lady to see me at home...

The support from the Family Fund was important not only in providing information on sources of support, but also in confirming that other parents have similar concerns, and validating her right to express her needs.

After many years of struggling Sharon now has considerable support from the David Lewis Centre, a charity based organisation which specialises in epilepsy and the British Epilepsy Association. They have provided essential advice on support available, and counselling for both Helen and Sharon, so that she is able to go to work with more peace of mind.

WHAT ELSE WOULD HELP?

1. Better access to information and support

Access to information, without having to fight for this would help. Sharon would have liked information, from the time that Helen's epilepsy was diagnosed about the possible course of the illness and advice on where to go for practical or financial help. This would have enabled her to be better prepared for the difficulties which could arise in caring and working.

Sharon: If I had a list somewhere I could say, right if this happens this is what I can do... that would make life bearable.

She feels it would have been very helpful if the family had contact with one liaison person who could provide advice and guidance about where to get this information and support. Support is available for epilepsy sufferers and their families but Sharon was not told about this for many years. Information about what is available in terms of supports and entitlements is very important.

Sharon: I didn't know that I could ring up the British Epilepsy Association any time twenty four hours a day, and the David Lewis Centre, so can Helen.

Nobody tells you what you can have... that you can claim these benefits

It cannot be assumed that because parents appear to be coping with multiple and difficult commitments they do not need support. It would have helped if Sharon had been asked if she had any problems and offered support, rather than having to reach the stage of desperation before help became available.

Sharon, like many parents does not like to appear to be asking for what she sees as charity. It would help if there was someone to tell her about her entitlements and if these are constructed as entitlements of the child.

Sharon: If people said to you like this thing with Disability Living Allowance, like they said to me in the end, that is Helen's by right and it doesn't matter how much you earn she's still entitled to thatand you don't feel like you're begging or a second class citizen.

Sharon agreed to be interviewed for this study in the hope that her experience may prevent other parents having to go through similar experiences because of total lack of information and support.

Sharon: at least something like this might stop other people having to go through the same, years and years of horror, you know without someone, somewhere saying this is what you do...its down to information because if you know what you're entitled to...if you know what you can have and what you're entitled to and what help you can have, it can only make it easier.

Sharon also feels that it may have helped if Mike had been offered help and support earlier. This may have saved their marriage or at least enabled Mike to be more supportive.

Sharon: maybe given the help and advice in the beginning the marriage would have survived..... nobody suggested that somebody could counsel him.

Support in coming to terms with Helen's illness and encouragement to be involved in her care from an early stage may have helped Mike to cope, and have empowered Sharon to expect more support from him. Lack of attention to the father reinforces the view that childcare is a mother's responsibility.

2. Flexible and affordable daycare services

Now that the children no longer need full time daycare, services that are flexible and affordable to deal with the unpredictability of Helen's illness would help Sharon to manage her multiple demands. A pool of service providers who can be contacted in an emergency would meet the needs of this family.

Sharon: I just need someone to help me for half an hour, that's all I need.

I don't need somebody everyday of the week, but if I do need someone I don't know until an hour before that I need them. So I can't book the in advance like home helps..... you don't know from one moment to the next.

3. Business support for self employed people with multiple commitments.

Family credit is important for the economic support of the family while Sharon's business is struggling. However, it does not help in the day to day running of the business. It is possible that the decline in the business was due solely to market factors. However, Sharon feels that her frequent absences have added to the problems. Support with the day to day running of the office when Helen is ill would therefore be beneficial.

This may be achieved via subsidised help for self employed people with multiple commitments, to ensure that they do not have single handed responsibility for a business and care. A subsidy might pay the salary of an assistant. Alternatively a pool of temporary staff

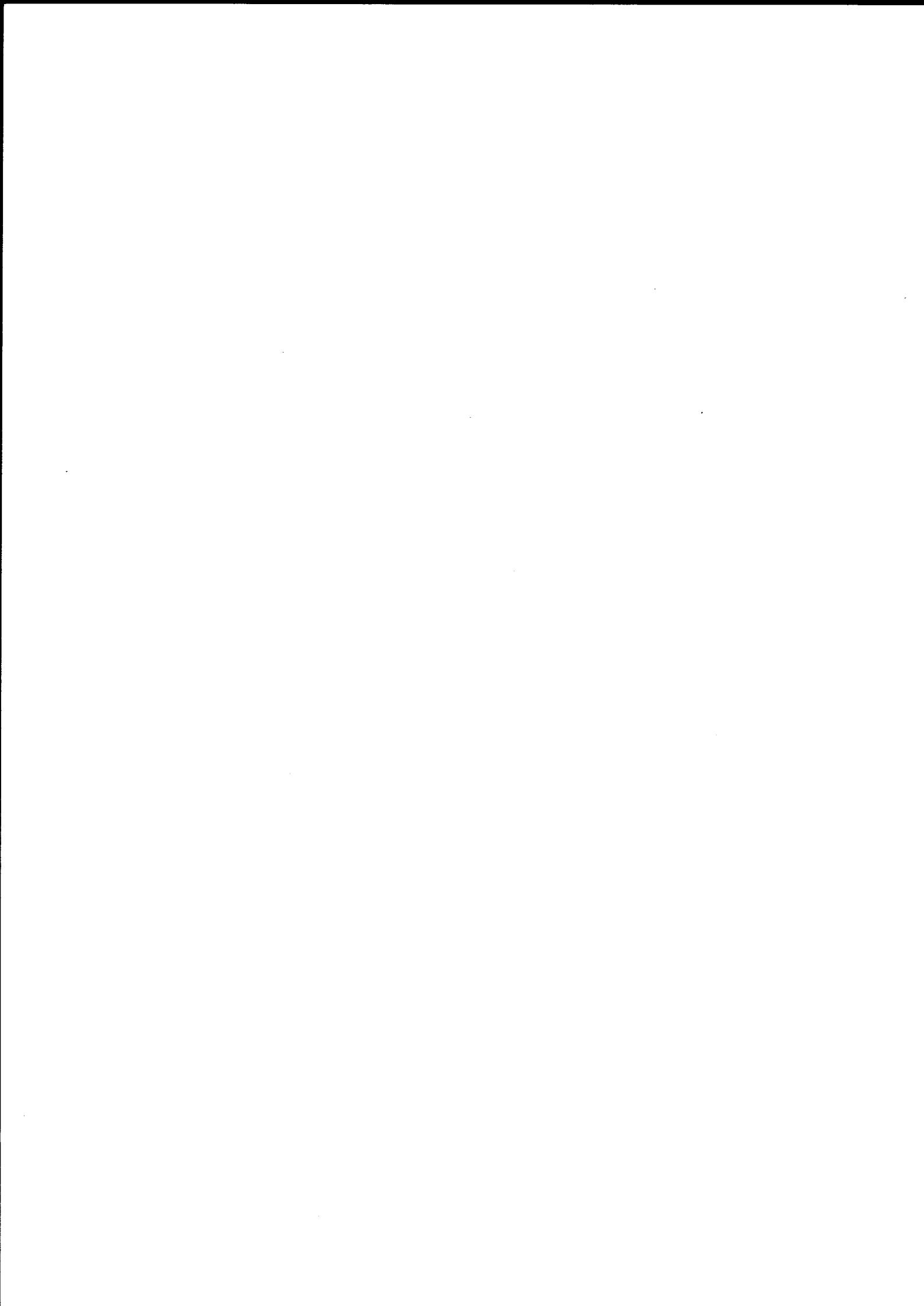
might be available to fill in when an employer's dependent is ill. This could be organised locally by a chamber of commerce, TEC, etc. It could be funded by government, or by a sliding scale of "insurance" payments by small business owners who can afford to do so.

If such schemes were available, accessibility of information would again be important. A local small business advisor or help line would help to disseminate this or other solutions.

Conclusion

Sharon tries hard to be self reliant and is reluctant to ask for the help that she needs to work and care. Because she appeared to be coping she was not offered help until she was quite desperate. Sharon's story shows that it is important that parents are offered support whether they appear to be coping or not. Better access to information and support, flexible and affordable support services for help with caring responsibilities and with self employment would help Sharon to manage her business and the care of her daughters, reducing unnecessary stress and enhancing well being for the whole family.

2. The Greens: For whom a helpful extended family and flexible employers make it possible to combine work with caring for their four year old disabled son



The Greens: For whom a helpful extended family and flexible employers make it possible to combine work with caring for their four year old disabled son

Introduction

Jenny and Dennis Green have two sons. Len (11) and Alan (4). Alan has a condition known as 'cri du chat' which results in mobility, language and intellectual impairments. Dennis works eight to five, five days a week, as a driver of children and elderly people for a local authority. Jenny works 4 hours a day, four days a week as a family aid worker with a social care charity. Her hours are arranged to fit with school hours, enabling her to take Dennis to work and the children to and from school. Their joint income is approximately £20,000. They receive the higher rate of disability care allowance, covering mobility and personal care. Jenny and Dennis, parents have all taken an active role in looking after both children from the outset, enabling both of them to work, although Dennis' parents have now died.

Need to Work

Jenny has worked for the past ten years, In the past, Dennis had been made redundant, and they had experienced extreme hardship then. Financially things were difficult, too, when they moved house.

Jenny: It were a struggle at first weren't it? When we first moved in this house, before I had Alan..I just thought 'Oh God' you know...that's why I had to go back to work (when I had Alan) because financially we could not just live on Dennis' wage, not at that time. His outgoings were more than his incomings at one time wasn't it?

After Alan was born, Jenny returned to work after short maternity leave. Her mother looked after Alan.

Jenny: Well I went back after he was six months didn't I?...If you have a year off you don't get paid for it...So, yeah, My Mum actually cared for Adam while I worked. Sometimes (Dennis') Mum had him...Len was at school you see, so when it was the school holidays they brought him to my Mum's or Dennis' Mum..we've always had that.

