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Dual Earner Parents with Disabled Children: Pressures, Needs and Supports

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PRESSURES, NEEDS AND SUPPORTS**

Suzan Lewis, Carolyn Kagan and Patricia Heaton.
Manchester Metropolitan University

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Introduction

The demands and rewards of the dual earner lifestyle, especially for families with young children are well documented. (eg Hertz, 1986; Lewis and Cooper, 1987;1988; Sekaran, 1986; Schwartzberg and Dytell, 1996), as are the strategies adopted by dual earners to manage their occupational and family demands(Hall and Hall,1980; Wiersma, 1994). However, the diversity among dual earner families has received less attention. In particular, the dual earner family literature is based on the experiences of parents with children without impairments. The care of disabled children is more demanding, although it also brings its own rewards (Beresford, 1994). Furthermore the demands are not restricted to the early childhood period but often continue into adulthood. This paper examines some work family experiences of dual earner parents with disabled children. Drawing on parents' accounts, it highlights the determinants and outcomes of different strategies that they adopt in order to manage to generate a family income and care for their children.

Medical advances, together with a public policy emphasis on community, home based care for disabled children, increase the demands for informal family care (Levick, 1992; Parker and Lawton,1994). At the same time the growth in the numbers of single 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. However, fewer parents of children with disabilities than without are in employment, and work has proved particularly difficult for single parents and for women (Bennett and Abrahams, 1994; Smyth and Robus, 1989; 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 symptoms such as depression. Employment can offer some protection against these outcomes, providing satisfaction and respite, and can therefore have a positive impact on family well being (Kagan and Lewis, 1993; Neal et al, 1993). However, the employment of both parents of disabled children involves a challenge to traditional assumptions about work and about family, and a rethinking of the supports available.

Dual earner families and social change

Early research on dual earner, and especially dual career families suggested that they were in the vanguard of social change (Rapoport and Rapoport, 1971). It was argued that traditional norms governing work and family roles would be challenged as dual earner partners negotiated new forms of roles and relationships within the family and new practices and structures within the workplace. In reality the pace of change has been slow, despite the steady growth in the number of the dual earner family which is now the norm for two parent families. There has been some shift in gender roles and responsibilities within some families (Gilbert and Dancer, 1992;) although women frequently retain the major responsibility for family care (Hochschild, 1989). Similarly, some organisations are

recognising the need to adapt policies and practices to meet the needs of a growing numbers of employees with family commitments (Hogg and Harker, 1992). However, the male model of work which constructs the ideal employee as one who works continuously and full time from education to retirement, without accommodating work for family (Peck, 1977; Cook, 1992) remains the norm (Lewis and Taylor, 1996).

Within this context, dual earner families adopt a range of different strategies for combining work and family care (Hall and Hall, 1980). These vary according to financial need, gender ideology, supports available and work-family priorities. Parents whose children are disabled face additional constraints. What supports are available for dual earner families are directed towards parents with children who do not have special needs. Indeed, dual earner families with disabled children are largely invisible to policy makers. For example, a recent consultation document on child care strategies to support the combining of work and family, published by the Department for Education and Employment, mentions diverse groups, such as rural and ethnic minority families, but make no mention of families with children with special needs.(DfEE, 1996). It is assumed that these mothers do not seek employment.

The transition to parenthood is a crucial phase in determining future roles and relationships, for all couples. Gender roles and relationships established tend to be challenged by this transition, which is often accompanied by a shift towards more

traditional arrangements even among previously egalitarian couples (LaRossa and LaRossa, 1991). The transition can be easier to manage for couples who have planned and negotiated the distribution of labour within the family as well as employer expectations, prior to the birth, especially if this planning is associated with a high level of "multiple role realism" (Weitzman, 1992), that is an awareness of what the demands are likely to be. Even the most realistic couples however, are rarely fully prepared for the reality of the demands of caring for a new infant. Parents of disabled children face additional difficulties which are rarely anticipated. Plans generally have to be radically revised as parents attempt to renegotiate social and workplace arrangements based on an assumption of healthy children, or of mothers who do not work outside the home.

