

WEST SUSSEX COUNTY COUNCIL

DIRECT PAYMENTS:

An investigation into their impact on the lives of carers of disabled people with particular reference to employment.

David Littlejohns

A report submitted to West Sussex Adults Services and West Sussex Independent Living Association

June 2006

CONTENTS:

| | |
|--|----------------|
| 1. Research Questions & Methodology | <i>Page. 1</i> |
| 2. Findings | <i>Page. 2</i> |
| 2.1. Impact of DP on carers ability to enter or maintain employment. | <i>Page. 2</i> |
| 2.2. Impact of DP on wider issues for carers | <i>Page. 4</i> |
| 2.2.1. Relationship with the person they care for | <i>Page. 4</i> |
| 2.2.2. Family life and relationships with other family members | <i>Page. 4</i> |
| 2.2.3. Leisure and social life | <i>Page. 5</i> |
| 3. Factors that lead to the positive impacts of DP for carers | <i>Page. 6</i> |
| 3.1. The flexibility of PA working times and the tasks they can perform | <i>Page. 6</i> |
| 3.2. Control over the appointment of PAs | <i>Page. 7</i> |
| 3.3. Relationship with PAs | <i>Page. 7</i> |
| 3.4. Positive impacts for the DP user | <i>Page. 8</i> |
| 3.5. Quality and reliability of care provided through DP | <i>Page. 8</i> |
| 3.6. Support from the ILA | <i>Page. 9</i> |

| | |
|--|---------------------|
| 4. Difficulties with DP identified by carers | <i>Page. 11</i> |
| 4.1. Recruitment and retention of PAs and other staffing issues | <i>Page. 11</i> |
| 4.2. Administration and management of the DP | <i>Page. 12</i> |
| 4.3. Availability of sufficient care hours | <i>Page. 13</i> |
| 4.4. Other factors | <i>Page. 14</i> |
| 5. How did the carers hear about the DP Scheme | <i>Page. 15</i> |
| 6. Carers suggestions for improvements to the DP Scheme | <i>Page. 17</i> |
| 7. Conclusion | <i>Page. 20</i> |
| 8. Recommendations | <i>Page. 22</i> |
| REFERENCES | <i>Page. 25</i> |

LIST OF TABLES AND DIAGRAMS

| | |
|--|-----------------|
| TABLE 1: Carers perceptions of the link between provision of DP and their ability to be in paid employment. | <i>Page. 3</i> |
| TABLE 2: How did carers hear about DP? | <i>Page. 15</i> |
| TABLE 3: Carers suggestions for improvements to the West Sussex DP Scheme | <i>Page. 18</i> |
| Diagram 1: Carers Confidence | <i>Page. 21</i> |

1. RESEARCH QUESTIONS & METHODOLOGY

- What has been the impact of DP for carers in terms of their ability to continue with or enter into employment, education or training?
- What has been the impact of DP for carers in other areas of their life?
- What difficulties have carers encountered with the DP scheme?
- How do carers think the West Sussex DP Scheme could be improved?

Six carers of DP users were interviewed using a semi-structured interview approach.

The six carers were chosen from the carers who responded to a previous questionnaire survey of carers carried out for the RISE Project by West Sussex Social and Caring Services Research Unit in the early part of 2005.

Three of the carers were caring for adult children with learning disabilities or mental health issues.

Four of the carers were caring for spouses with physical disabilities.

(N.B. one carer was caring for a disabled spouse and an adult child with a learning disability.)

All six carers were of working age and had indicated they would like to be in paid employment.

Four of the six carers had indicated in the questionnaire return they thought DP had helped with their employment and two said it had not.

For the purposes of this report I have called the carers Mr. or Mrs. A to F

2. FINDINGS:

2.1. Impact of DP on ability to maintain or enter employment.

One of the carers (Mrs. C.) had not been able to enter employment since the start of DP and one (Mrs. E.) had found paid work but had been unable to maintain it.