Recently Jenny has cut her working hours, in order to spend more time with Alan, although she would not wish to return to full time work.

Jenny: I did work more hours, I actually cut me hours down...I used to work five days, still part time, but I asked work if I could cut my hours down because I wanted some quality time with Alan on a Monday. I used to go into nursery with Alan and help out so that there would be some contact there really...

Interviewer: Would you like to work full time?

Jenny: Would I..No, I wouldn't like to work..I have done, I have worked full time, no, no...I couldn't manage it. I couldn't do it with everything that Len does. It's a shame, I have to take Dennis to work in the morning, come back here, get Len ready - well, Len gets himself ready now -, take Alan to school,

then go to work and do exactly the same at the end of the day you see. It really is a full day in itself.

What made it difficult to work?

Alan's condition means that he requires additional care. He cannot feed himself and is not mobile by himself. Although Jenny and Dennis believe that some childminders are able to look after children with Alan's needs, they have always relied on family to help out. They are both adamant that they had no particular difficulties working. They acknowledge how lucky they were to have so much help from their parents, and considered that both their employers adopted a flexible approach to giving them time off when required.

Jenny: (we) never really had a problem did we? Because I've got a bit of an extended family, there's my Mum and Dad and there were Dennis' Mum and Dad. My Mum actually worked - actually paid - for Alan when I worked...They wanted to, they were very willing to.

Dennis: It weren't like we threw him at them and said..I mean they still have him now..well, Jenny's Mum and Dad does, yeah.

Alan has an older brother Len. Len has been told about Alan's specific difficulties from the outset and plays with him like any brothers would. Jenny and Dennis think that he is mature for his years, but do not attribute this to giving him particular responsibility for Alan.

Interviewer: What about Len? he's a bit young yet isn't he?

Jenny: To have what?...

Interviewer: To share and things

Jenny: Oh yeah he is...he does a lot of things with Adam, doesn't he?

Dennis: He likes to play with him.

Jenny: He does, he actually plays with him. He's really got good patience with younger kids hasn't he?

Dennis: He's a lot older than his peers round here.

Jenny: Yeah, he is. He's a lot more mature for eleven, you wouldn't think..

Interviewer: Do you think that's the presence of Alan?

Jenny: No, he's always been like that I'm afraid, yeah.

What made it possible to work?

Not only did Jenny's and Dennis' parents look after Alan when he was new born, they took him to a toddlers' group when he got a bit older, and apparently thoroughly enjoyed doing it..

Jenny: They have this scheme, what we call Kids Plus..it's a mother and toddler group and they have it Tuesdays and Thursdays..and they integrate kids with special needs with kids that have good mobility. So Alan actually used to go there twice a week..with his Nanas. Both his Nanas used to take him you see because I..obviously were working and I couldn't do that. But is were a nice sort of set up for them weren't it?

Dennis: They got to chat...

Jenny: That were then, with them two weren't it. And they got on really well. And Dennis' Mum and Dad used to pick up my Mum and drop the two off. And Denies' Dad used to go off wandering somewhere, didn't he, and then come back for them. So they used to take him, so that were nice twice a week. And then he started nursery two or three times a week there, which put grandparents' noses out a bit, didn't it? Stopped their social activities, yes it did.

Already then, Jenny and Denies had parents to help them and a mother and toddlers' group that welcomed Alan. Before long, he moved on to a nursery attached to a special school, which did a lot of work on integration.. Initially he attended two or three times a week. This was increased to all day for the six months prior to going to school, where he now is.

Not only have Denies and Jenny been able to arrange child care when Alan was little, they have also both worked for understanding and accommodating employers.

Jenny works part time and is at home before and after school. Even so, her employers have allowed her additional leave time to enable her to attend hospital visits linked to Alan's condition, and she thinks she could manage if she had to go over this leave time..

Jenny: Work's been very good, they have actually allowed me extra dependant care dates, actually negotiated it. I did have at the beginning..was using my holiday time and sort of talking to my supervisor about it and she said 'we'll try and negotiate something for you'. And, I mean, if a social worker agency aint understanding then no agency is really, is it? So they've been really good ... they actually allowed me an extra twelve days a year.

Interviewer: Now that's a formal thing, a form of agreement that you get an extra twelve days a year to use..?

Jenny: Yeah!

Interviewer: What happens if for some reason you need more than twelve days, say he was ill or something?

Jenny: Then I'd either have to leave holiday or else dependent day care really.

Interviewer: What happens if he's poorly one morning and you don't feel you can take him to your Mum's..

Jenny: I'd ring in and say I'm taking to dependent day care.

Dennis, too, is able to take time off, seemingly at the discretion of his manager and with the co-operation of his colleagues.

Dennis: Well, when he's got appointments at hospital, if they're not just routine and I'm needed, I can get the time off. I just go in and tell the office and they'll cover my job..

Interviewer: Is it a formal policy, or is your manager saying 'no, take the time off'?

Dennis: I have no idea whether it's a formal policy. I just go in and say 'Well, I got an appointment could I have a couple of hours, and he'll say 'Yes'.

Jenny has considered how she will carry on working as Alan grows older and becomes too big for her parents to manage (Dennis' parents have now died). She has discussed

possibly changing jobs with her employers and their response has been to offer to re-arrange her hours again so she will be free during the school holidays.

Jenny: I mean I'm on about..sort of..whether I will increase my hours now, because..my Mum's getting older now, having kids on school holidays. I ought to really find a job when I can have school holidays off...working in a school or something. And I actually told work this and they (are) going to try and negotiate for me to actually have the school holidays off...I had actually said there was a job coming up at Alan's school that I was actually thinking about..because Dennis' Mum and Dad died last year..so that support system's gone. So alarm bells were like sort of ringing a bit and she's sixty odd, my Mum. I mean, she'd have them and have them and have them, but there will be time when he's too much for her...to handle...So I've got to think more long term now. Urm, so they panicked a bit at work 'cos I'd been there for ten years...'We don't want you to leave'...and they kept on trying to change things for me, so I'm actually having a think about it now.

It is not only family and work that have provided the flexibility and cover needed by both Dennis and Jenny. They have also found professionals to be accommodating and to fit in with their schedules.

Interviewer: How flexible were the hospital and assessors...with appointments and times? Were they prepared to make their appointments flexible to fit in with your working (life)?

Jenny: Well they had to...I used to say 'I'm off on Mondays, if you can get to see me then, that's great'. You know, then there's no hassle at work you see, that helps me as well, you know...and a lot of times (they) could do that...the physiotherapist...would always come on a Monday, 'cos she knew. Or she would come after school hours so she was very good.

Now Alan is at school, some health workers see him in school itself. Clinic sessions, however, have not been as flexible as the peripatetic health professionals, although Jenny has found that she has been able to change dates for routine clinics if necessary.

Jenny: I mean, if it coincides with, say...a case conference, then I will ring up and say 'Can I change it?'...If it's not an important appointment, it's just a check up. Urm, so, I mean, I suppose clinic days are not that flexible because they are on certain days, but I suppose the dates..it's me that's got to be flexible there.

In addition to assistance and flexibility in different areas of their lives, Jenny and Dennis were helped considerably by gaining information about Alan's impairment and by being put in touch with other parents whose children had Cri Du Chat. Initially their GP gave them some basic information, but it was via Contact-A-Family that they met others who had had similar experiences. This helped them get their own experiences into perspective.

Jenny:...we just wanted to know more about Cri du Chat didn't we. Because our GP, sort of, he didn't know much about it and all he gave us was something out of a book which..

Dennis: He photocopied it...

Jenny: Out of a paediatric book, but it was very sort of...black, you know. Bleak outlook on it which I didn't..I mean it were like it were a study of a child that's been institutionalised... we were in touch with somebody...given to us by Contact--Family...it was all very small, weren't it? And she was the one with the Cri du Chat bit of it. So her little girl had Cri du Chat, so it was like a named person to just get into contact, so I did. ...Alan's condition affects one in fifty thousand so it's quite a rare one...we had the very first conference meeting to get to know, get together. About forty odd families it were from all over, from Ireland, Holland weren't they?

Dennis: Yes, from abroad

Jenny: We went just to find out, and I think we came out feeling a lot better, didn't we? 'Cause there were some that were worse than Alan and some that were better..

What would help?

Jenny and Dennis have had information as well as support from their families and enabling employers. When asked to speculate about how they might manage in several years time if Jenny's parents were no longer able to help out, the only thing they mentioned was trained and competent childminding.

Jenny: Well, I would have to look into some sort of care. I mean, people do these sort of things every day. I'd see if I could get a childminder.

The nature of Jenny's work has given her insight into the capabilities of some childminders and how it is possible to find care for children with multiple impairments.

Jenny: I've actually found childminders for families that I work with you see, and I know that some actual childminders will actually put that they will have kids with special needs.

If she were not able to find some suitable help, Jenny would consider changing her work to night time hours, or even getting a different kind of job.

Jenny: If I couldn't (find a childminder) then I'd have to think about finding a job where I'd have to work at night and Dennis would have to have the kids. I'd have to really think about that, like you do...and if a job...I weren't qualified to do... in a shop or something I would do it. Do you know what I mean, so I've no qualms about that, if we needed the money.

At no point in the interview did either Jenny or Dennis discuss the possibility of giving up work.

Summary

Both Jenny and Dennis have flexible employers. She works for a charity that has a clear policy about flexible working and dependant care leave. Dennis does not know of any policy within his workplace. Both of them have managers who will use discretion to enable them to fulfil their caring activities. However, most flexibility and provision of care is undertaken by Jenny, who also has the main responsibility for

making alternative care arrangements. Despite her being potentially able to earn more than Dennis, it is she who works part time.

The major factors that have facilitated her being able to work at all, albeit part time, are the supports of both sets of grandparents, the flexibility of both their employers, the acquisition of information and contact with other families and the accommodating nature of the peripatetic health care workers.

