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The Context of Work and Caring for Parents of Disabled Children

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Introduction

The discipline boundaries of organisational studies can no longer be separately defined (Editorial, 1994). Similarly, realisation that the world of work, and work organisations, can no longer be separated from other spheres of life is reflected in the growing interest in managing diversity in the workplace (Loden and Rosener, 1991) and in socially responsible business practice (Reder, 1995). However, even though organization theory now includes the environments of organizations, Friedlander (1994) argues that inadequate attention has been paid to the institutions and activities of which organizations' employees are a part. He suggests that

organization theory has turned its back on the person's home life. Yet home and home life is the major institution and major set of people supporting its employees. Perhaps of even greater impact, one's home life is the major competitor with the organization for the person's energy, time and devotion.....work and home life may be in conflict, but in our culture both are essential for a full life. In this sense we must optimise both, Yet, more often than not, we tend to optimize work and let our home life limp along as best it can. (p.61, 62)

Friedlander points out that the schism in our thinking about organization as separate from other institutions of which workers are a part,

allows organizational practitioners to ignore the repercussions of the organization. And it allows organization theorists to ignore the mutual interactions between the world of the organization and the world of the workers' personal lives (p.64)

Nowhere is this schism more apparent than in the lives of working parents of disabled children.

Medical advances, together with a public policy emphasis on community, home based care for disabled children, increase the numbers of children being cared for in their family homes (Parker and Lawton, 1994). At the same time the growth in the numbers of lone parents and the economic need for two incomes in two parent families, means that a growing number of parents caring for disabled children are also in employment. Even so, fewer parents of disabled children are in employment compared to parents of children without impairments, and work has proved particularly difficult for lone parents and for mothers (Bennett and Abrahams, 1994; SSI, 1994). Lack of opportunity to work can result in extreme personal and financial hardship (Glendenning, 1992), as well as exposing parents to increased risk of stress and even depression. Employment can offer some protection against these outcomes, providing some satisfaction and a break from caring, thus having a positive impact on family well being (Kagan and Lewis, 1993).

The demands and the rewards of a dual earner lifestyle are well documented (e.g. Hertz, 1986; Schwartzberg and Dytell, 1996). However the work has looked exclusively at the experiences of parents with children with no impairments. The care

of disabled children, whilst having its own satisfactions, is more demanding and generally extends beyond the early years, often into adulthood (Beresford, 1994).

This paper highlights the context of work for the hidden population of working parents of disabled children. We will draw on the accounts of parents from five families with different experiences of the inter-connections between work, family arrangements and community services, with particular reference to flexibility. We will argue that flexibility in domestic arrangements, childcare, working life, employers attitudes, health and social services, education and voluntary work is necessary if parents are to be able to combine working with care of disabled children, and if employers are to retain and benefit from the experiences of the parents as employees.

The Study

The parents' accounts are taken from a larger qualitative study of 42 households, within which parents work and care for children with impairments, which was, itself part of a larger study of developing organisational audit frameworks with reference to the employment of parents of disabled children¹. Participants were recruited via the Family Fund data base, and through voluntary organisations. In-depth, semi-structured interviews were carried out with families caring for children between 6 months and 29 years old, with a range of physical, intellectual and sensory impairments. 32 households were dual earner families, and the rest were lone parents. An initial meeting was held with participants, prior to the interviews, in order to build rapport. Family interviews (mother, father and sometimes children), and some separate interviews (mother and/or father) were carried out. The interviews covered work-family decisions making, strategies adopted within the family, formal and informal supports, and workplace practices and policies. Interviews were taped, transcribed and analysed thematically.

The Families

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

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's 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.

The Phillips: for whom a self-employed lone mother has minimal support and has to struggle to get support from formal services

Sharon is a divorced lone mother with three teenage daughters: Lisa (17) who has left home, Helen (15) who has epilepsy which is difficult to stabilise and Jenny (13).