This paper draws on a qualitative study of parents of disabled children to examine the strategies adopted by parents to combine employment with the care of disabled children at various life stages, the determinants of different strategies, and their consequences for families.

THE STUDY

Participants for this study were recruited via the Family Fund data base and voluntary organisations. In depth semi structured interviews were carried out with 40 families with children between 6 months and years 29 of age, with a range of physical, intellectual and sensory impairments, in which both parents (or the single parent) were employed. Thirty two of these were dual

earner families. Family interviews (mothers, fathers and in some cases children) and some separate interviews with mothers and fathers were carried out. Following an initial meeting to establish rapport with families, the main interviews covered work- family decision making and strategies adopted, the experience of formal and informal support from extended family, the workplace and community, and gaps in supports and barriers to coping and to quality of life. Interviews were taped and transcribed and thematically analyzed.

FINDINGS AND DISCUSSION

The need to work

Most of the mothers in this study, like the fathers, reported that employment was a financial necessity. Whilst all families were in receipt of some benefits, these did not adequately replace lost income. However, employment also fulfils other functions. Most mothers reported important psychological benefits to being employed, including a break from constant caring, companionship, and the opportunity for self-fulfilment.

I don't come out with a great deal, no no I don't, but yes it saves my sanity.

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 five children and one a sick child, I am actually a person in my own right, that has got qualifications that I can use, and I've got something to give, to prove that I can do

something really.

I think, you know the friendship at work...was important to me and actually getting out of the day to day situation

There are therefore clear economic and psychological needs for both parents to sustain employment in these as in other families. The decision for both parents to work, and the possible sharing of the caring role which might accompany this, is however constrained by both ideological and structural factors.

Ideological Context

Dominant socio-political ideology in Britain constructs family as an individual rather than a collective responsibility (Dally, 1996). Within families prevailing gender ideology constructs women as the major care givers . The debate about whether mothers of young children should work outside the home has a long history (see Tizard, 1991), but maternal employment is increasingly accepted as the norm for parents of healthy children. Views about the acceptability of maternal employment have tended to shift according to national need for their labour force participation. Women have been described as a reserve army of workers, to be mobilised at times of need, such as during wartime or more recently, to compensate for skills shortages . Dally (1996) has also described a reserve army of nurses; working women who can be mobilised to care for sick, disabled or elderly relatives in their homes. The lack of supports for mothers of disabled children to work and expectations that they will become

full time carers illustrates this process.

Gender ideology which constructs women as carers, who both care about, and care, for family members creates the conditions in which "a view that holds women to be caring to the point of self sacrifice is propagated at all levels of thought and action" (Dally, 1996, p21) However committed women have been to their paid work, and however great the need for their financial contribution to family income, the birth of a disabled or sick child who is more dependent than most, and who is likely to remain so all their lives, is expected to signal the end of their labour force participation. This view is internalised, to different degrees, by women themselves as well as by men (Dally, 1996).

The assumption that mothers of disabled children should not work is conveyed to parents both explicitly and also implicitly through the practices of numerous institutions within the community. At an explicit level, mothers of disabled children report comments from health professionals and others, such as this comment from a Family doctor:

when I told him (GP) I had plans for going back to work he said "you can't go back to work. If it was my wife she wouldn't be going back to work. You can't do that, you can't look after a handicapped child and go to work".

The mothers themselves, also believe, explicitly, that caring is their responsibility, and that they should not be working. The implicit assumption that mothers of disabled children should not work is pervasive. It frequently goes unchallenged by parents and underpins the policies and practices of schools, hospitals and health professionals, transport systems as well as workplaces. Where supports are available which would help parents to manage the dual earner lifestyle, information is often difficult to come by. This all makes it difficult for parents in these families to both work and care.