Of the four carers in paid work, **TABLE 1.** overleaf describes the links they make between DP and their ability to be employed:

TABLE1: Carers perceptions of the link between provision of DP and their ability to be in paid employment.

| CARER | Current Work Situation | Carers perception of link between DP and employment |
|---------------|---|---|
| Mr. A | Full time employment | Mr. A sees a clear link between DP and his employment. He states: <i>“But without a doubt if it hadn’t been for Direct Payments I don’t think I would ever have been able to go back to work”</i> |
| Mr. B. | Full time employment | Mr. B does not see a direct link between DP and his ability to work but sees some benefit to his work life. He states: <i>“... but I don’t suppose it’s affected my ability to work ... not terribly. But the fact that I know they’re there (PAs), I’ve got more time to allow, to put to work ... “</i> |
| Mrs. D | 34 hours per week during college term times | Mrs. D sees a clear link between the DP Scheme and her ability to maintain her paid employment at its current level. She states: <i>“I would have had to have gone to a four day working week if I hadn’t been able to have Direct Payments for (daughter) ... “</i> |
| Mrs. F | Part –time work | Mrs. F sees a positive link between DP and her employment. She states: <i>“ ... DP has enabled me to go back to the work place definitely.”</i> |

2.2. Impact of DP on wider issues for carers.

The research identified positive impacts for carers in the following areas:

1. Relationships with the person they care for
2. Family life and relationships with other family members
3. Leisure and Social Life

2.2.1. Relationship with the person they care for:

All six carers reported improved or more satisfying relationships with the person they care for.

Mrs. C. carers for her physically disabled husband. They had not previously had any social care prior to accepting the DP scheme. She said:

“ ... the caring that you give is very repetitive ... and it's also quite hard when it's a member, you know, when it's a husband and wife relationship ... so it's a very good thing to take hands off and be a wife instead of a carer.”

Mrs. E. cares for her daughter who has mental health issues. With the help of DP she has been able to live independently in her own flat. Previously she had needed to live in the family home. Mrs. E continues to provide some care for her daughter. She said:

“ I go in and I do my carer and we're talking business or we go out as mother and daughter for the day and it's been much easier to relate to her ... much more workable and rewarding.”

2.2.2. Family life and relationship with other family members.

Carers who were parents of adult children with disabilities found that DP enabled them to spend more time with their spouses e.g. Mrs. D. said:

“ ... so it needed to be what they wanted to do and a by-product of that must be that it gives us time for ourselves too.”

Carers of spouses found that DP gave them more time for the other members of the family e.g. Mrs. C. has been able to spend more time with her children. She said:

“ ... because if you want to go out with the family to do something, you can actually do that with confidence that your husband is taken care of in the meantime.”

2.2.3. Leisure and Social Life

The carers reported improvements to their leisure and social life resulting from DP e.g. Mr. B. who cares for a daughter with learning disabilities is now able to meet friends with his wife without having to take his daughter along because she can do things she wants to do with her PAs. He said:

“ ... the social life we've had has been much restricted so it's much improved. If my wife and I went to meet some friends, they live in Hampshire, we meet them half way a couple of times a month or whatever, we used to take (daughter) with us. Of course that wasn't the same as us four being together as friends .. “

3. FACTORS THAT LEAD TO THE POSITIVE IMPACTS OF DP FOR CARERS:

Carers identified the following factors that enabled them to achieve the positive impacts identified in Section 2.

1. The flexibility of PA working times and tasks they can perform
2. Control over the appointment of PAs
3. Relationships with PAs
4. Positive impacts for the DP user
5. Quality and reliability of care provided through DP.
6. Support from the ILA.

3.1. The flexibility of PA working times and tasks they can perform

The flexibility of the PA working times and the tasks they can perform was important for some of the carers in terms of their employment.

Both Mr. A. and Mrs. D. gave good examples of this.

Mr. A. cares for his wife who has a chronic illness. He said:

“ ... this is why I like the flexibility of the direct payments is that we've changed the carer from a Friday to coming in on a Sunday so that Friday night I put (his wife) to bed, Saturday I put her to bed, Sunday her carer will put her to bed so that if I'm tired it means I can get to bed and get up refreshed ready for work on Mondays.”

Mrs. D. who cares for two learning disabled daughters is able to work more hours because the flexibility of DP allows one of her daughters an alternative to attending a day centre which she does not want to do. Mrs. D. said:

“I would have to have gone to a four day working week if I hadn't been able to have DP for (her daughter) because she definitely didn't want to go to the Day Centre and there wouldn't have been another option for her ... “

Although domestic tasks might be small in themselves the fact that PAs could do them provides an important psychological benefit and morale boost for the carers. Mrs. F. states:

“... and it's really nice when you go out to work and you come home and someone

has done the washing up for you, ... you know you don't have to worry about those other tasks as well, it does help, it helps a lot."

Other carers pointed to PA flexibility enabling other benefits.