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 business was very successful. It provided an income to support her three daughters and the flexibility to provide the care the 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 (lower rate mobility) and family credit. 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 Browns: For whom, as West Indians, combining work with the care of their 21 year old autistic son in Britain has got too much.

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. 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.

The Jones, for whom the patterns of shifts and part time work enable them to combine work and care

Dot (44) is a part time District Nurse, working 3 days a week, and being paid approximately £12,000 a year. Mark (44) is a fireman, paid £18,000 a year and working two day time and two night shifts a week. They have a son, Trevor (8) who has a below the knee amputation of one leg. Because of this, Trevor needs more help than most 8 year olds would need. Between them, Dot and Mark manage to be available for Trevor as their working days rarely coincide. Both employers have formal policies regarding special leave and this has been used by Dot and by Mark. Neither parent envisages any particular difficulty getting emergency leave as required. Working locally means that Dot can provide additional assistance to Trevor in he lunch times if necessary.

The Evans, for whom decisions about how and where to work mean that they are able to meet the predictable and unpredictable care needs of the children

Ann (39) is a self-employed pharmacist doing mostly locum work, term times only, and earning £15000 a year. Maurice (41) is a maintenance engineer in a local chicken factory, working 50 hrs a week and earning £15,000 a year. They look after their daughter, Helen (12) and son, Gary (10) who has muscular dystrophy. Gary's condition is worsening and he has little mobility in his body except for fine motor movements in his hands and head movements. Both children go to school locally, and a friend does childminding as needed. Maurice is available at weekends, and Ann

organises her work so that she has the school holidays free, although this means she works long five and a half days or six days a week during term time. They have moved house several times and now live near the schools in a bungalow that is big enough to take Gary's wheelchair. After some difficult negotiations, Gary is in mainstream school.

The Accounts

Flexible working hours

With two parents in the household, the dovetailing of working hours can enable them to cope. Dot and Mark work their shifts so that there is always someone to care for Trevor.

Mark: (my shift pattern) assists Dot with her work pattern and it means that I work 2 days and then 2 nights, I am away when Dot is here. I am back the following morning so at times like school holidays etc. it works very well.

Interviewer: Would there be any possibility of adjusting your shift?

Mark: Yes, if it became really necessary, I could go on to regular days in some capacity or another, whether it be the training department... They are quite sympathetic. The fire Brigade is very good that way.

Interviewer: What if it was just a one-off?

Mark: No problem. I think there's a system for taking short leave before, and what we do is I ask for it and they agree that it's necessary, they would allow me to go and I would have to pay it back with my days off. Yeas, they would be very sympathetic towards that.

It helps that both Dot and Mark know their shift patterns well in advance

Dot: I usually work three days a week. Normally it's Monday, Wednesday and Friday, half eight to five, but occasionally I do a weekend and then I have my days off in the week. It works out about one weekend in six...I think my days remain very much the same. There is another part-timer that works the other days, we do it between us. It's not a job share as such. Mark, he works shifts. He does two days, two nights. His days are nine 'til six, and his nights are six 'til nine, so they're quite long shifts. Mind you, they go to bed on nights.

Interviewer: Do you know your shift patterns well in advance?

Mark: Oh I know my shift pattern from now 'til virtually I retire.

Interviewer: So, planning's not a problem?

Mark: No.

Ann and Maurice have arranged their working hours so that one of them is available over school holidays and at weekends.

Ann: Maurice works about 50 hours a week as a fitter. He works a 13 hour day on a Monday; Tuesday he works 6 'til 6; Thursday he goes in at 5am and finished about 3 pm, so he's back for the kids, and Fridays the same. He used to work Saturdays but they have dropped the Saturday overtime, which means I can now go in Saturdays without having a childminder....I work, the hours

vary. ...Most of the time I work five and a half days weeks, sometimes 6, but that's during term time. It peters out a bit in the winter...I'm lucky really being self-employed, inasmuch as I don't have to work school holidays, but I'm unlucky in that I don't get paid if I don't work.