Within this context parents work out arrangements to manage work and care, weighing up the specific constraints of their situations and the supports available. Their accounts indicate that their decision making is purposeful, and they constantly respond to new circumstances with new adaptations. They construct their decisions as choices. Four types of dual earner families emerged in this study: modified single earner families; one and a half earners; full time dual earners; and flexible dual earners. Each type is characterised by slightly different determinants, and has different outcomes for the families. There is some fluidity between these patterns, with families moving between categories across the life cycle. Below, we discuss the characteristics, determinants and outcomes of each pattern. The supports available and constraints operating on the families are discussed elsewhere (Kagan, Lewis and Heaton, 1997).

1. Modified single earner families

Six of the 32 families could be described as modified single earner families. Here, one parent (the father) works full time without any flexibility and the other (the mother) fits in a minimum amount of work around the child's needs and the father's non working time. This pattern emphasizes the father's provider role and constructs the mother as carer, first and foremost. A nurse doing casual work at weekends explains;

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 only work at weekends.

One of the fathers describes a similar pattern.

I work full time. My wife helps out at a residential home, but just recently I've been doing a lot of overtime so Amy hasn't been able to do many hours at all. She's been going in just the odd Sunday.

Determinants

This is a deliberate strategy adopted by some of the parents to ensure one secure income plus one person available for care. It is a response to a combination of ideological, social and economic factors.

In terms of gender, this is the most traditional arrangement. It is underpinned by an ideology of caring within the family, of women's responsibility for family care and men's provider

role. Mothers' responsibilities become particularly clear when her child is ill:

If L's ill I'm not prepared to go (to work). L 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 L.... My place when L is ill is with L.

Because caring tends to be constructed as mothers' primary responsibility, however, the psychological benefits of working were often constructed as something for women themselves, while the economic benefits to the family were underplayed.

The ideology of motherhood is strong among the women in this group. The mother quoted below has a strong sense of what she ought to be doing, relayed explicitly by her own mother.

Its like my mum says, you need the time really to be with him if he's ill or if they (school) are going on outings and they want you to be there.

Despite saying that they would, ideally, like to work more hours if that were possible, the women in this group are clear that there is an important element of choice in their decision.

I chose to, you know, not to work..I wanted to be the one that took her to the hospital appointments and to find out as much about this as I could.....I mean I know things like

the hospital would be very accommodating but I decided I wanted to do it so I gave up (full time job).

This pattern is reinforced by the myth of male incompetence (Blain, 1994) which constructs men as being less able to provide the necessary care, and excuses them from acquiring what are perceived as the necessary skills.

So if she's not right I stay at home, because I know everything that matters, whereas Pete is still a bit unsure really, even after 7 years, he gets a bit nervous over it.

I mean all the time when he has been out of work and if I've nipped out and he's had to look after her he's said I could not do it. He couldn't do anything like role reversal and I know he couldn't. He hasn't got the temperament at all.

This approach involves a gendered notion of family commitments and responsibilities; manifested by job commitment for men and commitment to caring by women.

Once he's working for a company he's very loyal to them and he does work very hard so er I moan at him when he's not home at the normal time when I needed him, but you've got to understand. If you want the job and you're enjoying it, you do the hours. I used to work a full night sometimes when I was in computing, *but that's before I had any commitments.*

Economic factors

It is clear from the parents' accounts, however, that this decision is not just a function of gender roles, but also a response to economic and structural constraints. Many men said they would like to be more involved in child care but are, for example, unable to ask for flexibility at work, or concerned about job security. Most of the fathers in this group have experienced redundancy in the past. In these circumstances employees are generally reluctant to ask for flexibility (Lewis and Cooper, 1996), and more so when in this situation.

Perceived difficulties with other arrangements

Some couples resort to the modified single earner pattern after trying to sustain other arrangements and finding them impossible to manage. Others have very low expectations of finding jobs with the required flexibility, or sense of their entitlement to flexibility with their current employers.

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

Father: 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 have a disabled child and you would have to have time off... so she said it was just not worth it.

Even a mother who is working for her own parents does not expect them to offer her more work.

Oh no I couldn't expect..Like my Mum and Dad are at retiring age and I think its time they were enjoying their life now. They need somebody (to do the work) and I feel guilty having all this time off.

Outcomes

Positive

Even a minimal amount of work can provide mothers with some "sanity time". This pattern also enabled mothers to care, which they view positively.