Mrs. C. asked her husbands PAs to work at a time that enabled her to accompany her daughter to an interview for a place at university. This meant a great deal to her. She said:

"Now if I hadn't had that care, I'd have sent her on her own and she would have had to come back and remember to tell me and we'd talk about it, but it's not the same and I think that's where people perhaps don't see how much of a difference it makes if you can go to things."

Being able to get away for a few days or at week-ends by storing up PA time so they can cover was mentioned by Mrs. E. and Mrs. D. as important. Mrs. E. said:

"This year we've managed to do some week-ends which has been wonderful."

3.2. Control over the appointment of PAs

All of the carers saw this as a great advantage.

Mr. A. said:

"... when you're actually recruiting you get what you want. At that recruitment stage you are finding out what that person is willing and not willing to do."

Mrs. C. said:

"It's someone you've chosen, it's somebody you've probably chosen because you feel you can have a real rapport with them."

Two of the carers appointed relatives of the DP user to perform some of the PA tasks and saw this as very positive. Mrs. F. appointed their daughter to work with her father on some afternoons in an attempt to motivate him to be more active and Mrs. E. appointed her mother i.e. her daughter's grandmother to work on specific tasks. Mrs. E. said:

"My mum's the perfect person to go and help her cleaning because she understands her very personal issues ... you can't employ for that."

3.3. Relationship with PAs

Most of the carers valued the fact that their relationship with the PAs and the relationship between the PAs and the DP user became something more than purely professional.

Mr. A. said:

“ PAs come to you because they like you and they stay with you because they like you as a family group.”

Mrs. C. said:

“ They become like a part of the family if you get the right person.”

Mrs. F said:

“ whoever got the job would have to be somebody who would fit into the family ... we've been very fortunate with the ones that we've employed because they have.. “

3.4. Positive impacts for the DP user

Carers were pleased when they could see positive impacts for the DP user,

Mrs. C. when talking about her husband said:

“Although he wasn't keen at the start, he's actually benefited because he's had interaction with other people which he wouldn't normally have had, so I think it's got benefits for everybody.”

Parents of adult children with disabilities were pleased that DP allowed their children to be able to have choice about their activities e.g. Mr. B. was pleased his daughter was able to do more of the things she wanted to do and Mrs.D. was pleased her daughter had an alternative to day centre attendance

3.5. Quality and reliability of the care provided through DP.

The carers of DP users who had been receiving care direct from social services or through agencies commissioned by social services considered the quality of the care and the reliability and appropriateness to be better through the DP scheme and in some cases much better. Two of the carers related this directly to their ability to go out to work.

Mr. A. has sufficient confidence in the quality and reliability of the care to do out to work. He said:

“ I think that with DP there's the flexibility, the confidence of how it is being run, how the family are being looked after, it means I can go out to work.”

Compare this with his perception of the care they were receiving before DP:

“And you were literally at their beck and call, they'll just send in people when they want and take them away when they want whether you like it or not.”

Mrs. F. also has sufficient confidence in the quality and reliability of DP to think about paid work. She said:

"I also did some voluntary work at the local theatre, but it wasn't until we came onto DP that I could really look at seriously taking up something a bit more."

Compare this with her comments about the care her husband was receiving prior to DP. She said:

"... people did their very best, but you were forever being let down. (Husband) was sometimes in bed 'til midday, that sort of thing ... in the end you just turn around and say, forget it, I'll do it myself."

The contrast between carers perceptions of care provided through DP compared to previous care is very striking.

3.6. Support from ILA.

Without exception, carers were complimentary about the support offered to them by the ILA. This centred around three areas:

- Advice at time of transferring to the DP scheme
- Help with recruitment process
- Good availability of ILA staff to deal with queries.

Quotes from carers as follows:

Mr. A. said:

"I've felt nothing but confidence with them and I know if we phone them up saying we've got a problem they would help one way or another or put us in contact with the right people."

Mr. B. said:

"The fact that they help you with all the interviews and all the recruitment and set up and all that sort of thing you know, you couldn't ask for more on that."

Mrs. D. said when talking about starting off with DP:

"We had (an ILA staff member) who came out and talked me through it all ... and I've phoned up and she's always been available or got straight back to me."

Mrs. F. said:

"Well I think the support we've had from the ILA is great."

"We came across several little queries that I didn't quite understand and I'd pick

up the phone and if (an ILA staff member) didn't know, she'd get back to me."