Both parents are aware of the future, when their parents will no longer be able to help out and are optimistic that their knowledge and local provision for the support of children with impairments will be sufficient to enable them to continue to work.

3. The Whites: For whom the wife's earnings are greater than her husband's and the difficulties of combining work and caring for their disabled son extend beyond the childhood years



The Whites: For whom the wife's earnings are greater than her husband's and the difficulties of combining work and caring for their disabled son extend beyond the childhood years

Introduction

Pam and Bob White have four children. The first three were born very close together and Barry was born seven years later. Jackie (25) has left home, has her own baby and works as an auxiliary nurse. Tony (22) has also left home and works as a chef in Tenerife. Dave (24) still lives at home and attends college. Barry is 15 and is still at school. Pam's mother (Nana) and father live nearby, although her mother has died. Bob works a 45 hour week as a machine operator in a plastics manufacturing firm. He is paid a weekly wage of £140 (Approximate annual equivalent £7,500). Pam works a 39 hour week as Head of Care Organiser with a local authority social services department, earning approximately £16,500.

Need to Work

Bob has worked throughout their marriage although Pam did not work when the children were small. She then began to take casual evening work and proceeded to take term-time-only-jobs in schools close to David's own school. The early days were difficult. Pam considers them to have been

Pam: ... a real baptism as I wasn't able to earn the income I'm earning now.

They were particularly difficult to Pam. Before David went to s she was unable to work at all:

Pam: I couldn't even consider working at that stage, couldn't try anything. I mean, when I got him into the nursery I wanted to go and do some further education myself and got booked in to do Maths credits and a bit of English. I had to give it up. I tried initially with him in the crèche before he went to nursery and they couldn't cope with him...and so I couldn't even do that.

Thus the family were confined to one low income and Pam was unable to further her education. Nevertheless, eventually she was able to take casual work in the evenings which served as a break from the demands of three young children.

Pam: The first three were so close and I was a very young Mum...I was only 17 when I had the two of them...quite a number of my friends were still at school...and they were going to college and University and stuff...and I was there with these kiddies and Dave was so badly behaved..Oh, it was dreadful what I was going through..awful. If he didn't get what he wanted immediately he would scream and lie on the floor. There were these tantrums, it was like all of the time, so, more and more people..I wasn't welcome if I went anywhere, so I didn't. ...Well, I ended up I had to do something, so I would go cleaning at night or work in a chippy at night.

For several years Pam could only consider evening work when Bob was able to look after the children.

Pam: ...all my work in the early days would have been done in the evening when my husband was around for him to mind the kiddies and that is exactly how it went for many years. I couldn't do anything during the day...Casual work, Christmas time catalogue work - again evenings- where you pick up stuff. Oh, I've done loads and loads of jobs in that vein...I cleaned above a launderette and I had the cleaning. I could go when I wanted and I fitted that in when Bob was home with the kids.

What made it difficult to work?

Apart from the demands of three young children, Dave's behaviour made it more difficult for Pam. For several years she did not know whether he was just a particularly naughty boy or whether he had specific difficulties.

Pam: He wasn't diagnosed 'til he was four or five anyway. There was lots of behavioural problems and we didn't know what they were, and he told me he was bordering on severely subnormal, that he had hyperactivity, and he had..urm..what did they term it.. oh, that he was an oddball and he didn't really fit into a category. I'm not one for labels, I wasn't then, but I wouldn't have minded knowing something....He had very poor speech in those days and required speech therapy..was very anxious, very frustrated, lots of temper tantrums so he was just like a very naughty child.. (We) took a long time to realise that he was a little bit more than just being this naughty child. But that is all that was ever said to me, just bordering on autistic tendencies...and a mild spasticity...in the back of his calves, which has disappeared with time.

Whilst Pam suspected something was wrong with David, the professionals kept reassuring her.

Pam: I was constantly saying 'Oh, Jackie's doing this and he's not', you know, comparing, and all I got from the clinic was 'stop, she's a girl, she's quicker, that boys are slower', bla de bla. I was fobbed off an awful lot, but even so when I think about it, I certainly was, and I had worries all the way along.

In the early days, matters were made worse because of the lack of support available and the fact that other people found Dave's behaviour very difficult to cope with.

Pam: There wasn't any support at home or..we didn't have any, or didn't particularly want people in the home. but we didn't have any social work intervention, or any support. There was nobody...(there was) nobody to leave him with anyway... Friends? Few and far between..never would have him on his own....Even my family couldn't have Dave. They couldn't look after Dave. No, they would have little Jackie, a little placid girl, they would have her any time, but not David, and certainly not the two...No, nobody would have him.

Interviewer: Public or private arrangement?

Pam: Didn't have the funds for anything private you know. We were very limited income then...the other two, I could place independently and they did go to nursery...but David was always a stumbling block - no-one would want him and you just couldn't leave him because his behaviour was pretty bizarre you know.

When eventually Pam did get Dave a place in a nursery, he was soon asked to leave.

Pam: ...first of all they said there was nothing, and then they said 'can you keep him off, we're having a puppet show'.

As Pam began to question the professionals, Dave eventually received an assessment, and after what turned out to be inappropriate school placements, was allocated a place in a special school. Until then, Pam was largely caring for David at home or challenging the services to remove him from inappropriate schools.

Pam: He missed out on quite a lot until he was probably 12 or so, and then he got placed correctly, and then did settle down and come on a bit.

As he got older and a bit more settled, other family members were able to help Pam out a bit, even though he still required close supervision

Pam: My sister had him a couple of times, but she felt too pressured with him, you know. She was worried because he would do dangerous things, you know, the hot water, the fire, and he actually did fall into the fire at her house. He stumbled and, oh, she didn't have a guard...he got a burn on his leg but it wasn't as bad as it could have been.

Even in his late teens, Dave required someone to supervise him - not just anyone, but someone with whom he was familiar and who the other children would accept.

Pam: When he was 18, 17 ...he had to (have someone to supervise him) because he was very able, and in fact dangerous...I've had the fire brigade out..one stage he was going through (was) experimenting burning paper..there were lots of dangerous things..cut himself with the tin opener and knife.

Interviewer: So even when he was then nearly an adult...you had to have somebody available?

Pam: You had to have somebody familiar as well...it was his Nana he would have that would come...as Barry got older, you know the young lad, he didn't want minders round or whatever...but they tolerated Nana.

In later years Barry himself would help out a little. Pam considers that Dave is still at risk at home (from cookers, fires, knives etc.) if left unsupervised. Thus whilst most parents are able to reduce the amount of supervision they give their children as they get older, Pam and Bob have had to maintain it for David, who is now 24.

Pam: My mother-in-law is still round the corner. She pops in and out but he has more and more time alone. I mean, it's risky...in a lot of ways he's developed on and it's fine, but then it will only take one thing really went it? And then I think 'oh shit, not again' and you wonder what to do for the best frankly.

Lack of information and a sudden change to David's routine have added to Pam's difficulties. Dave's daytime activities have recently been changed with no consultation with Pam. Dave had been working full-time on a work placement, and this was suddenly changed to a three day college placement, leaving David with a more irregular routine and Pam with the difficulty of arranging supervision.

Pam: I'm a bit annoyed at the minute because his (work) placement..he finished it, and they put him on a three day college course. Not five, not four and a half day placement. So now he has time at home.

Interviewer: On his own?

Pam: Yeah, on his own. Not certainly sorted out with myself or..you know..just happened. 'Oh, we're moving him to that'.

Interviewer: No consultation?

Pam: No consultation, or, for instance, if we're happy with that. Anyway, as a result, two days a week now at home.

Interviewer: I can't believe they did that without consulting you.

Pam: They said 'Did Davey not talk to you or mention it three weeks ago?' They mentioned it to somebody who's got a learning disability. Do they not realise he's supported - and that's why he's available as he is, because I support him?...Wednesday, he says he thinks he's leaving Friday, so I phoned them up and said 'Oh, thanks for mentioning it'. It's ridiculous...I'd been to a referring out meeting, (they said) 'let's look for another placement for him, I'll talk to you after Christmas'. And (the move) was prior to Christmas. Nothing to do with what we'd discussed.

No-one had asked Pam if there would be anyone at home when David was not at college. A minor incident, such as forgetting to change the central heating clock when David was home led to a crisis.

Pam: I didn't click on it had gone cold. Heating's on a timer so it wasn't going to come on. Dave's off work..he gets up and he thinks 'Well, I've got to get it back on'. Doesn't light it properly does he? My Dad, luckily, he knew. I'd told Dad he was off, so he walked round. There's a smell of gas and he had half lit the gas fire. Now, luckily Dave had only just fell out of his pit around twelvish, so it had only been about 15 minutes, but there could have been an explosion...He was doddering on the chair. He could have been dead and gone, 'cos he hadn't even lit the stupid fire properly.

She has to rely on family members, still, now David is 24 years old. Now, however, her mother has died and her father is recovering from lung cancer, so he is more limited in the help he can offer. With a more irregular week, there have been more attendant problems for David as there is no-one to co-ordinate his activities. It seems as if no-one knows where he is meant to be or where he is at any one time. Pam has found the services unreliable and she has had to put pressure on them to let her know what is going on.

Pam: I just flipped and I just phoned up.' Have you no system at all? He's been off twice and you never even said...I'm sending him out in the morning and he's not getting there. I need to know'. They didn't even bother at all...It sounded bizarre to me, somebody who's got a learning disability and they weren't having any system to say they had arrived or not. A new route for travelling...I mean, anything could have happened couldn't it really...and I wouldn't have known anything.

What made it possible to work?

Despite the difficulties of finding some help and an appropriate school placement for David, Pam found a way of being able to work during the day. She began to work as a lunch-time helper at David's school, whilst still keeping up some of her evening work.

Interviewer: Once he started at the special school could you work then?