I've enjoyed being with Sally and seeing her you know. I wouldn't mind doing some part time work ..

Negative

Although potentially satisfying to be able to care for children, constant caring, can also be very stressful.

Mother: I just broke down. I didn't know what to do. I'd had enough. I said to my mum I know my husband's got to work but I've got him 6 days a week. I ain't got one break from him.

Interviewer: It gets to you.

Mother: It does.

Interviewer: Does going to work help you?

Mother: It does.

This pattern can create considerable hardship for families.

At the moment we could do with (extra income). ...we got into a difficult financial situation and every bit helps, but it would be too difficult to find (childminder)..

The mothers are trying to fit their work around their children's unpredictable needs and their partner's working hours. They are often doing casual work. This is, in itself, insecure and unpredictable, making it difficult to plan, and excluding the women from realising employment rights:

Very often there's just not work available. I only work (nursing) banks, so if there's no work available, there's no choice and that's it.

I've only ever had a temporary contract, and that doesn't give you any rights to anything as far as I can see.

Although mothers adopting this pattern tend to construct it as a choice, they also express regret for opportunities lost.

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.

2. One and a half earner families

The majority of the families were one and a half earner families. Here one parent (the father) works full time and the other (the mother) works flexibly. This flexible work may be part time, job

sharing, term time only or working at home, and is usually combined with also undertaking most of the day to day caring. This is the most common pattern for all parents of young children in Britain. However it continues well beyond infancy with disabled children. Mothers adapt their work in keeping with the needs of the disabled child and changes in other supports such as availability of support from grandparents.

Determinants

Some couples had planned that the mother would work part time to spend time with the child, and managed to fulfil this , albeit with more difficulty than had been anticipated. Other mothers had anticipated full time employment but adapted to the constraints of their situation. Some had attempted full time work and found this to be unmanageable. Some of the mothers turned to new, flexible occupations, which did not reflect their experience or qualifications.

This strategy is a way of ensuring two sources of incomes and the flexibility that is needed for caring, in the context of prevailing job insecurity and in keeping with traditional gender roles. It often involves mothers in considerable feats of management.

I juggle hours, holidays, flexitime and whatever I can.

Fathers' higher earnings were generally given as a reason for prioritising their jobs. However, there were some couples in

which the mothers were potentially higher earners.

Although this pattern tends to be associated with a traditional division of labour, many of the men in this category were flexible when they judged it necessary. Their partners' flexibility enabled them to distinguish between more or less important demands, thus protecting their jobs or income.

Reluctance to rely on benefits, either because of a need for more income, or because of a belief that work is important to self esteem is also associated with this strategy.

Outcomes

For those families who had planned that the mother would work part time this pattern was in keeping with their needs. For others, who had expected to continue as dual earners it created financial hardship or career frustration for mothers. Some who had not planned this strategy nevertheless appreciated the quality of life that this permitted.

Part time work tends to be associated with overload for most dual earner women, because it is less likely than full time work to be associated with a relocation of family work (Cooper and Lewis, 1993). Many of the women in this group had very demanding part time jobs and managed caring with some 'help' from their spouses. They experience the most demands as well as rewards from caring for these children. Men in these families are spared the difficult every day problems that arise in some cases, such as

when children have difficult behavioural problems. A mother of a child with severe learning difficulties told how her family, and even professionals could not manage him, and yet she was expected to do so day after day.

I wasn't welcome if I went anywhere (with the child), so I didn't. I couldn't, I didn't have anyone who would mind himEven my family couldn't look after Derek.....Even the nursery wouldn't have him, ...they asked for him to be kept away, so it was very difficult.

3. Full time dual earners.

In some families, both parents work full time. These are full time dual earner families. Six of the 32 families in this study were full time dual earner families.

Determinants

This decision for both parents to work full time is made on the basis of an economic need for two incomes, and although some parents chose or aspired to this pattern it was not always the preferred choice.

Like erm a problem with me if I like go onto part time um, with the money what he's fetching home..is not going to feed us..... after all these years of, you just feel like, I'd rather be at home now, every day.