Flexible decisions are made

Many of the parents had actively made decisions about how they were to work and what hours, once they realised the additional caring needs that would be required. Maurice changed his job, took a drop in pay and longer hours for the convenience of working locally.

Maurice: I went to the chicken factory 12 years ago as a temporary thing just to find something else and, like I say, I've been there 12 years. The hours are long and the money's not great, but it just seems to fit in quite well with what we do. Like I say, it's only 5 minutes down the road...It's very convenient. It would probably cost me £3000 or £4000 a year to run a car. We only have one car, and that saves....It saves a lot of money, so although I probably earn say \$14000 a year

Interviewer: It's worth more than that to you?

Maurice: Yes it is. Plus the fact that I get away early Thursdays and Fridays, I don't work Saturdays and Sundays.

Ann, on the other hand, decided, after several years of trying to manage in a full time job, as an employee of a large company, that the only way to get the flexibility she required, was to change her work and become self-employed.

Interviewer: Was your decision to become self-employed, was that part of your decision?

Ann: Yeah, that was a big part of the decision, but it was forced on me really because I couldn't find a job that would be term time only when I wanted it...there was nobody that would do that. So I thought if I went self-employed and the terms were mine, not theirs, up to a point and it works like that. I do Saturday in the summer and things, just to keep the wolf from the door.

Interviewer: You can't be flexible with your hours apart from the days you have?

Ann: No I have to do the hours they want. It's either I work the hours they want or I don't work. There's not usually any option to that. They want a full day or they don't want a full day...If I've contracted to work for somebody for a week, I've got to work for them for a week. I mean, I've got one or two regulars who are flexible. If I rang them up and said, 'Look, I've got...(whatever)...do you want me to do the Wednesday or do you want me to swap to another week altogether?' then they will do that, but ..When it's a big company..they do tend to ..want you to be there.

Sharon, who has always been self-employed, cannot envisage having the flexibility she needs in any other form of employment.

Sharon: I can't work for anyone 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.

It was different for Dot, who negotiated part-time hours when she returned from work after maternity leave.

Dot: When he was very small I went back to work. I had the maximum amount of maternity leave and he would have been, what, five, six months old by the time I went back to work. I'd previously worked full time until I had him. Then I went back part time. I negotiated that with my manager at the time, and I used to work two and a half days. I paid to a private day nursery which opened at eight in the morning and closed at six at night, so it was very convenient. I dropped him off on the way to work and picked him up on the way home.

Jenny, too, has changed her working hours as Alex has got older.

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...

Inflexible workplaces

When work places are inflexible, greater pressure is put on parents. Carla considers her employers to have the attitude that once at work, family problems are forgotten.

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

A similar difficulty was experienced by Sharon, who felt that she could not telephone Mike at work too often.

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 having personal phone calls.

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. In contrast to Maurice, though, if he left work for whatever reason, 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.

Flexibility through working and living locally

Living locally, helps some parents combine work with caring, and the time taken to get too and from work, as well as being able to leave work at lunch time, becomes a vital part of their arrangements. Dot describes how she is able to prevent Trevor's condition worsening at times.

Dot: ..Last summer though, in the hot weather, his stump sock gets saturated. It gets wringing wet and I was going up to school every day in my dinner hour

to change his stump sock....If I didn't go and do that he ended up with, like, a sweat rash, and then he can't wear his leg. So I find it easier to go to school every day...It would have been nice if I could have got somebody at school to do it for me, but I didn't ask..it seemed the easiest way and I know that I would do it right, and I worked very near. I only worked down the road...and we lived down the road...It was easier to give up half an hour of my lunchtime, whether I'm working or not, to go and do it myself and know that he would be OK, than risk him trying to go to school in his wheelchair....I If I moved out of the vicinity of working round here I don't think I could (go into school like that)

Maurice, too has given Gary assistance during work hours, aided by local people who know where he works.