Pam: I started most of my work as a lunch organiser, or as it was then, a dinner lady at his school. That continued on, he got a full-time placement there, that was when I did the lunch job. I was still doing my evening job with it....it was the only way I got into earning anything other than evening cleaning, the chippy work work..I'd not do anything during the day, it was unheard of..I worked there for four years in the end. He moved from that school when he was reassessed. (he was) 12 or 13. Once he was at (his other school) he started to get a little bit more specialist help, but by this time I'd evolved on. I had started doing a helping in another school which was near to me, where I eventually worked for five years as a child care assistant. It was only in the day time and (I had) school holidays.

Having a job that was during school hours and term-time only gave Pam the flexibility to fit work in with caring for her children, especially David.

Pam: That was why I stayed in education so long, because I got all the holidays and I was home relatively early. Even with staff meetings, I'd be in for half past four. It was only down the road, literally down the road.

Even now, several years after Dave has left school, Pam needs to work the hours that enable her to be home with him as it is not safe to leave him on his own.

Pam:...this job that I'm doing now, I can finish relatively early and I'm usually home before five..because of course, you know you couldn't leave David a full day...I've been out straight from work on occasion, but I've always made sure that someone's gone round...

It is only the fact that his grandparents and younger brother have been in the house that serious accidents have not occurred. This need for continuing supervision limits the kinds of jobs that Pam is able to take, and means that his routine and any changes made to it will directly affect the arrangements she has made to balance work with family.

Pam: Other things that have helped Pam progress her career and enable her to continue to care for David beyond his childhood years, include the adaptability of others.

When David left school and started to go to college, his hours did not correspond with Pam's working hours. She was working in a school at the time, and her headmistress managed to accommodate her in various ways that made it possible for her to continue.

Pam:...if it hadn't been for the headmistress there, there's a lot of stuff that, you know, I couldn't have done...Dave finished his college down the road at a quarter to three -they were very haphazard in their timing. They don't

appreciate when they do special courses for people that are disabled...they cut it right down to the minimum, and so they go in later and come home earlier, not working out that (parents) need some help with these people. So he was at school for 10 to 3 for instance, and I don't finish 'til three thirty, 'til I got the kids off and everything. But she (headmistress) was very adaptable. She said it was all right for (Dave) to come when (I) came...He went in for a good year and a half. He came and sat in reception on a chair, winter, summer...That was easier than tying him down to be at the house, to have keys. Couldn't have keys in those days, he'd lose it...(college just said) they finish before the other people (students), and it was down to me to sort it out in advance with other people.

In the early days, Pam's working hours enabled her to attend Dave's day-time assessments. Later on, it has always been managers in Pam's workplaces that have used their discretion to give her time off to attend Dave's assessments and reviews. It was only after she had been working in the care system herself for some time that she discovered entitlement and provisions for special leave.

Interviewer: If you were allowed to take him for assessments or hospital visits or anything, how do you get time off?

Pam: During the day when he was having these visit assessments, I was night working anyway or evening working...so it was OK. I did a couple of things for reviews..if you need to go to his review you go. She would allow it.

Interviewer: She would allow little surprises if you needed to go?

Pam: Well, I obviously know the system now a little bit, so I know I could get special leave... there is a special leave that you have to apply for...

Interviewer: There is a policy and practice?

Pam: There is, yeah. certainly is for that, if I had a crisis I can do that, and I've had to when it (David's current arrangements) first broke down.

Interviewer: So what did you do?

Pam: ...I just booked a couple of days, you know, well, emergency leave, I didn't take it as special leave. I had leave that I had to use up anyway, so she just let me take it quick...you're supposed to put in for a couple of days off...

Interviewer: So ..she could bend the rules slightly?

Pam: Yeah, Yeah! I mean, I suppose I could have had special leave but I thought in this instance, I thought, 'no, take it off and perhaps do a couple of things round it'.

Pam's experience of working in the care sector has given her access to short term care services, about which she previously knew nothing.

Pam: I didn't know that was available..it wasn't on offer, it wasn't there. He's actually started recently, he's picked up on some respite care as well, which is something..I was deputy there and ... some of these bodies were twice as able as Dave and they were having these respite breaks for them and their parents. So, I got his name on the list and eventually it came through. It didn't come through straight away, but he'll have a weekend, Friday to Monday, learning some of these skills away from me.

What would help?

Pam was asked to talk about a time in which working and caring for David was relatively easy. Pam identified the time he was on a full-time work placement, himself, with regular hours.

Interviewer: I was going to ask you about a particular easy incident, or an easy time...When he was doing full-time work placement, was that about the easiest?

Pam: Yeah, I suppose it was quite good, in that he did go there and I knew he was there every day. (It) felt more, you know, he'd gone to work. I knew he'd be there all day and he wouldn't be coming home 'til four, and...he got into a routine in that place. His Dad had his operation, and he'd get off the bus and see his Dad, and he'd do it every night. It would be 5 o'clock he'd get in. Now, he almost timed it to the minute.

This was the work placement that had been stopped abruptly giving Pam little chance to accommodate his being at home for nearly half the week. Pam is well aware that some parents eventually give up work entirely because it is just so difficult balancing work and adequate supervision and care of their young adult children. Right at the end of her interview, she talked about a friend of hers who had retired early from a good job for just this reason.

Pam: Well, I had a friend who's a headmistress, who actually had to give up, you know, she resigned because her dependent was in a day service which they put back. It was one more place closed and she got virtually half of what she was getting. She was getting near the age of retirement, but she took it earlier, because she said 'I can't stand them. I can't stand them putting my Kath through all of that'. So she gave it up, you know. People don't give a damn really, do they?

Summary

Pam's story tells us several things about combining work with caring for a learning disabled child.

Firstly, apart from the assistance Bob gave in looking after the children when they were young and Pam did casual evening work, he is invisible in Pam's account. Even now that she earns more than he does, she tells her story as if all the responsibility for making arrangements for Dave are hers. Secondly, different pressures are apparent at different stages in the family life-cycle.

During the pre-school period, Pam has all the usual difficulties of any young Mum with young children, plus the added difficulties arising from Dave's need for constant supervision and behaving badly. She was living in an information vacuum and received no professional help. Nurseries would not take David; friends and family could not manage him, and so he was with her constantly. Nevertheless, because her husband worked days, she was able to work in the evening whilst he looked after the children.

During the school years there were difficulties getting Dave properly assessed and placed in school with appropriate support. It was not until he was 12 that he got some specialist help and began to settle down a little. Nevertheless, apart from family members, Pam received little assistance and no help from services. During this period she began to work in jobs with school hours.

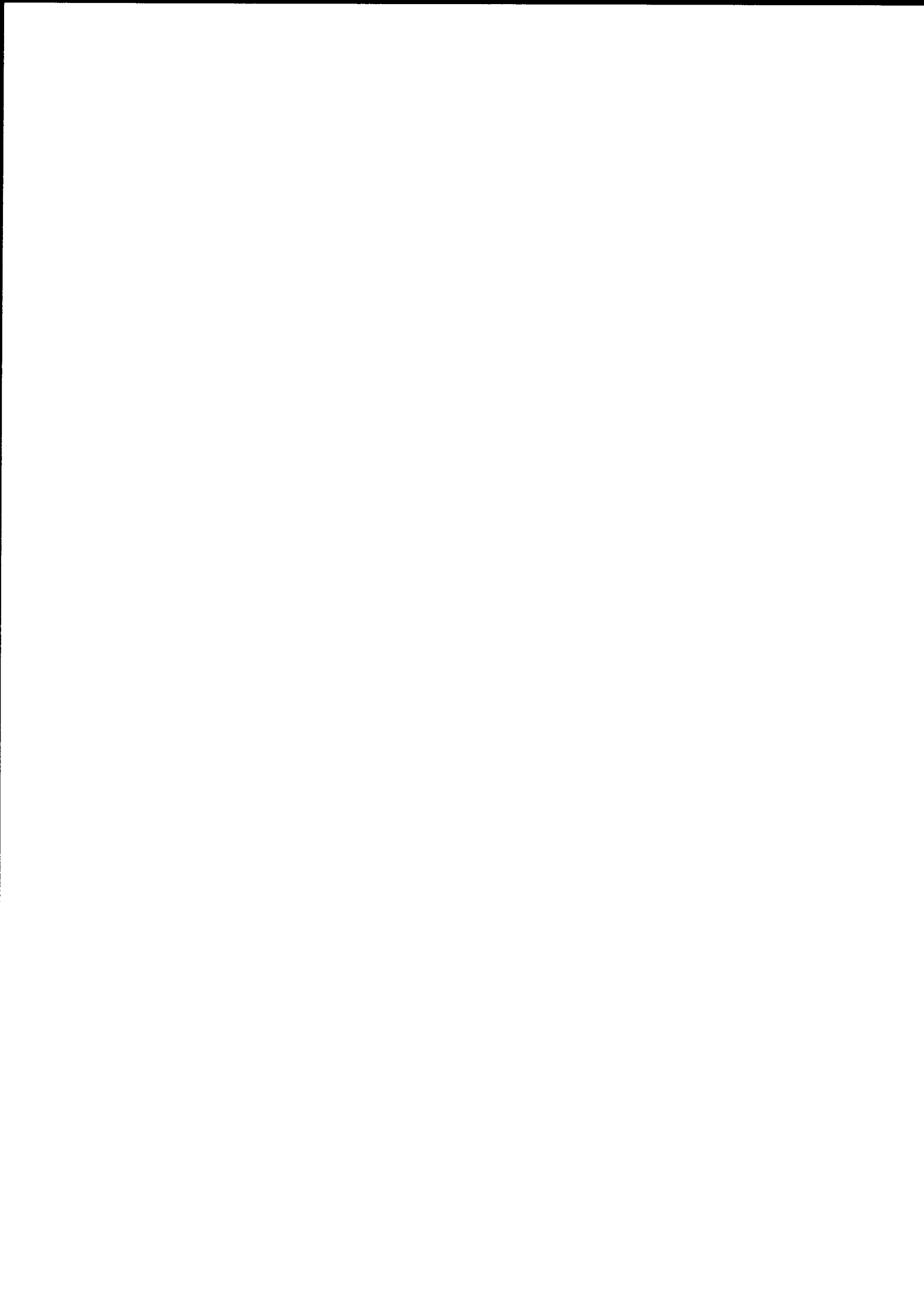
As David finished and left school and went to college, Pam was able to extend her qualifications and experience, but only with the assistance of accommodating workplace managers who enabled her to have time off and for David to come and wait for her in the workplace. It is Dave's continuing need for supervision that perpetuates the difficulties for Pam, working. These difficulties were ameliorated somewhat when Dave began to work full-time and regular hours. For the first time in 22 years Pam could be sure that during day-time working hours, David was adequately supervised. At this time she, too was able to work normal hours.