In some cases there are extra costs associated with the child's

illness, and lack of information about benefits would they were entitled to.

There is often a weaker attachment to traditional gender roles than in the previous two types of families. This is associated with more sharing of care and work in some but not all families.

The success of this strategy is dependent upon flexible work, supportive managers and the perceived nature of parents work. The men still find it more difficult than mothers to ask for time off when necessary, but this strategy works best if both are prepared to do so at times.

A supportive workplace can make this decision easier.

I was due back at three, when she was three months old and she didn't have the operation till she was three and a half months and I talked to everyone at work, and my manager talked to higher authorities and they basically said that I could take as much time as I needed, and then said if necessary I could take unpaid leave, but they said, no, just take the time you need.

An expectation that employers and service providers will be flexible, and the ability to ask for support, helps to make this deaccession.

We made it clear (to physiotherapist) that we were taking too much time out of work and we could only personally see to these things about once a month.(father)

It never really occurred to me to be honest that they (health professional) wouldn't be prepared to be flexible, because you know, they should have a child's best interest at heart. (mother)

This involved a recognition that mother's work is for the family and not just for herself, in contrast to those mothers described earlier.

Where employers are flexible all the parents are concerned to compensate in some way for time lost, that is flexibility is mutual (Gonyea and Googins, 1996). For example a school dinner supervisor did all the stock control and other paper work while on sick leave caring for her terminally ill child.

mother: So I did it all at home.

Interviewer: So even though you were off sick you were actually doing some of your share.

Mother: Yeah, yeah, I was still doing all the work I should of done whilst I was there, except the cooking.

One family has previous experience of the mother not being able to work more than casual, and later part time work. The

transition to full time work represented the result of a continual and ongoing struggle on the part of the mother.

All my work in the early days would have to be done in the evening when my husband was around....casual work, Christmas time catalogue work... I cleaned above a launderette... I started most of my work as a lunch organiser, or as it was then, a dinner lady... I was still doing my evening job with it. It was the only way I could earn anything other than evening cleaning. 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 bit more specialist help, but by this time I'd evolved on. I had started helping in another school which was near to me....It was only in the day and (I had) school holidays).

Her work centred around the education system to allow her the flexibility she needed. Now that her son, who has learning disabilities, is 24 and attends college, she is managing to work full time. However, he still needs supervision when he is at home, so she still needs flexible work.

This job that I'm doing now, I can finish relatively early and I'm home before 5 because of course, you know you couldn't leave Dean a full day.

The decision to both work full time was often associated with some sharing of family work. However, because this mother had begun by fitting her work around the father's hours and doing all the caring, this pattern had persisted. Despite the fact that she is now earning more than her husband, he remained largely invisible in her account of how she manages work and caring.

Outcomes

The outcomes of this pattern depend on the balance of supports and constraints. For those with flexible, supportive employers and a range of other supports, and who preferred this pattern this enabled them to manage to achieve optimum satisfaction from work and family, as well as financial security. For those with more constraints than supports, it led to extreme overload and stress. In one family both parents of a 21 year old son with learning difficulties have both worked full time for 19 years, but with a lack of formal and informal supports from employers or service providers. This has all become too much for them. The mother is now off on sick leave and doubts if she will work again. The father is also suffering from depression.

Couples who adopt this strategy for primarily financial reasons when they would prefer to spend more time with their disabled children also experience this as stressful.

I get very frustrated at times because I feel that I ought to move on in my career, but I can't go anywhere part time.....there;'s no part time jobs and I really do feel T

is my responsibility. I say my responsibility. I mean our responsibility, and I think M feels the same. I don't want to be farming him out to everybody.....I like looking after him... I love it and so I don't really want full time work but there is really no choice of job.

4. Flexible dual earners

Families in which both parents work part time or non standard hours in order to manage to share both family care and generating a family income are known as flexible dual earner families. Only 4 of the 32 families in this study had such flexible arrangements. These couples achieved balance on the basis of what is practicable and were not constrained by traditional gender norms. Although the mother may still be perceived as the major carer there is an attempt to juggle two work schedules around each other and around the child's needs.