4. DIFFICULTIES WITH DP IDENTIFIED BY CARERS.

There were three areas in which carers expressed drawbacks with DP:

- Recruitment and retention of PAs and other staffing issues
- Administration and management of the DP
- Availability of sufficient care hours.

4.1. Recruitment and retention of PAs and other staffing issues

PA recruitment was probably the main difficulty referred to by the carers. With the exception of Mrs.D. all of the carers had experienced difficulty in this area.

Mrs. C. said it took eight months for the first PA to start working from the time she and her husband decided to use DP

Mrs. F. became so despondent about the inability to recruit that she contemplated giving up the idea of changing to DP. She said:

“But we were nearly ready to throw the towel in, simply because of the recruitment.”

Because of the difficulties in recruiting carers are worried about retaining PAs once appointed:

Mr. B. said:

“ ... it's finding that person, once you've found that person, hanging on to them is the biggy, it's the biggest issue.”

Mrs. E. expressed her concerns about retaining PAs when she said:

“ ... having had five different staff turnover since we've been doing the scheme, which isn't a lot by some people, but it's always in the back of your mind.”

Difficulties with recruiting and retaining PAs and covering periods of unforeseen absence of PAs e.g. through sickness are cited as barriers to their employment by some of the carers.

Mrs. C. described how at one stage she had two good PAs working with her husband and was advertising for a third to act as cover for the other two. Within a week both PAs had resigned and there had been no response to the advertisement. She said:

“ ... I've got to have pretty much 100% back-up so that if I can go back to work, that I can do it with confidence that his needs are being met.”

Mrs. E. left the paid employment she had found following her daughter receiving DP. She said:

“... and the job worked very well when we had the full complement of staff. But three times during that period of fifteen months we lost a member of staff ... and there was a two or three month turn around in training and re-employment and that on top of the work I couldn't deal with.”

Difficulties in covering periods of unforeseen absence such as sickness was also a concern for some of the carers in terms of maintaining employment.

Mrs. F. said:

“... and it doesn't matter how good your employer is, it still makes you feel pretty rotten inside if you're forever ringing up” Basically you panic, the moment someone goes sick you go into this panic, because it's the one thing you don't want to happen.”

Mr. A. said:

“If one of (his wife's) staff go sick and she can't get hold of one of the others to swap round it's down to me and I've told my work that I might not be able to come in one day because I can't get someone to get (his wife) out of bed.”

Other staffing issues identified by carers concerned the management of PAs.

Mrs F. was concerned about how she might challenge one of the PAs when they were not working as well as could be expected. She said:

“... but you almost become over familiar with each other, so when you get to the point when you need to say, now come on, you've had a lot of time off, or something like that, its very hard to address it because this person is your life line, you don't want to upset them.”

Mrs. E. spends a lot of time training and monitoring the work of the PAs. She said:

“... I devise all the care plans and the structure in the house. I oversee all that and I support the staff who are doing that. I train them initially and we have team meetings every three months with (her daughter) to actually work out where our next goal should be.”

4.2. Administration and management of the DP

With the exception of Mr.A. all of the carers interviewed were managing the DP with little or no help from the DP user. In most cases this was due to the DP user being unable to manage the scheme due to their disability but in some cases due to a lack of motivation on the DP user's part.

Mrs. E not only manages the administration of the scheme but acts as her daughter's "care manager." She said:

"Yes (her daughter) couldn't, isn't interested in managing people at all or anything to do with the administration of her home or the DP's really, she just puts that down to me. I devise all her care plans, I oversee all that and I support the staff who are doing that."

Generally, the carers considered the amount of paperwork to be too much. The process of completion was seen as tedious and time consuming and something that would potentially deter some people from taking the option of DP.

Mr. B said:

"... filling out the tax return isn't that difficult once you've worked that through, that's probably the thing that puts a lot of people off though."

Mrs. D. who is the carer for two daughters described the amount of paperwork as being out of proportion to the amount of care received by one of her daughters. She said:

"I think well, I'm doing it for (second daughter) it's just a case of doing a little bit more. I think if I were only doing it for (first daughter) I would perhaps feel it wasn't worthwhile."

Some of the carers thought that the degree of accountability required is excessive.

Mr. B. said:

"... that is the worse part of DP, the regular returns, you have to account for every penny."

Mrs. E. said:

"But I find the paperwork and the returns very tedious and very petty actually, to have to justify every penny I find very petty."