However, when these arrangements suddenly changed without consultation, Pam's ability to work was jeopardised. Once more she had to call on now older family members to look in on David when he is home alone. Her other young adult children have already left home, but David remains. She did not mention any possibility of him moving out as the others had done. She has also had the additional hassles of negotiating with David's support services adequate supervision and proper communications with her and Bob. David's need for supervision continues.

Throughout, she has struggled on in the absence of formal help and information. It is only now that she herself works in the same care sector, that she is able to secure some additional support services and employment practices like special or emergency leave. She has discovered these by accident.

Throughout David's life he has been prone to accidents and has at times put himself and others in danger. Pam has forgone college education and has taken a long time to develop her own career, beginning with casual work and then combining this with school time only work, before being able to work full-time.

4. The Browns: For whom, as West Indians, combining work with the care of their 21 year old autistic son in Britain has got too much



The Browns: For whom, as West Indians, combining work with the care of their 21 year old autistic son in Britain has got too much.

Introduction

David (52) and Carla (51) Brown have a daughter, Tina who is 25, a son Alex who is 21, and another son, Gerry, 11. Alex has autistic tendencies and at times has behaviour that is difficult to manage. At various times, nurseries, playschemes, schools and day centres have been unable to manage him and he has been sent home. David works from 8.00-3.30 at a tractor firm, and earns about £12,000 a year. Carla has worked as a midwife, from eight to six, five days a week, earning approximately £1500 a month. She has recently been off work, sick, and thinks it unlikely she will work again. David reports feeling depressed. The only extended family in Britain is David's mother who lives 100 miles away: the rest of the family live in the West Indies. Very recently, a behaviour outburst, during which Alex damaged much of the house and hurt people at home resulted in his leaving home to live in a private residential care home. The family had reached a crunch point and could no longer cope. Throughout, ethnic and cultural factors have made their circumstances more difficult.

The nature of work: culture, flexibility and family friendliness

David and Carla's ability to work and care concurrently has now broken down after 21 years. Carla is off work on long term sick leave and Alex's recent outbursts have proved the last straw for David.:

David: sometimes it's not easy, but the problems she is experiencing at work at the moment..she's off sick at the moment...she's got a problem which affects myself and me daughter. Because it doesn't come through like the sun shines through, but you know it's there, it affects us in a way. But we take it in our stride because...-..like you go to work every day and the foreman might be on your back, and you manage to ride whatever happens for the day. But you know at the end of the day - the shift- you're going to come home and you're going to forget it for a couple of hours, but you goes back again. So, it's similar to that. It's there. You manage to ride the storm so to speak, but this situation of Alex coming along.- it's too much to take.
David describes feeling preoccupied at work when Alex is behaving badly.

David:...when (Alex's) mood is coming on...he never goes out of my mind...as it says in the article yesterday ... what depressed is like. They count the numbers non-stop. It's like that for me during the day, because I'm on my own you know, and it's in my mind. I'm thinking about our problem and Alex's problem and I suppose I'm thinking about her Mum who's not well...everything comes to you at once.

Recent events have led him to the point where he feels he can no longer cope:

David:...So, things that wouldn't worry you before...you know it's a problem that you normally think of and think 'Well, some day (we) might be able to address it'. It comes to you with the present one, and the lot becomes too

much for you...I think at the moment I'm a little depressed, but I'm trying to fight it.

David considers the recent changes in services for Alex to have been a positive thing. The inadequacy of supports for Alex in the past has been at considerable personal costs.

David: Everyday you learn. I mean, we paid with Alex's behaviour to get this other experience (services) we're getting now, which we did not get two months ago... And we could have done with it then, you see, because it (his violent outburst) come on so sudden. ...It have a devastating effect on me and my life, you see. And I don't know when I'm going to get back to normal. I'm never one to worry about anything. ...I never worry about anything, and now, because of this, he's in there. I'm worrying all the time. ...So it makes me depressed. If Alex comes here now, he makes me depressed in a sense, because at the back of my mind I'm just thinking 'When is he going to go spare again?', you see. ...I will not replace the glass in the door, ...but it will always be a reminder and you never know he might just come and (do it again).

In some ways, David considers it would have been easier if they had put Alex into care earlier on.

David: ...Some (parents) put them in care very early, and..er.. I think it's less of an impact on you if you do that. But because of, some, most people demonstrate the love and attention, they keep them for longer, like we had. And it's a wrench having to send Alex..but, I mean, if you've got no choice...there are others in a similar situation...there are some (disabled) people of 29, 30, going on 35. (Their parents) are suffering the same thing. They find that they just can't cope. They are getting older, they are not getting younger ... I think the way Alex is at the moment, I think it is best for him to stay in care. We can see him. He's happy even if you don't see him ... He's more relaxed.

Carla, though, is upset that they can no longer care for him at home.

Interviewer: Do you think he's better there, Carla?

Carla: Me?

David: She misses him. She thinks he's better here.

Interviewer: ...You wish he was here?

Carla: (begins to cry)

However, although he thinks it is for the best, David recognises that concerns about Alex will still affect his working life to retirement.

David: I don't see why I should worry (my)self. I am approaching retirement in a decade, so why should I worry myself? I want to ... slowly unwind when I reach this stage where I can retire or take early retirement. I want to relax under my tree. Only problem, my mind feeling all sorts of things you see.

For nineteen of Alex's 21 years, both Carla and David worked full time. They took care not to ask their employers for any particular concessions. This was partly because of their belief that family problems were private affairs, to be solved within the family, partly because they believed they might lose their job if their employers thought they needed special leave, and partly because, despite being able to take occasional leave, this would result in loss of earnings. Carla described the culture of her workplace, and why she would not request any special leave

Carla: You forget about (family responsibilities) once you leave the home...We haven't arranged with them to give any special leave for us, so I mean we just have to figure the problem that you have with your family and work on your own... If you are not too fortunate they are not really accommodating if you've got a problem. If you've got a problem you keep it to yourself... The fact is, if you had a problem, then you don't apply for this job.

Further more, both she and David believed that if personal messages were left for Carla at work, her job would be in jeopardy. There was no way for private messages to be got to her anyway, as any message would be broadcast over the community health service radio. Even if Alex were about to be left alone in their house, they thought Carla should not be contacted.

David:...when the escort bring him home, no-one was here and they couldn't...leave him. It causes problem, you see if they ring her (Carla) ...at work. It upsets her employer.

Interviewer: They didn't pass the message on to you?

Carla: You better not do that, because if they did that they wouldn't employ you.

Interviewer: Really, it's that serious?

Carla: Yes.

Interviewer: Family messages and you'd be in trouble?

Carla: You could do that, but at your costs.

David:...They call on the radio...

Carla: In the area

David: Everybody from here to (the other side of town) knows..

Carla: They want to know all the details

The nature of Carla's work as a midwife, meant that she could not always work regular hours, and it was difficult at times to consider asking for time off. Nevertheless, they still consider the organisation she works for to be uncaring.

Carla: I used to work 8 o'clock while 6 o'clock in the evening...and then that altered to 8 o'clock while 5 o'clock. And there were a rota call where... we were on duty from 8 o'clock evening to 8 o'clock morning.

Interviewer: So, 24 hour on call?

Carla: And sometimes that extend even longer if you've got a mother in labour....but what I'm saying is, that you are not able to get out for such..if anything happened to your family...it was every fortnight you were called.

David: But they don't care whether she has a dependent person at home. They don't care.

David, on the other hand, showed that it was possible for him to get away at short notice. The only snag was that he would lose pay.

David: Well, getting time off there is no problem. If I need to leave, if there's any big problem and they ring me at work...I just go and say 'Can I have a pass out?' and they say 'yes'.

Interviewer: Do you have to make up the time later?

David: No, you don't make up any time, you don't get paid. The only time you get paid is if you have a medical pass out...and you can prove...you have a medical appointment...then you can get paid for it... You can have a week off, but you know, you explain to them why you're having a week off, but as I say, you don't get paid for it...'I'm having a bit of a problem, I have to have a week off', but you don't get paid for it you see.

David is entitled to three days 'lieu time' with pay.

David: well, we got three lieu days which we get paid for...so you can add those days any time you want, any time. You must have it within the year...or you forfeit them...those are the only three days for which you get paid.

As far as they know their employers do not have any provision for family leave. Furthermore their employers have not been in a position to make discretionary leave available, as David and Carla have not told them about Alex. David describes how, whilst his colleagues know he has a disabled child, his supervisors do not.

David: I spoke to my ..er.. personnel officer about it .. we started talking about family, and about my family, and somehow he just crept in. I think he's the only one that knows about it, you see, although the others are telling me, as when they ring me at work, and they said 'It's about your son', I'll explain to them why. ... Many of my colleagues at work ..er.. know about ..er.. me having a disabled child ...so I don't disguise the fact that I have a disabled child, but again, I don't go out and advertise it. ...I've never felt the need to tell the employer.

Despite the perceived inflexibility of their employers, David and Carla have managed to combine work with caring.

What has made it possible to combine work with caring?