A mother who works just less than full time and whose husband job shares explained;

We did both work full time but we found it too much so, and at that time it was easier for him to go part time than me, so he did so.

In another couple, both work part time, with the mother as main earner and father doing much of the caring, which takes account of the availability of work, and the need for a strong carer to be able to lift their daughter.

My wife, basically she is the breadwinner. She has the stable 9 till, well its three nights a week job, which keeps the basic money rolling in and I do a variety of things because I have to stop when Elaine (daughter) is off. If you suddenly get a break day or a headache or a tummy upset, somebody has to stay at home and its me, and also *I'm bigger and stronger and so I can carry her about....* I just try and make a living somehow built around our daughter.

This type of arrangement involves give and take between the partners to be able to juggle all their commitments.

I've always said its not easy for me to make meetings (at work). If its essential for me I'll do it, and what we do is, we swap and my husband will take him (their son) and I'll pick him up.....occasionally he'll (husband) ring me up and I'll have to go home early because he's had a crisis (at work) that's in the later part of the day, and I'll have to drop everything and go, but its not often enough that for it to be a problem.

This couple are flexible enough for each partner to be able to try part time and full time work and work out the best solution

for them, and can change about as circumstances change.

What makes it possible? Hm. Peter (husband) makes it easier for me to go to work, as I made it easier for him to go to work when I gave it up (earlier).

Determinants

Couples who made this sort of decision are not strongly attached to the male provider and female main carer ideology. They are however, aware of gender expectations, and like other couples they too struggle with stereotypes and expectations at times.

I went back as a staff nurse... a temporary post because we didn't know how P (husband) would cope with not being in full time employment,

We probably manage better than most because of our particular jobs, its more flexible. If 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's 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.

The parents are flexible in what they are prepared to do. Rather than attempting to make old plans work they adapt to new possibilities. Their construction of what is best for the child figures strongly in the decisions of these, as other parents, but

they have different perceptions about what this involves.

Mother: We thought we didn't have enough time for Neil (when both worked full time). We thought he wasn't thriving, actually.... we assumed there was too much pressure in our lives to make him feel comfortable, so we had to reduce it.

Interviewer: And your husband chose to reduce his hours because it was easier for him to...

Mother: Well it was easier because.. I got a secretarial job and once you go to job sharing one of those you can't really get the other half back....,whereas A is a social worker, it was much easier for him to move from full time to part time and back.

I need to work for what I need but I think I need to work for me as well, and I think I need to work for N (son) because I'm better for him if I've been away and come back that if I'm there all the time.

Like many of the full time dual earner mothers, this mother made the explicit connection between her need to work and the child's well being, which protected her from much of the guilt reported in the more traditional families.

The nature of the services available also affect this decision. Lack of services such as after school and other care creates a need for one or both parents to be available. In one case

however, the very good services available were given as a reason for not relocating to find the father a full time job, and therefore contributed to the decision to both work part time.

We decided that we weren't leaving this area because the services for Elaine were quite good and the other places in employment for him (husband)... didn't actually provide many services at all.

Of course the availability of flexible work is also a major contributor to this decision.

Its essential that one or other is able to just not do whatever they planned to do

One of the fathers in this group had been made redundant from his job and used this as an opportunity to create more flexibility for the family by becoming the major carer. This is in contrast to other families which constructed the fathers' previous experiences of redundancy as a reason for prioritising his job.

Outcomes

This mutually flexible strategy enables parents to work out arrangements which they see as best for themselves and their children and increases the options available to them to adapt to changing circumstances. This includes the possibility of reversing traditional roles, not seriously considered by other

parents. Both parents make some compromises and they support each other. Because of this flexibility they are in a better position to work things out for themselves, albeit with some support from others.

These couples are strongly influenced by an ideology of self reliance. They do not feel that they have to ask for concessions at work, or to rely on benefits and this is seen as very important for their self esteem.

I've not had extra time off for anything, I've always had to use my own time, so I've never had anything extra.