Ann: I mean, he's nipped out. Gary got halfway to school one morning and his tyre came off, and somebody that was passing knew where his Dad worked and rang him on his mobile phone and his Dad came out, fetched his manual wheelchair and sorted him out. He was probably gone from work for half an hour...Maurice can walk to work from here and the kids are at school here.

Maurice, suggests that his employers are understanding and let him leave if a problem comes up. It helps that he never needs long away from work, because it is so local to home and schools.

Maurice: ..because I work so long hours they are pretty good or very good at letting me go. I mean there was a problem last week with Gary at school. He'd dirtied his trousers and pants so I was able to come home. I mean, work's only five minutes away, it's only in the next village so I was able to come home, get some clean clothes for him and then take them to school. I shouldn't think most people would be able to do that, but I was allowed to do it....I think they realise at work that I'm there for a long time, and you can't ..get normal things done..so you know, they're pretty good on letting you go off work.

Interviewer: Do they pay you for that hour?

Maurice: Yeah, Yeah they pay me. They're pretty good...It's the foreman at work lets me go, you see. We are a small department, there's only five of us and the others cover while you are away, you see.

Ann: Maurice is lucky really, he's only in the next village, he's only a mile away. In an emergency he would leave. He says 'If they sack me, they sack me'...but ..in an emergency, he would leave.

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.

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 won't 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...

These are all informal working arrangements, either sanctioned or not. Some employers have formal, compassionate or 'special' leave that can be used on occasion.

Flexible Leave arrangements

Flexibility over leave, especially in an emergency, can be helpful. Maurice can leave work at short notice, if necessary, and usually gets paid if he is away for short periods of time

Interviewer: And what about your husband, does he have any flexible working?

Ann: Not really, although they are quite good...It's 'oh, I don't think we can really spare you', but most of the time mean, he's nipped out. Gary got halfway to school one morning and his tyre came off, and somebody that was passing knew where his Dad worked and rang him on his mobile phone and his Dad came out, fetched his manual wheelchair and sorted him out. He was probably gone from work for half an hour...Next week we've got an educational review meeting (they have one every term) his Dad will have to go to that one.

Interviewer: Will they give him time off work?

Ann: Yeah, but they might not pay him for it. It depends what mood his foreman's in as to whether he makes him clock off and clock on again...or whether they just cover for him.

Ann, however, is more restricted. Once she has said which days she is working, there is little flexibility.

Ann: Maurice says, in an emergency..he says 'I would have walked out of work'....There's nothing I can do (except) ring round - I could probably find somebody, but it would take at least an hour for somebody to get there. If it is the middle of the summer, no change, because everyone is busy, everyone takes holidays.

Sharon, running her own business, in contrast to contracting to work for someone else, found things were easiest when she had assistance at work.

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.

Now this has gone, things are more difficult.

Sharon: Three years ago I had two offices and nine full-time staff, and two subcontractors that I kept in work every day on 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...now that I've made her redundant it's very difficult...if Helen's ill I've got to try and find somebody, anybody that will actually come and stay here with us.

She suggests a vicious circle in which business slack leads to lack of help, which means she is sometimes taken away from work which leads to further loss of business.

Sharon: I wonder how much business I lost by not being there,...(sometimes) 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?'

When Trevor was to go onto hospital for a major operation, Dot arranged compassionate leave.

Dot: I decided there was no way he was going into hospital without me there every moment you know, and I negotiated very easily to get some time off and I was given it. Compassionate leave, and I had some holiday and some time owing, so all in all it was OK

Mark, too took compassionate leave at the same time. He pointed out that this was a formal policy, about which everyone knew, and that there was no difficulty asking for it.

Interviewer: Do you know if they have any policy whereby if there is an emergency, additional emergency leave, not taking your annual leave?

Mark: What they would call it is compassionate leave, so I would ask for compassionate leave for whatever the situation was, and they would more than definitely grant it.