Over the years Carla and David have had to find different ways of managing to combine work and family. As their work situations changed their solutions had to change. As Alex moved through different stages and thereby services, they had to devise different ways of balancing their conflicting demands.

Services-work 'fit'

In the early years, Carla was at home and David worked night shifts. Although there were nurseries Alex could go to, he did not settle and they could not manage his behaviour, so he was at home most of the time.

David: She (Carla) spent- what is it? - two years I think with him before she went out to work...During that time I was still on nights..er..and we tried to get him into...day nursery. But he didn't like it...we had to take him back home, so I had him during the day with me...eventually we got him into another day nursery. Again, he didn't like it, he didn't settle in properly. Eventually he settled down and I'd take him down in the mornings and..er..collect him in the evenings, because she couldn't do it because of her work....He settled down all right 'til eventually (they sent him to the learning disability school).

Holidays became a problem when Alex went to school. A local playscheme could not manage his behaviour. Sometimes, David was able to book holidays when the schools were closed. However, schools were often unable to publish the holiday dates in time for him to book his holidays.

David: I used to do (work) the September (workplace) holidays. Request it, you know, because the children, the kids, er, no school holidays at that time of the year. They normally falls in October...(and) there is no-one whilst she's at work....So somebody needs to be off then, so I used to request to work the September holidays... when they (the factory) close down for September...but the last time, I missed out on that...I put the request in from January and they said I should have made the request in October. So I says the schools cannot tell me in October of this year...when they are going to have the holiday in October of next year...You've got to wait until the education authority issue it... So (work) just said I'm too late.

By the time Alex went to school, finding after-school care was difficult. When David worked night shifts, he was at home when Alex returned from school. When David was transferred to day shifts, they had to rely on Alex's elder sister, or paid workers. All of these arrangements collapsed at various times because of Alex's behaviour.

Interviewer: So how did you manage to look after Alex when you were working?

David: Well, during the day Alex was at school. He used to go to school. But, er..I used to work nights, as I say, for a long time. So when I started days..when the bus brought him home..Tina used to be here...We used to pay people just to collect him...(such as) the escort of the bus ...for an hour while we get home. But, er..again, his behaviour, you know...So in the end we could not see anyone because no-one want to help us with him...so we just give him a key...he was about thirteen fourteen...

After Alex left school, he attended a day centre. Initially this was for three days a week. As David worked five days a week and Carla worked a pattern that gave her one week day off a fortnight, this created particular difficulties arranging care and

supervision for Alex. Carla did manage to drop in during the day, but this was not officially sanctioned. For a while neighbours helped out, but they could not manage Alex's behaviour.

David: ...This came about with him being left alone for those two days, because at first the centre...would only take him for three days...and it went up to three and a half days...we used to ask (neighbours) ...to care for him. But he hit out at a small child...they didn't want to know again, so we said OK. ..I'm only allowed three days off. I couldn't have every Friday off, they wont entertain it...She's (Carla) off once a fortnight..so...I said to her 'we have no choice, just to see how you're working round the locality, you can steal a little time'. And because they're allowed to work from home, so she was working at home...I would say she was stealing time, but she could pop in and have a look at him and then go back out. And you know, if he needs something..then she can say 'OK, here!' and then out again...

Once Alex received a five day placement, David and Carla had to fight to retain it, and to ensure it was available irrespective of Alex's behaviour.

David: There used to be several meetings and we had to put that issue to them, that he's got no care for those..er.. one and half to two days. So, that's when they found this other place...And they wanted to reduce it to four days, but we put our foot down and eventually we got five days....When he started misbehaving again, they had a hurried meeting and they want him out, er,, but, er, we says 'we're at work so what are you going to do? so, eventually they say 'OK he can come'.

Carla: When I was working, we had to leave him one or two days and we had to leave things for him to eat...In actual fact, we came back and it was still there.

Formal support

For many years, Carla and David requested some regular, short respite care, but this was not available. The only respite care they were able to get was block short term care enabling the rest of the family to go on holiday.

David: (When our needs were much greater) we asked them (for some respite). They said they couldn't help us. Like, you know, there's a problem coming home from school and couldn't they keep him for an hour on the way home?...

Interviewer: That would have made life a lot easier for you?

David: They could, if we'd wanted to go away on holiday, they could care for Alex, so we said we'd never leave him...but that's all they could offer, holidays respite. But offering us respite for just an hour in the evenings you know...no.

For a short time they had a night of respite care a month, but once again Alex was excluded from this because of his behaviour.

Interviewer: You told me you had some respite care..

Carla: ..very minute amount of respite...he spent about one night of a month, but for about 6 months. No longer than six months...

David: He used to do one night, and then eventually sometime they increase it to two nights, but...when he misbehaved it was discontinued.

Informal support

Although Carla and David tried hard to balance household and caring activities, they were able to draw on a very small extended family network.

Interviewer: How do you manage to organise your time, to make it possible for you to go to work?

Carla: Well, it's a combination of the pattern of my children and myself

I; So, it's family?

Carla: Family

David: ... We share the things in Alex's life. Like, I do a lot of the caring and she do the, like, the other kids. She do, like, you know, sort of things for the school, which school they go to. She sort out things like that...you know, social work. She has more (knowledge).

Although Carla and David have managed, on the whole, to juggle their time and work and family roles, this has been made harder by a number of factors. The fact that most of their extended family was still in the West Indies, made it more difficult for them, and means that they have had to rely on paid support.

Interviewer: Have you got any sort of wider family support?

Carla: No, in this country I've got one auntie but she does not respond at all.

Interviewer: have you got any friends who help?

David:...They used to help but not any more...Close friends have never helped, we have to ask strangers and the strangers we ask is people that come and they get paid to do the work...we have to give them a lot of praise because without them we don't know, especially when Alex used to go to school, and during the school holidays...He smacks them you know. Of course, we had to give some sort of remuneration you know...until it becomes impossible for them to care for Alex. Other than that, there is nobody..there's no other...we're just here on our own really.

It is this isolation, along with the absence of an extended family, that Carla considers to have been the most difficult thing over the last 20 years.

Carla: Your isolation is the worst part, and the other one is the extended family network...To me the network to me is supportive, because in the West Indian community, if our child has abnormalities, it's not institutionalised. You see, that person is cared for by society, by the extended family...when I say extended family, it doesn't mean your blood ties, it means all the other people that comes to your family as well. So, in a matter of fact you see, we miss that, because we haven't got that extended network.

Cultural factors

Deeply ingrained in the West Indian values of family values, then, are notions of caring for and supporting disabled family members within the family. It is this belief that will have contributed to Carla's resistance to and sadness about Alex going into care. However, these values, imported to Britain, have had a further isolating consequence. Not only is the extended family absent, but Carla believes the size of the West Indian community means that solidarity and communality are difficult to achieve, leading them to be culturally as well as physically isolated.

Interviewer: Do you think being from an ethnic minority has made your life more difficult?

Carla: A hundred times harder, a hundred times harder.

Interviewer: In what way?

Carla: Because you haven't got any kind of ..er.. comradeship with people... We're foreigners abroad. And people see us wanting to succeed in all aspects and if you fail by half even, if you fail this kind of a circle by having an abnormal child, then they actually shy away from you...

David: ...The disability is like a criminal offence...

Carla: ...Isolation. You're isolated... I think we remain isolated because (in Britain) it's not accepted for a child to be abnormal...

Interviewer: So you think it's to do with Alex's disability, rather than to do with your racial group or culture?

Carla: Well, I think racial as well. I think because there's not enough of us who have handicapped children to rely on each other. ...I was speaking to a friend of mine who had a child with a bit of abnormality.. when I recently thought I would go up to her house and see her because her child... as been put into a flat being cared for by social workers... she told me about somebody else autistic, like Alex is. And I went to see this person..

David: Well, I know the father of this young lady. I know him for over 20 years (but didn't know his daughter was autistic).

Carla: And he didn't know (about Alex) himself did he?

David: ...That's why I say the disability is ... a criminal offence.

Carla and David's situation is exacerbated by cultural factors. Carla, too, is dissatisfied by the extent to which the services take proper account of Alex's cultural background and needs. Whilst she and David disagree about the extent to which Alex would notice and respond to cultural aspects of everyday life, Carla is certain that it is important. She illustrated her concerns with reference to the food that Alex is now getting in residential care.

Carla: Well, I would say...that culture needs are not met...In actual fact ... to cater for a minority you've got to go deeper than actually singing a few songs or something like that...I couldn't expect them really to cater for ...specially prepared meals and ..er.. things that the parents would usually do...They haven't made any attempt as far as I'm concerned...she (the home manager) tries her best...she doesn't know how to do certain things, but at least she is willing to learn.

Interviewer: Does she ask you?

Carla: She does more than ask...she gets me to show....When I was preparing some meals (For Alex's birthday) I actually..er.. showed her what I did and so forth.

David:...Alex, when he is at home, here, like, our cuisine he have...although it's not a divine thing for us, we have a mixture...so Alex is used to that sort of thing...If he doesn't like something he will not have it...if he doesn't want it, he will tell you

Interviewer: But it is nice if he can have some of his home type cooking as well?

David: Yeah. And when he came last week he quite enjoyed the meal that we prepared for him, but ...we can't tell them how to run the show.

Carla:...What I'm saying is, if you're going to look after a group of people minority, I think you need a caterer to actually prepare things...you can't expect an English person with no knowledge...I think they've not really addressed the problem. I think the part of the (food) is very very important. I think some people tend to overlook it, that it isn't important...it's part of who you are...people say 'what is culture?' Well, I say culture means a lot to me. He's lost a lot already. Without your culture you're nobody, that is how I feel. And I can make sure that the situation is much happier, by actually mixing both cultures together for everyone.

If the services do not adequately meet Alex's cultural needs, it will remain hard for Carla to accept what they have to offer in terms of appropriate care.