There were suggestions that the requirement for monthly returns could be extended to longer periods e.g. quarterly but some carers thought that there were advantages to monthly returns. Although Mrs. C. thought that the paperwork could be streamlined she said:

"I mean somebody said about doing the returns less frequently, but the difficulty with that is that if you need to remember something that you've done, it's probably easier to do it more regularly."

4.3. Availability of sufficient care hours.

There was a sense from some of the carers that there was insufficient care hours available. Sufficient care hours is seen as an essential factor to enable carers to be employed.

Mr. A. explained that at one stage his wife was only in receipt of two to three hours care which was not sufficient to enable him to work. He had to arrange for a new assessment to be undertaken in order for his wife to receive sufficient care to enable him to work.

Mrs. C. also talked about needing more care hours before she was able to consider paid work She said:

“When I got past the worst of it and I started to look to return to work, that’s what it was it was then extended to double, because there was no way I could go back to work on the number of hours I had, so that’s when I was given the extra.”

Later Mrs. C. said:

“So it’s probably only just about enough to get me back to work, but I would always think, I would assume that if I ever had the potential to go back to work that I could ask whether it would be extended any more.”

Mrs. D. also links the care hours available with the ability to work in the future. Her daughter currently attends college four days a week and has DP for the fifth because she does not want to attend a Day Centre. If Mrs. D. is to maintain her current 34 hours of employment over five days when she finishes in college, her daughter will either have to agree to attend a Day Centre or receive a substantial increase in the amount of DP she receives. Mrs. D. said:

“I must admit it has occurred to me that when (her daughter) leaves college, if she still continued to not to want to go to the Day Centre, that would have quite an impact. I would want to have DP for her for those five days ideally, if that’s what she wanted, so that I could continue to work ... and if we couldn’t get funding for that then I’d have to reduce my hours.”

4.4 Other factors

Although not related to the DP scheme itself, financial issues were seen as a barrier to employment or at least a disincentive by some of the carers.

Both Mr. A and Mrs. C referred to losing carers allowance if they were earning over £82 per week and Mrs. F. referred to her understanding that if she worked more than 16 hours per week she would lose entitlement to benefits such as income support and housing benefit making it uneconomical for her to work more than her current 16 hours.

5. HOW DID THE CARERS HEAR ABOUT THE DP SCHEME?

Table 2 summarises the ways in which the carers heard about DP

TABLE 2. How did carers hear about DP?

| CARER | Heard about the scheme from? | Social worker involved at the time? |
|---------------|--|--|
| Mr. A | Heard about it through the OT working with his wife | Yes |
| Mr. B. | Was aware of Direct Payments Schemes in other parts of the world prior to its introduction in the U.K. | Yes |
| Mrs. C | Heard about it from a Social and Caring Services OT who was helping with her husband's discharge from hospital | No, but had brief involvement from a Social Worker when husband was hospitalised |
| Mrs. D | Heard about it from a friend | Yes |
| Mrs. E | Was offered by a senior manager following formal complaints procedures | No |
| Mrs. F | Husband heard about it from someone who attended the same Day Centre | Yes |

Four of the DP users had social workers at the time they heard about DP (a fifth (Mrs. C.) had had recent contact with a social worker)

Of the four, Mr. B. was very well informed about DP prior to its introduction in West Sussex. And will have discussed this with the social worker involved. The other three heard about

DP from a non social worker source. Two of them, Mrs. D. and Mrs. F., heard about it from non-professional sources.

The carers involved say that once the issue of DP was raised with their social workers, there was no objection from the social workers and they moved swiftly to set the process in motion.

It is worth pointing out that Mrs.C.'s husband had not been in receipt of care services prior to DP as their view of social services provision was not positive. Would her husband have accepted help from DP earlier had he known about the scheme? Mrs. C. said:

“But it would have been a different situation yes, I mean we would probably have had a different attitude towards it, but we didn't know about it.”

Later she said:

“ and then when DP was talked about, that seemed a much more acceptable facility to him.”

Mrs. F. also makes the point that there was considerable contact with staff from other agencies such as district nurses, hospital staff none of whom mentioned the possibility of DP for her husband.

Although this is a small sample, there would appear to be issues about how people hear about DP and in particular the role of social workers/care managers.

The CSCI Report: Direct Payments: What are the barriers? Published in 2004 cited low staff awareness of DP and what they intend to achieve plus restrictive attitudes about the capabilities of potential DP users coupled with a reluctance to devolve power as barriers to the take up of DP.