Interviewer: Would it be a problem, asking for compassionate leave?

Mark: It would be a problem in the sense that...it would mean we would be one short on that particular appliance, but generally speaking they would waive the rules on that.

Interviewer: Is that a problem for you? Does that put a brake on it?

Mark: It wouldn't be a problem for me because I'd be allowed to go, but it would mean...they would be riding at one below strength. If it was a suitable emergency or a problem that wouldn't affect me going, they would just send me, they would just say 'go' and they would sort that out after I had gone.

Mark:...I've taken compassionate days. When (Trevor) had the operation to have his foot off I was given compassionate leave then. They were very sympathetic towards me.

Interviewer: Did you feel it was OK to ask for leave?

Mark: Oh yes, absolutely, yes.

Interviewer: So they are flexible?

Mark: Oh, indeed, yes...It's Service policy

Jenny did not have to ask for special leave, it was offered to her.

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 take 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.

Sometimes, lieu time can contribute to days of when needed, although to qualify for lieu time, parents will have had to have worked overtime in the first place. 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.

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'.

Flexibility for holidays

Once children get to school age, holidays can present a particular problem as school holidays rarely coincide with working holidays, as illustrated by Dot

Dot: I get about 7 weeks holiday a year and school's closed for 12, so there are five weeks....We probably manage better than most because of our particular jobs, it's more flexible. If it comes to the point he's on days and so am I, it's usually me who ends up saying 'Oh well, I'll have a holiday then'. Although I must admit he has got better over the last couple of years or so...He will say 'Well, they owe me some hours so I'll tell them I'm having the day off'.

She and Mark are lucky their working hours enable them to manage school holidays with Trevor, but Dot notes that there may be a danger that they would never have any time together as a family if they did not make particular arrangements.

Dot: In holiday times how do we manage? Well, it's not too bad because with Mark's shifts, between us we do it. Very rare do we have days when there's no-one to have him, although I try to book holidays so he's not always just with Dad, and I don't get any time with him. Because none of us would have any time together...If Mark did a 9 to 5 job, we would struggle.

Alex's behaviour made it even more difficult for Carla and David, as local playschemes could not manage him. 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, within the schedule required by work.

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.

Flexibility in the voluntary sector

The need for flexibility extends beyond employers and workplaces, to voluntary activities in the community. Ann was a school governor, but had to give up as meetings were changed at the last minute.

Ann: I was a school governor for a while but they kept shifting the dates of meetings at a week's notice. We would set the next meeting, the next term's meeting a term in advance and I work it out in advance, and I would say to people 'I can't do that day or I can do the morning but I can't do the afternoon because I've got a meeting at 4 o'clock' (because they persisted in having the meetings at 4 o'clock because that's when the teachers are still there). It doesn't seem to figure that if they want working parents to be school governors, or anything, that really they've got to fit in outside people's normal working hours by which I don't mean teacher's normal working hours....I had to resign because twice I'd booked a day off work. I'd given up £100 work to go to a Governors' meeting and they said 'Oh, we can't get to this one, so and so from the Education Department has got a prior appointment, we'll have to have it next week instead. That'll be all right, we've rung round and three of the Governors have said OK'. 'I'm sorry I can't come' 'Well, we've checked with everybody' 'No, You didn't check with me' 'Well, we knew you wouldn't be able to come t short notice, so we didn't ask you'. We didn't ask

you, because we knew you'd say 'no' and that would make it more complicated, so we didn't ask you!

Flexibility at home

Flexible childcare and home help arrangements will often make it possible for parents to work. When her business was doing well, Sharon employed a 'nanny', who helped out with Helen when she was ill, or general household tasks at other times.

Sharon: I used to go to work and the nanny was someone who was known to us, and she's known Helen from being a baby, so she knew how to cope with her illness. If Helen was fine and well at school, she'd just do my ironing and clean up and cook the tea..I'd just go to work and be what usually the man gets. y tea would be cooked, it'd be ready and could sit down and eat my meal.