Financial aspects

Throughout Alex's life, Carla and David have had to pay for extra support. This is partly, as we have seen, because they do not have extended family supports available to them, but is also partly because the services provided for Alex do not coincide with work hours. It is also partly linked to the ways in which the services actually operate. Transport to and from school was paid for. However, once Alex left school, Carla and David had to pay for his transport, and at time his escort's transport costs.

Carla: (Day services were) very costly because we had to pay for the transportation.

David: They wouldn't provide the transport.

Carla: When he went to the Centre, they wouldn't pay.

David: ...When he finished with school he went to the (day) project. ..They provide an escort, but the escorts weren't allowed to use a vehicle because they (social services) wouldn't pay a mileage charge. So, whatever the weather they had to walk, collect Alex, walk back to the centre with Alex. They had to do that twice a day....whatever the weather, rain, hail, snow, they had to walk. So he stayed there for about three or four months. Again, the same thing. They sent him to another place...we had to provide the transport...so we manage to get someone I know...we agreed on a fee of £6.50 a day...at first we had the black taxis and it could have been anything between £8 and £10 a day. It wasn't a set fee...you couldn't pay them on a weekly basis....When he moved to complex needs (another day project) we continue to pay..that was £65 a fortnight, so that was a lot...when he had that emergency care (his transport to the day project)...we had to pay £50... in two days.

To assist with these costs, Alex is in receipt of personal allowances, including a mobility component, of £140. Although he is entitled to this, it has been a struggle for Carla and David to discover his rights and entitlements. Although he has had assessments from early on, the professionals involved have not always given them the necessary information. Indeed, Carla even questions whether the most appropriate professionals have been the ones undertaking the assessments.

Carla: It isn't straightforward, you've got to fight for everything...nothing is given...

David: When he was much younger the doctor used to have to come here and assess him all the time...now before you can fill these forms in as well, you have to get a doctor, your GP...

Carla: ...as far as I'm concerned ...they shouldn't have assessed the family..as a matter of fact (The GP) have very little to do with the child...they will need specialists to assess his..whatever Alex gets from the welfare rights aspect.

Interviewer: That's the person who helps you the most?

Carla: Yes, I went to the welfare rights group and they actually asked him to get his mobility allowance..they regularly write us..

Interviewer: You need to know somebody who knows their way round the system don't you?

Carla: No-one knows the way round the system. But doctor didn't know there was entitlement to...

David: It's like everything else, you don't know what you're entitled to...

It is not only about financial matters that David and Carla believe they have had insufficient information. Carla is a nurse, and this has helped in some ways. However, they have found it difficult to find out about his condition and about possible ways of managing his behaviour. This has contributed to their disappointment now they find they can no longer care for him at home.

Carla: ...(being a nurse has helped me) knowing where to go. I think it has given me more skills. ...(but) ... if I was more prepared to cope with him I think if the health professionals actually knew how to treat him more, you would be more ready for it. And I think I miss him a lot because you weren't -prepared enough for what was to come, what was going to happen eventually.

Interviewer: You don't think anybody gave you enough information earlier enough on?

David: There was this Autistic Society when he used to go to school, and they used to send us leaflets I think once a month. I used to attend some meetings, but, er, again, the information that you were looking for wasn't there... They used to talk about building places for adults to go to, and at that time I (was not interested). ..I was a bit annoyed the doctor give him that (autistic) label ...at a very early age, but at these meetings this is what they talk about. They talk about the things..parents should or could expect (of) people like Alex with his sort of problem...eventually I discontinued...If at that early stage I was receiving the information which more or less I get now, because of what happened, then I would have been more enlightened...But, that information, may be the people there at the time, maybe they didn't know themselves.

What was the easiest time?

When asked about the time they found easiest to combine work with family, David and Carla both agreed it was whilst he was at school. They talked of how the regular hours Alex was in good care at school enabled them to work with an easy mind. This was the easiest time even though the after school hours were difficult to organise, and Alex still needed supervision even as a teenager.

David: When he was older it was easier. ..It was much easier when he was older, because, you know, the bus would come for him in the morning and take him away... You're not here during the day with him, he's with somebody else...it's only when he comes home, then you have to look after him again.

Carla: But Alex was not such as needed looking after, you know, like he came home and you had to wash him, feed him...he would just..a child need guiding

David: He need any special attention

Interviewer: You needed to keep an eye on him?

Carla: That's right.

David: It's just that he gets up to a lot of tricks, you've got to keep your eyes on him, like, now he's older

On the other hand, when asked about the most difficult times, Carla and David agreed it was when the care provided was irregular, part time or uncertain. When Alex began to attend different day centres and projects, he was unsettled. He regularly absconded from taxis and became lost. His behaviour was difficult to manage and he was excluded from three different day activity services. Whenever he was excluded because professionals could not manage him, it was expected that he stay at home. His working parents were expected to be able to manage him when the professionals could not.

Carla and David both agree that the post school years are particularly difficult, and lament the absence of what they consider to be clear plans for school leavers. This could be either in the way of service provision, or, if parents are expected to finish work and look after their young adult children, by way of financial compensation.

Carla: This could have been helped by the social services having more preparation for the children. ...not children, but you know, teenagers or young adults. They haven't actually prepared or cared for the handicapped kid...what I'm saying, whatever will they do with these young people, and these adults?...(there is) nowhere for them, I mean, unless parents are prepared to be there 24 hours a day...

David: ...Even if you are prepared to give your job up and stay at home and care for them...you are not offered the sort of...er...compensation to look after them, because what they give you is just minimal

Until the recent crises which precipitated the provision of residential care and specialist day activities, Carla and David consider the support they received as a family to be virtually non-existent. The onus was always on them to request help, but if they believe their family difficulties are their burden to bear alone, this will be difficult for them to do.

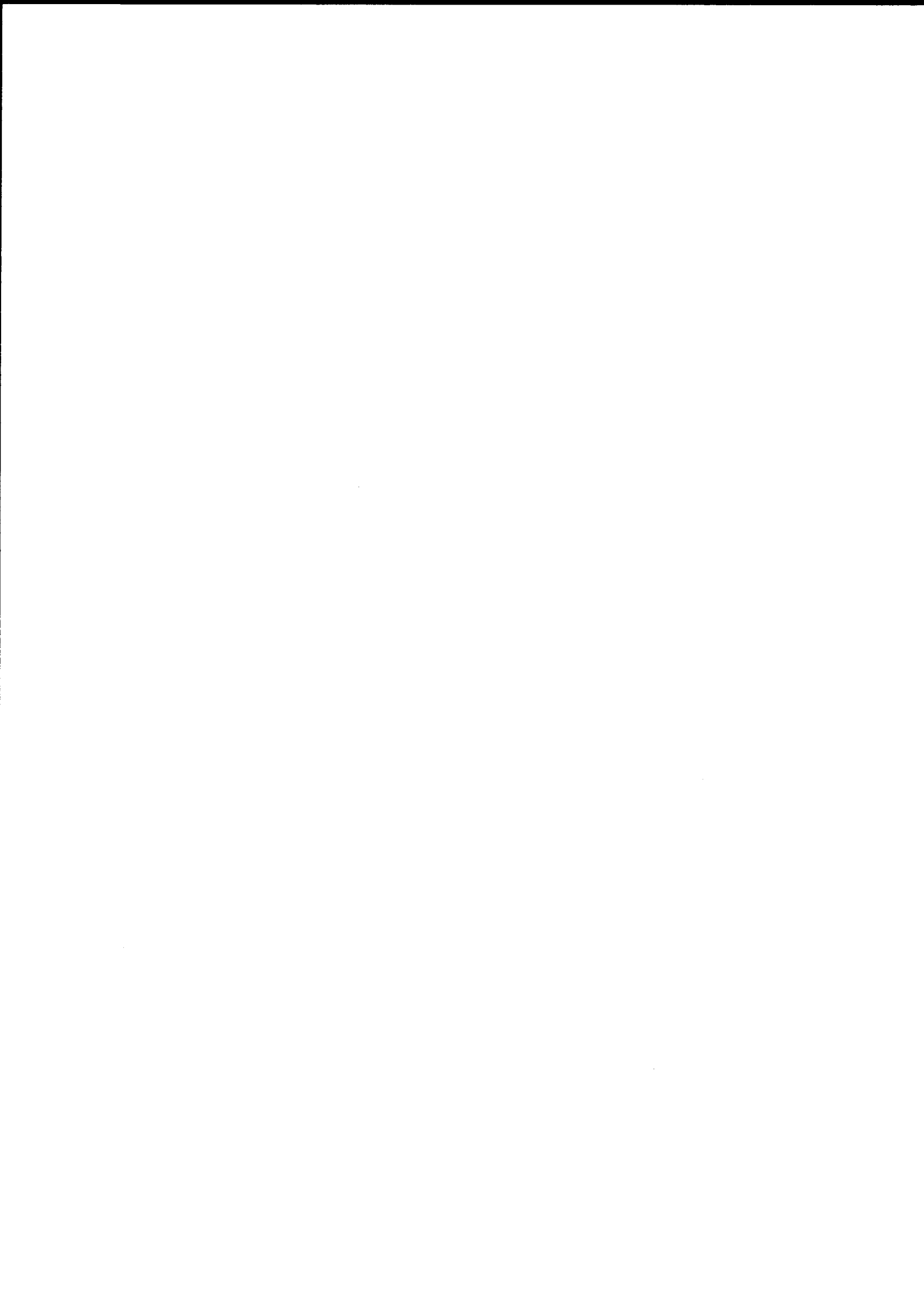
David: Another thing is .. you don't see the social workers. I don't know if they normally go to school and centres and see..Alex maybe...Alex had a social worker back in the day centre who used to come here, said 'Yes, that's fine'. He's the only one that ever come to the house and occasionally sit down and talk. But once he left, if you want a social worker you have to request them to come..I said to them that at least, you know, even once a fortnight, they should come. I know that they basically have a lot on their plate, it's a wide area for them to cover. But they can come once a fortnight or make it even once every four months or every six months and say 'OK, I've got this client, let me go and see how..er..the relatives are coping now, talk with them, see what we can do'. But unless you make a request for a visit...