We haven't gone on benefits. You know Peter didn't give up his job and not do anything. I told him we'd be better off.. he'd stayed on benefit and milked the state.... I mean we couldn't do that... because we couldn't maintain our self esteem.

Although they were reluctant to make what they see as too many demands on the flexibility of their employers, their experience of juggling work and caring made them particularly understanding of others' work-family problems in the workplace.

because I work in personnel, I think I'm harder on myself than I am if someone comes to me.

These parents felt that their arrangements contributed to quality

of life, as they defined it. One father remarks

I don't want a lot of materials, I want the quality of life... a million pounds, its very nice, but it isn't the be all and end all if you're never at home.

Nevertheless all the parents in this group were aware that their career had suffered in some way and were frustrated at times, both for themselves and their partners.

I was very happy working... there was just enough. ... I enjoyed it. We weren't mega rich but we were getting along, and now she's having her go, and she is well regarded, bless her cotton socks, and she tries hard but she has been frustrated in her career...

Parents can become stuck in a particular job because it offers the flexibility which may not be available elsewhere. A mother felt that her career had been held back by small and unnecessary rigidities in the system.

Its affected, its silly things like the qualifications..and the daft thing is that the reason I can't go and study for it is because the thing starts at 9 o'clock in the morning... and I couldn't guarantee that the once a week, every week in school terms I'd be there..... I can't easily be on a residential....it need us both to cope with the ins and outs, so its affected my career.....

These parents also accept that the constant juggling of commitments, and determination to not ask for favours limits opportunities for other activities.

I've always managed it ... either by flexi...,by annual holidays, so I suppose it's meant we've not had as much fun time together as we would've.

I suppose over 17 years I've got used to having my horizons cut back, always aware that I can't go off and leave (wife and child), and the sporting side of my life stopped dead when Elaine was born.

The balancing acts that these parents perform however, can be fragile and break down in some circumstances. When this happens they can lose the important feeling of being in control. For example, a family relying on the mother's part time nursing salary while the father has cut back his work to care for their daughter, find that the mother's back problems which mean that she cannot currently work causes great problems.

My wife has been unable to go to work... because of a bad back..... we have felt in a corner, not only financially but emotionally.... very boxed in and not in control of our own destiny... .

There are also some concerns about the future for all these families. Not only is the future unsure for their disabled child,

an issue which all the parents share, but also flexible jobs often do not provide the security of other jobs. Nevertheless this group were fairly optimistic that their experience of being flexible would stand them in good stead.

What will we do the ? (when she is older) I don't know. We will, we will adjust our working regimes then to work round whatever time she comes home. If she comes home every weekend on a Friday night... and goes back on Monday morning well we shall make damn sure that the both of our working incomes, you know, how we generate out income, is done when she isn't here.

CONCLUSIONS

Working parents of disabled children develop different strategies for combining work and caring over long periods of time. All arrangements involve parents compromising on their hopes and aspirations. They also serve to preserve family cohesion and the capability of parents to provide financially and emotionally for family needs. From the accounts offered by parents in this study, four patterns of combining work and caring emerge: modified single earner families; one and a half earner families; full time dual earner families; and flexible dual earner families. Each pattern is determined by particular factors including ideological assumptions within the family, in the workplace and permeating community support services; financial needs; skills, capabilities and earning power of each partner; availability of work and flexibility of work practices. Each pattern, too leads to

particular outcomes for families. Whilst all maintain the integrity of the family, this is often at personal cost to parents, and disproportionately so to mothers.

Many of the issues to emerge from these parents' accounts are similar to those of any working parent with small children. However, many of the disabled children in these families are well beyond their early school-age days, and yet their parents are still tussling with how best to balance work and family. The assumptions and expectations about the availability of parents (usually mothers) helps to maintain these families in what may be called the pre-school life stage of the family, long after this stage has passed. This means that neither parents, nor the children are helped to move on through the family life cycle. In order for this to happen, detailed examination of the supports and difficulties encountered by the families, particularly in relation to work place practices, and the operation of formal and informal services in the community is needed. Only then will it be possible to identify particular practices which might change in order to enable families to follow their natural life course.

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