Sharon considers that the ability to be able to pay someone, made it easier to ask for help at home.

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 pay for it, that's the difference...I didn't feel I was begging people for charity, so that made me feel better about myself.

The unpredictable nature of Helen's illness, made it difficult for Sharon to arrange any formal help once she could no longer afford a nanny.

Sharon: I just need someone to help me for half an hour, that's all..if you go into people like the Social Services, I don't need somebody every day 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 them in advance like home helps...you don't know from one moment to the next.

Carla and David did try to get some formal help with Alex.

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.

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, and Alex is now in residential care and Carla is off work on long term sickness absence.

Less formally, Jenny and Dennis relied on help from their parents to enable them to work.

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.

This help extended to the holidays.

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.

Most of Carla and David's extended family was still in the West Indies, which 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.

Ann and Maurice had childcare arrangements that were unsatisfactory for a number of years. They moved home on more than one occasion in order to secure better care arrangements. Eventually they found a good, flexible childminder, and this has made a great difference to them.

Ann: I've had a really good childminder since Gary was 7. She's flexible, she'll not see him for 3 weeks and then she'll have him for four days in one week, and things like that.

Interviewer: She's prepared to tailor her hours around yours?

Ann: Yeah...She's not actually registered. She's just a friend.

Unusually, her childminder also helped out when the children were ill.

Ann: (one time when one of the children was ill) she rang and she said 'if you can't get away it doesn't matter. She's asleep on the settee, and I'll just keep an eye on her. I'll give you a ring if I really think you ought to come'. But childminders are not obliged to take sick children. It's only because this is, like, a private, personal arrangement. You have to be nice to people in the hope that they'll be nice to you in return, but it does help.

Flexibility in the Health Service

Children with impairments often have special health requirements. For most of the parents, flexibility in health service approach made things easier, but inflexibility made things harder. Dot managed to arrange most of Trevor's health appointments when she was not working.

Dot: I always made his hospital appointments on the days I didn't work and I suppose like most Mums I sort of do my housework when I'm not at work, and go shopping and all the rest. You just cram everything into your days don't you? And that was how I managed when he was small.

Even though Ann is able to do the same, she illustrated how this does not always work out in practice.

Ann: Gary had an operation last August on his back, a planned operation..which we were told was going to be the beginning of July. So, I'm self-employed. I took 9 weeks off that summer..so that I was in hospital with him for 2 weeks and he's got a month's post operative...About the month we were supposed to be going in, we got a letter..'Your son will be going in in September'. And I'm thinking, that day was the day I went back to work after taking this 9 weeks off. And I rang them up and said 'You can't do this to

me'...(they said) 'Well, there's nothing we can do'. (eventually) we went in in August. It still meant Gary went back to school three weeks after a major operation.

She has found, over the years, that individual health workers will try and be flexible, especially in arranging appointments, even if this is not always easy.

Ann: We talk a lot to each other's answer machines, me and the OT. We leave messages. She'll leave a message, 'I've got appointments available in this, this this and this, ring me back', and I'll ring back and say 'Actually none of them are good but the week after I can do this, this and this'. She'll ring back and go 'Yes, we'll have that Wednesday' It goes backwards and forwards.

Similarly, Jenny has found that if she insists, appointments can be changed. Equally, working part time means that it is possible to change her working hours to fit in clinic appointments 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.

Flexibility at school

Once children get to school age, the problems of balancing school hours with working hours become acute. If schools are flexible, this helps. Dot was lucky to have found an after school club in a local nursery that would take Trevor.

Dot: (our working arrangements) worked fine until he went to school, because school doesn't accommodate anybody does it? The hours, you know, the children are at school, they're not the hours that everybody works...(I knew of an after school club in a nursery)...they said 'oh yes, of course Trevor can come'. It was such a relief because I didn't know what I was going to do with him when he was at school, and I was at work. I'd worked out all these ideas about working my hours differently to do shorter hours over 4 days or 5 days, but I didn't really want to because I like to have days off you know. I did try it for a while as well. It was horrendous. It's like working full-time.