6. CARERS SUGGESTIONS FOR IMPROVEMENTS TO THE DP SCHEME.

All of the carers with the exception of Mrs.D., made suggestions which would address the difficulties carers experienced with recruitment and retention of PAs and covering unforeseen absences e.g. due to sickness.

Common suggestions were the setting up of banks or pools of PAs and one carer suggested a co-op arrangement for PAs. Other suggestions were DP users local to one another grouping together to share PAs or PAs working with more than one person at a time.

Specific suggestions were made by individual carers about finding PAs from Nursing Banks or using Crossroads staff as PAs and paying more to particularly good PAs as a way of retaining them. Another suggestion was for details of potentially good PAs who had been unsuccessful at a previous interview to be passed on to carers and DP users looking for staff.

Three of the carers made suggestions to alleviate the administration of the DP scheme. Suggestions included requiring returns less frequently and more help with the paperwork. Three of the carers suggested the DP scheme could be better advertised with a specific suggestions around automatically informing carers whose names are placed on carers registers held at GP surgeries about DP.

Two carers suggested more emotional support one at the start of the scheme.

Other suggestions from individual carers included some management training, sharing of ideas with other carers about how to get the best out of the scheme and various suggestions for how the use of DP could be expanded to include attendance at Day centres run by Voluntary Organisations and to include residential respite care.

Table 3. overleaf gives the full list of carers suggestions for improvements.

TABLE 3: Carers suggestions for improvements to the West Sussex DP Scheme

| CARER | Suggestions for improvements to DP Scheme |
|---------------|--|
| Mr. A. | <ul style="list-style-type: none"> • An ILA managed “bank” of staff to cover staff shortages, sickness and holidays. • ILA negotiating with Social Services over funding issues • ILA to offer emotional support to his wife and monitor and advise re: the family situation • Comes across people with disabilities who have not heard of the Direct Payments Scheme – suggests better publicity for the scheme • Some consideration of having one to argue with Social Services on his behalf – Advocacy Service? |
| Mr. B. | <ul style="list-style-type: none"> • Accounts/paperwork to be done quarterly • Expanding DP to enable to attend Day Centres run by organisations such as Crossroads • Establishment of a pool of workers who might have surplus time which could be used by someone else – would like ILA to keep a database of such workers • Use of PAs to support more than one person at a time • Joint Health and Social Care funding • Accountancy Service to do returns without having to send all the information in to the current service • Clarification amongst Social Services staff about whether DP can be used to employ Agency staff • Expansion of DP type scheme to include residential respite perhaps through a voucher type scheme • Identification of hotels where DP funding could be used to buy a week-end in a hotel perhaps by a group of DP users to negotiate group rates |

| | |
|-----------------------|---|
| <p>Mrs. C.</p> | <ul style="list-style-type: none"> • A non-profit co-op or local pool of carers who might be able to cover sickness – will already know the scheme • Suggesting a method of introducing a PA working with a family in the same area to her family who would be able to cover any future needs • Passing on details of people who have been interviewed unsuccessfully for PA posts but who would be suitable to other people looking to appoint PAs – including developing a system to enable this • Could carers from the Crossroads Scheme be used and the money paid to Crossroads • Returns to be done less frequently • Carers who are placed on the carers register held at GP surgeries could be automatically given information about the DP Scheme |
| <p>Mrs. D.</p> | <ul style="list-style-type: none"> • Better advertising of the scheme – colleges, day centres, clubs etc |
| <p>Mrs. E.</p> | <ul style="list-style-type: none"> • Would like ILA to set up a bank of PAs but developing a sound knowledge of the PAs to enable good matching of needs and PA • Paying staff more as a way of ensuring retention of staff with a particular aptitude for the work • Someone to help with the paperwork • Identification of someone to take over the Care Management role for her daughter • Tapping in to NHS Nursing Banks |
| <p>Mrs. F.</p> | <ul style="list-style-type: none"> • Training around the management of staff • Need someone to provide emotional support at the beginning of the scheme because can feel exhausted as a carer • Sharing of PAs by grouping together with other DP users • ILA running a bank of staff who could be called on at short notice to fill gaps caused by sickness • A method of sharing ideas across DP users of how best to use the DP scheme to its full potential |

7. CONCLUSION.

The findings of this research clearly indicate that the carers perceive DP as providing them with a range of positive impacts in the following areas:

1. Relationship with the person they care for
2. Relationship with other family members and positive impacts on family life
3. Improved social life and/or leisure activities
4. Employment and related activities

All of the carers reported benefits in 1, 2, and 3 but only some carers saw DP as having a positive impact on their ability to be in paid employment.