Their situation can, perhaps be summed up, sadly, by a comment Carla made towards the end of the interview:

Carla:...In actual fact, you see, we got lost in the pile somewhere because we coped too well.

The price they paid of coping too well was ending up not coping at all.

5. The Baldwin Family: For whom managing the economic support and the care of a large family including a school aged disabled child is a challenge



THE BALDWIN FAMILY: MANAGING THE CARE AND ECONOMIC SUPPORT OF A LARGE FAMILY INCLUDING A PHYSICALLY DISABLED SCHOOL AGED CHILD.

Ann and David have five children: 11 year old Peter, Danielle (10), Sarah (7), Richard (5) and 18 month old Jenny. Their middle daughter, Sarah, has short bowel syndrome, an unpredictable physical illness requiring frequent medical attention. She cannot absorb enough nutrients during the day, so has to be have gastro-nasal feeding overnight.

Ann used to work as a staff nurse. She has gradually had to cut down her hours since Sarah was born and now does just one six hour session of basic nursing at weekends, although not on a regular basis, earning approximately £1000 a year. David earns £13000 a year working a 40 hour week as an administrator for a local authority. They receive invalid care allowance and mobility allowance at the highest rates.

The need to work.

Ann and David cope by adopting a traditional gendered division of responsibilities.

Ann: David works, full stop. That's his priority is putting food on the table, and I see to the family. Its the only way we can do it, which is why I work at weekends.

They attribute this strategy to their feeling that it is important to have one secure income, and belief that Ann's nursing skills enable her to give Sarah the best care. David has been made redundant before, and they feel that in the present economic climate it would be too risky for him to jeopardise his job by asking for any flexibility. So, his role is primarily that of breadwinner, with little involvement in Sarah's day to day care.

Nevertheless, Ann's income, however minimal, is essential for the family upkeep. As well as the usual costs of supporting five children, there are many additional expenses

associated with Sarah's disability, such as travel costs for frequent visits to the hospital which is 30 miles from their home. If she earns more than £50 a week however, Ann loses the invalid care allowance for that week and given the demands of Sarah's illness and of her medical appointments and frequent hospitalization, she does not feel she can risk losing this. So, she works just enough to top up the family income without jeopardising regular benefits.

Ann feels that her job provides the flexibility she needs to care for Sarah. However, the price of this flexibility is that her work is unsteady and insecure.

Ann: Very often there's just not work available. I only work banks, so if there's no work available, there's no choice. There's just no work and that's it.

Lack of opportunities for Ann to work more, not only creates financial hardship but also affects Ann's quality of life. Her work is important to her as a form of respite and a source of identity.

Ann: After 7 years, I feel as if it's my turn, you know, after 7 years I want to know that I can still achieve something in life, you know on a personal basis, and with David's high wages we could really do with the money.

Ann: I work and call it my sanity time....Uhm, it would make so much difference to think that I am not just the mother of a family of 5 children and one a sick child, I am actually a person in my own right, that has got some qualifications, that I can use, and I've got something to give, to prove that I can do something really.

Combining care and economic support is particularly complex in a large family. Ann and David both worry about the impact on the other four children of the financial hardship associated with the loss of Ann's earnings and the lack of time that they can spend with them.

What makes it difficult for both parents to work?

It is difficult for Ann to take a regular job because she has to be free to take Sarah to frequent hospital visits, often at short notice and to be with Sarah when she is in hospital. She also sets up and monitors Sarah's gastro-nasal feeding every night. Both parents believe that only Ann has the necessary skills to do this . so that rules out the possibility of her working night shifts.

Ann does not expect David to develop the confidence to care for Sarah during the nights, excusing him and accepting that he is fearful.

Ann: I know everything that matters you know whereas David is still a bit unsure really. Even after seven years he gets a bit nervous over it.

The family construct David as less able to care for Sarah, which reinforces the pressure on Ann to be continually available for her daughter. This is picked up by Sarah who is only confident with her mother setting up the nightly feeding equipment.

Despite the family's need for her income, and the fact that she only works when David is at home Ann sees her work as something for her, secondary to her caring role.

Ann: If Sarah's ill I'm not prepared to go. Sarah comes first. I've always looked after all her care and my husband, although he's very good, is still very nervous over a lot of things with Sarah.

Nevertheless she also feels that she has wasted her training and regrets that she has no opportunities for developing a career. She recognises that she has developed considerable expertise in caring for Sarah but feels that is not valued by employers. Neither does she foresee a time when she will be able to do more work.

Sarah's care needs and the perception that only Ann, as an experienced nurse can provide

this care also makes it difficult to find substitute care in whom they have confidence. The childcare needs of the other children and the lack of after school provision add to the complexity of the situation. Childcare would be expensive. Ann would need to work many more hours to be able to afford this.

David is reluctant to ask for flexibility at work to share the family demands. He does not know whether there are any specific policies for employees with caring responsibilities. Rather, he relies on what both parents describe as the good will of his line manager when he does need some flexibility.

Ann: I think it's the individual manager and I think his manager has been very good to let him have the time off really.... It's just him being very nice, implementing things himself.

They do not expect David's employer to be supportive and are very grateful for any support they feel they do receive.

Ann: David can't just suddenly get up and go from work. They are good with him, I think he came out early to collect them from me mum's but it's hard, it really is hard.

Ann is aware nevertheless that things could be better.

Ann: They have been good with him, in the fact that sometimes, they know if he comes in late there's usually been a reason for it, but like when she's been in (hospital) for long spells, it's not a case of ; David, you could do with a fortnight off while you see to these children, and you do the role as mother..It's a case of David, like has to drop them off at a neighbour, and collect them from them, so they are not that flexible.

At a time of great need formal procedures had to be adhered to:

Ann: when she was born and we were in a dreadful state of shock) -David had to have urm to have any time off, he ended up having to get a sick note from the doctor, and to have acute anxiety put on it, to get to have some time off you know.

David tends to use his holiday time to deal with emergencies. This means that he does not get any actual holiday which reduces even further the time that the family can spend together.

Interviewer: So you can't actually plan to take time off for a holiday in case you need those days?

Ann: What is a holiday? The children are all missing out of this free time that you are supposed to spend as a family. I mean because I work weekends, we don't even get weekends together, because that's the only way we can work.

Ann also has low expectations of finding flexible work in the present climate, and is reluctant to apply for jobs where she would have to ask for flexibility.

Ann: I suppose with jobs as they are, they are always going to take somebody that's going to have a ... family that's healthy.

David: In fact you were going to apply for a job last year didn't you and you decided against it because... you would have to tell them that you had a disabled child and you would have to have time off... so she said it was just not worth it.

Ann: I've not applied for quite a few jobs that I could have really contributed a lot to.

Inflexible services contribute to the family's difficulties. They often have to attend out patient hospital appointments in different departments several times a week, often at short notice. There is no attempt to integrate timing of appointments.

Ann Its not just on a regular basis when you can say Sarah's appointments will

be in two weeks time.... you can go on day and end up going back the next three days for something they've arranged, so you just don't know.

It even took several months of arguing before Sarah was allowed to collect Sarah's medical supplies while attending hospital appointments, rather than on a different, designated day.

Sarah often has to stay in hospital for several weeks at a time, often being admitted as an emergency. Difficulties can be exacerbated by misunderstandings and communication difficulties. Anne described one occasion, for example, when she took Sarah for what they thought was an out-patient visit to receive some new medication, and found that Sarah was expected to stay in for two weeks.

It is very difficult for Ann and David to find out what support services are available. It was not until Sarah was four years old that Ann learned that they had been entitled to an incontinence laundry service. This would have made life much easier, as Sarah's bedding often had to be changed several times a night. They wonder if the information was deliberately withheld to save costs.

David: You asked them why we hadn't been told before, and they said well, they unofficially told us, they are not allowed to (tell us).

Ann: They are not allowed to tell you, unless you know about it, so nobody comes out and says to you, this is available....So you have got to know, and unless somebody tells you how are you supposed to know?

Schools are sometimes inflexible too. Sarah's older sister Danielle's birthday was two days after the intake date for starting school. The education authority gave their permission for her to be admitted early, on the basis of reports from social workers and doctors, but the head teacher blocked this. Danielle was eventually able to begin school six weeks later, but this created additional difficulties for the family. The local authority

policy was flexible but the practice in this school was rigid.

So, the inflexibility of services, and of David's employer, together with the family's own belief that Ann should be constantly available to care for Sarah, make it difficult for Ann to work and contribute to considerable financial hardship for the family.

What makes it possible for both parents to work?

Family, friends and neighbours help out to ensure that David rarely has to take time off work if Ann is at the hospital with Sarah, but this involves very complex arrangements. Ann's mother who lives 20 miles away and has no car, collects the children from the home of a friend in the next town and take them back to her home, from where David collects them after work. Sometimes a friend of Ann's drops off and collects the children from their three different schools or bus drop off points, and in an emergency a friend meets the children from the school bus and takes them to her house until one of parents can get home.

Some of the hospital staff have been supportive on occasions. For example, they have allowed the younger children to 'live in' with their mother during long hospital stays. In an emergency the liaison nurse has delivered or posted medical supplies, although she has been in trouble for doing this. The hospital do not have the regular delivery services that are available in some other areas. re

What else would help?

At the moment Ann cannot earn more than £50 a week because she is anxious about losing the invalid care allowance and is not confident that she can replace this by regular income in her circumstances. A higher earnings threshold, and a system which would give her confidence that the allowance would be reinstated as soon as she lost income, would give her an opportunity to work more. However, if she were to increase her working hours she would also need access to affordable childcare and after school

£5.00