Things became difficult when this after school club closed. Like many parents of disabled children who find services lacking, Dot was active in developing an after school club linked to the school itself, which gave her extra duties and responsibilities.

Dot: ..(the after school club) closed down, because there wasn't enough finances to keep it going...so it was suggested that the parents whose children used the after school facilities should set up an after school club at school...So we did. It's a nightmare some days. I'm the Treasurer of it...it was half a dozen parents, we set up the whole thing..you name it, we did it....I've still survived. A few more grey hairs..So Trevor goes to that after school, which is wonderful actually because it's actually at the school, there's no

transferring...It's great for the kids because it's part of the school but it was horrendous to set up because it took up an awful lot of people's time.

Ann has experienced schools being really helpful and accommodating when Gary was recovering from an operation.

Ann: Schools were both very good. We sent some bedding to school and he used to have a snooze after dinner every day.....They had a corner of the hall where they used to put the dining tables away with a curtain across and they used to put the tables in there with this mattress on it and lay him in there, draw the curtains...They weren't obliged to, but they've been very good at primary school.

However, she finds that even the timing of parents' evenings assume that parents are available out of working hours. Schools have not adjusted to the living and working patterns of parents.

Ann: I can't get to a lot of parents evenings because they hold them between 4 and 6.

Interviewer: Most people can't get to them at that time.

Ann: Ah, but you are supposed to be the normal standard family, you know, the one that represents 95% you know, two parents, two kids, they think.

Interviewer: Mummy at home

Ann: Mummy at home, yes. Oh, she does a little work in a charity shop, a couple of hours a week...I mean, this village here, I bet there's no more, I mean we're probably just about as normal as you get and we both work.

Conclusion

The extracts from the accounts presented above demonstrate the importance of flexibility in enabling working parents of disabled children to manage their lives effectively. It is not only flexibility in the workplace that is important, but flexibility at home, in the health services, at school, in relation to leave entitlement, holidays, and childcare. Those families that can draw on support from family and friends are able to make more flexible arrangements than those who cannot; those families who have employers with flexible policies and flexible attitudes about work-family commitments are able to manage better; those families that are able to combine flexible childcare arrangements with work are able to manage better; those families who live or work locally are able to be more flexible about the contributions they are able to make to the care of their children, especially in emergencies. Yet, all of these different arenas of life are interconnected. For example, if working hours were different, school hours would not present such a problem; if childcare were more available in different forms, different decisions about working hours might be made; if work cultures were different, parents would not have to feel they were being underhand in snatching time to look in on their child, alone at home.

At the moment, all the arrangements are contrived by parents (usually mothers, although not exclusively). They decide what best hours to work, where best to work, what best work to do, how to provide what childcare. It is they that lose income, time to spend with their other children, lunch times, holiday entitlement, full participation in the life of the schools or community, career development, health and so on. Of course, they also gain from work and from caring for their children, but does this have to be at