In terms of understanding the reasons why carers are able or not able to maintain or take up employment, my proposition from the data I have gathered is that it is fundamentally one of carers having sufficient confidence in the constant availability of care to the person they care for that is consistent in its quality and quantity.

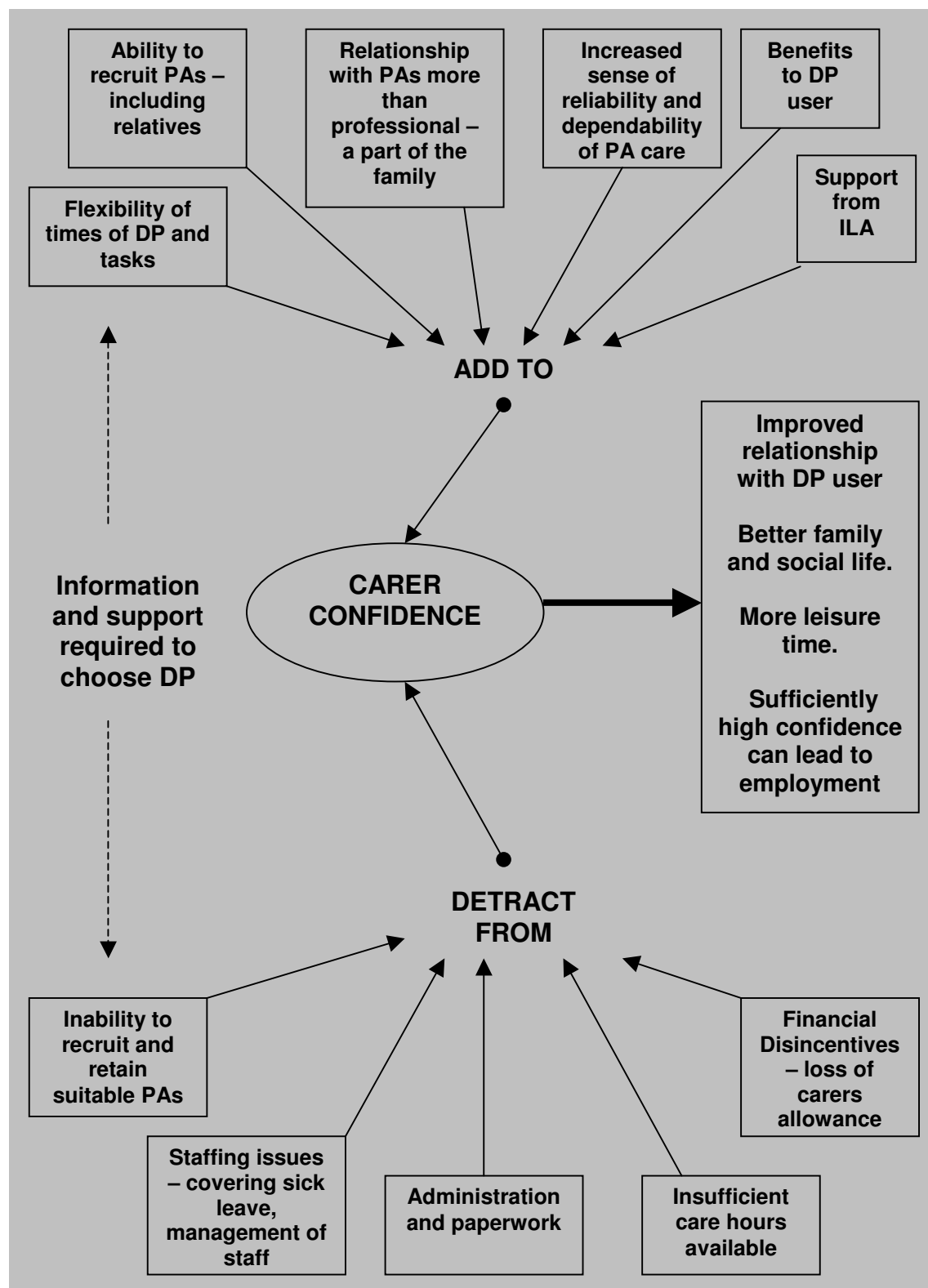
Although the same factors also apply to the realisation of the other positive impacts experienced by the carers, in terms of employment the difference is that the carers need to feel confident all or most of the time whereas improvements to social life etc. can vary over time.