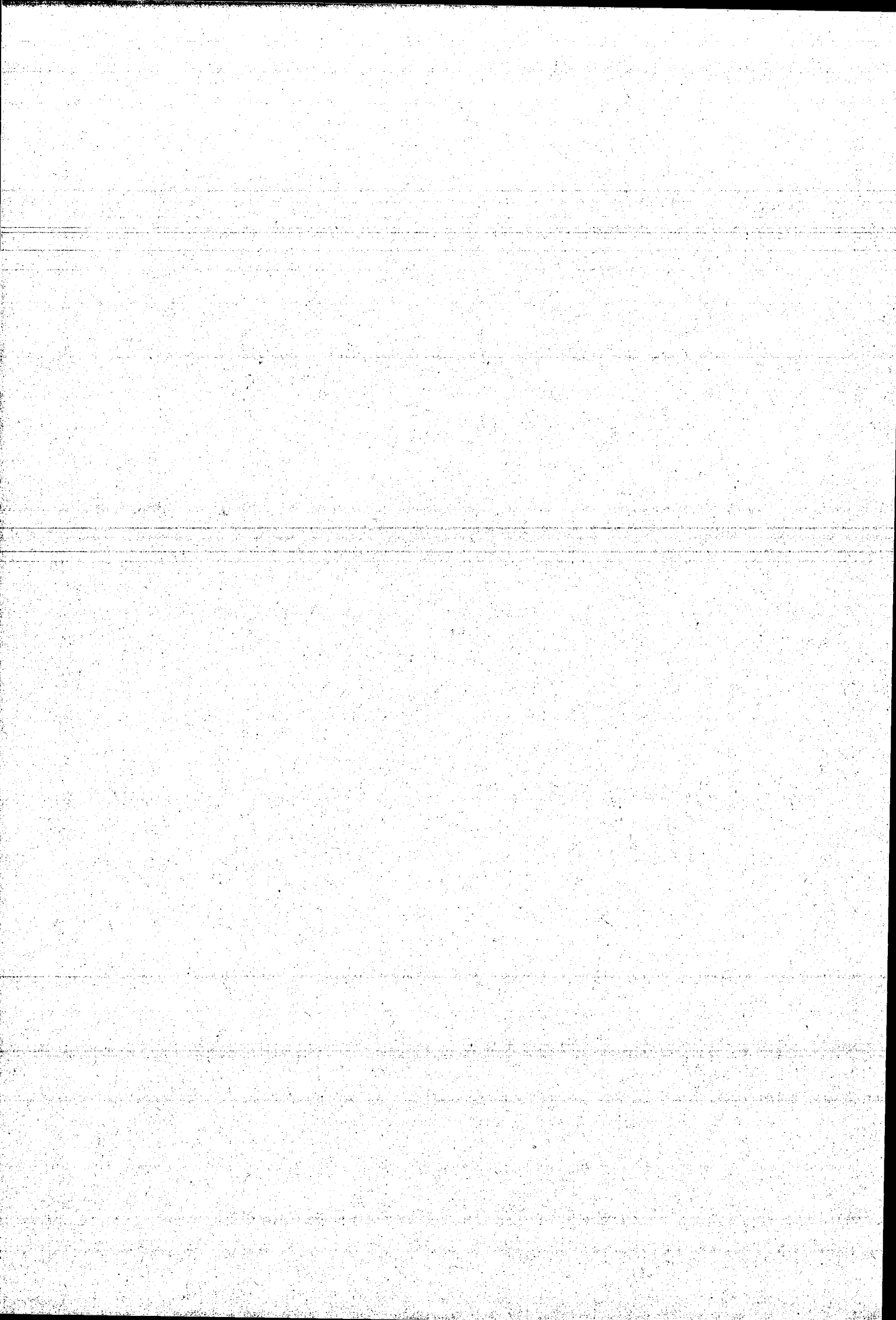
such personal cost? From what these families tell us, employers do nothing special or out of the ordinary. What little concessions they make, in terms of informal time off, permitting personal calls in the workplace or formal conditions of employment, parents are grateful for and consider themselves lucky. Health services seldom do anything special - it is remarkable when a health worker is flexible in making appointment, for example. Social services seem not to be able to accommodate the changing and often unpredictable care needs of these families, and schools have not adapted to the changing patterns of living of many parents. None of these institutions can be separated from the others, they all have a mutual influence, and it is time for them to open dialogue, with parents to all become more socially responsible. Employers, with their interest innovation and change, are perhaps best placed to begin such a process. Ben Cohen (of Ben and Jerry's) summed up the role of social responsibility in business thus:

Businesses have created most of our social and environmental problems. If business were instead trying to solve these problems, they would be solved in short order (Cohen, 1993)

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