However, before carers can benefit from DP, they have to hear about it and there is some evidence from this research that social workers are not informing service users about the scheme and also it is not well advertised for people not currently in receipt of services but who might choose to receive DP.

Diagram 1. overleaf is a diagrammatic representation of the factors that add to and detract from carers sense of confidence in the care provided. Please note I have added financial issues as one of the factors that detract from confidence because although it is unrelated to DP, some carers identified the potential loss of state benefits such as Carers Allowance as a disincentive to employment.

Diagram 1: Carers Confidence

FACTORS ADDING TO CARERS CONFIDENCE



FACTORS DETRACTING FROM CARER CONFIDENCE

8. RECOMMENDATIONS:

If carers are to receive the full benefits of DP which potentially includes increasing the prospects to enter employment the following issues need to be addressed:

1. Carers must be able to hear about and obtain good information about DP
2. The factors that detract from carers confidence should be addressed. These factors are:

Inability to recruit and retain PAS
Covering un-planned absence of PAs
Management of PAs
Administration of the scheme and appropriate paperwork
Insufficient care hours available
Financial disincentives (not addressed in this research)

The following recommendations are made to West Sussex County Council Adults Services and the West Sussex ILA:

1. West Sussex Adults Services staff be reminded of the requirement of Local Authorities under the 2003 Guidance to offer DP as an alternative to direct services or commissioned services.
2. A survey of Adults Services staff attitude to DP be carried out in the form of a questionnaire survey
3. DP training to become mandatory for all social workers and assistant care managers.
4. The DP scheme be better publicised generally – carers suggestions include providing all carers who are on the carers registers kept at GP surgeries with information about DP.
5. Whilst it is acknowledged that the ILA cannot act as an agency supplying or recommending PAs, it should do all it can to assist potential DP users with recruitment in addition to the current help with advertising and interviewing PAs. Suggestions from carers include keeping a register of PAs who might be looking

for additional work and of PAs who have been interviewed by other DP users who were suitable but not appointed on the day. This does not seem dissimilar to the current practice in Adults Services of handing out lists of Domiciliary Care Provider Agencies or Residential Care Homes without recommendations to people who want to make their own care arrangements in these areas.

6. Current plans to develop Co-operative type arrangements for PAs should include the involvement of carers in consultation and development. The model of Co-ops implemented should ensure that PA cover during periods of unforeseen absences and other short term requirements can be met. If some carers prefer to employ PA staff independently of the Co-op they should have access to the Co-op to cover periods of PA sickness or other short term absences
7. Steps should be taken by Adults Services to stimulate the market for PAs, taking into account geographical variation in availability. This could include a review of the criteria for current pay enhancements for PAs and by working with current Domiciliary Care Provider Agencies to provide PA type services.
8. Further consultation with DP user and carers for ways of reducing the administration burden and establishing what is essential – suggestions from carers include extending the period for returns from its current four weeks to quarterly where competence in administration has been demonstrated.
9. Better advertising of the administration and payroll services currently offered by the ILA and information and support for carers who wish to use private companies for this purpose.
10. Ensuring social workers and assistant care managers offer carers an assessment of their needs which takes into account the requirements of the Carers (Equal Opportunities) Act 2004 to include a consideration of whether the carer works or wishes to work, and whether they participate or wish to participate in any education, training or leisure activity recognising that carers should be able to

take up the same opportunities as those without caring responsibilities. Care packages to the service user should include resources to meet the requirements of carers in this area.

11. Offer some basic management training to help carers better manage PAs.

12. Steps should be taken to set up DP User and Carer Local Groups. These groups would have three purposes. Firstly, they would allow DP users and carers to share their experience of using DP and how to get the best out of the scheme. Secondly, act as focal points for the ILA to share information about the development of the DP and to receive feed-back from DP users and their carers. Thirdly, empower DP users and their carers to think about sharing PAs when appropriate e.g. to cover unforeseen absences or group activities.

REFERENCES:

1. CSCI (2004) *Direct Payments: What are the barriers?* London: CSCI.
2. DH (2003) *Direct Payments Guidance: Community Care, Services for Carers and Children's Services (Direct Payments) Guidance England 2003*. London: Department of Health.
3. DH (2005) *Carers and Disabled Children Act 2000 and Carers (Equal Opportunities) Act 2004 Combined Policy Guidance*. London: Department of Health.