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The Impact of Direct Payments on Service Users Requiring Care and Support at Home

Karen McGuigan, Lee McDermott, Cathy Magowan, Gillian McCorkell, Anne Witherow and Vivien Coates

Background: Direct Payments (DP) is a service user-implemented scheme in which the individuals assessed as needing personal, social or health-related care services are given cash payments, allowing them to ‘buy in’ services they require. Previous research indicates DP offer the user greater control and flexibility over their care. However, the literature highlights problems with the system including user responsibilities, carer recruitment, provision of information and support. Aim: To examine the impact of DP on service users in a large Health and Social Care Trust, in Northern Ireland. Method: Thirty DP users from the Trust area were recruited to the study. The sample consisted of 2 respondents who were in direct receipt of DP, and 28 informal carers who implemented the budget on behalf of an eligible DP service user. Each respondent completed an interview with the study researcher, following an interview schedule devised by the research team. Results: Findings show service users are generally satisfied with most aspects of the scheme; however, difficulties still exist around provision of information, support, user responsibilities and public awareness. Conclusion: The research has led to recommendations that may allow the scheme to function more effectively, whilst ensuring user benefits remain largely unchanged.

Keywords: Direct Payments; social care; user experience

Background

The NHS Confederation (2009, 5) defined Direct Payments (DP) as ‘means-tested cash payments made to individuals who have been assessed as needing services, in lieu of social service provision’. DP allow those with recognised personal, health or social care needs to avail of care, which they can tailor to their needs, and to source that care themselves rather than depend upon existing statutory or traditional providers. DP have been proposed as an
alternative to traditional care services, including day care, home care or respite care provided by local social service departments (Glendinning et al. 2000a). Over the past few decades, groups representing those with disabilities have campaigned for a scheme which provides users with money to purchase the care they require, as and when they require it (Glendinning et al. 2000b), creating a user-driven system of care instead of an organisational- or provider-driven system. The inclusion of the user in the process of designing care is one that has come to the fore within health and social care policy (Hodge 2005). It is suggested that DP have ‘moved to the heart of the Government’s drive for increased user choice’ (Fernández et al. 2007, 97).

The DP system appears to satisfy the desire for a user-driven system as it allows the user a higher level of control over their care (Maglajlic 2000). Glendinning et al. (2000b) suggest the policy of providing cash rather than direct services is widely accepted in the care system. However, DP come with responsibilities for the user, including recruiting and employing staff, keeping financial records, making requested returns and being aware of employment legislation (Maglajlic 2000). Some DP users remain in the dark about various issues related to being an employer (SCOPE 2002).

Research highlights that those with disabilities are being asked to enter the employment market to recruit and employ carers (Ungerson 2004). While Spandler (2004) acknowledges that DP are offered to those who are willing and have the ability to accept the associated responsibilities, these appear to vary depending on the locality and social service department (Glendinning et al. 2000a). Some users report concerns about the level of insurance cover required to have staff working in their home, opening a DP-dedicated bank account, submitting monthly paperwork (statements and returns) e.g. to HMRC (Maglajlic 2000; Carmichael and Brown 2002). Some reported additional training would be required for their personal assistants allowing them to recognise how tasks could be carried out whilst preserving the user’s dignity (Glendinning et al. 2000c). Whilst the tailoring of a care programme may be desirable for most users, sometimes the responsibilities may be too numerous or onerous for some who opt to stay with their current care provision rather than embrace DP (Carmichael and Brown 2002).

Benefits

DP schemes are championed by charities and government as they offer various provider- and user-related benefits. DP were found to be cost-effective for providers and had fewer associated complaints (Zarb and Naidash 1995), with the research indicating ‘user-controlled money’ was used more efficiently (Spandler 2004, 193). Early versions of the scheme reported higher levels of satisfaction than those using more traditional care provisions (Zarb and Naidash 1994). Glendinning et al. (2000c) report that DP users valued the ability to choose their own personal assistant to provide their care. Users reported this
provided them with an individual who could be trained to care specifically for their needs, offer a wider range of help with everyday tasks and was there on a regular basis ensuring continuity of care. Research argues that DP may allow for the provision of care services that are culturally appropriate, with the user choosing a personal assistant who is sensitive to their personal health needs and also conscious of any religious or cultural concerns (Spandler 2004).

DP appear to empower users, offering greater independence and control over the level and quality of care received (Hasler, Campbell, and Zarb 1999; Glendinning et al. 2000a; Ungerson 2004). The control and flexibility of the system allow users to dictate who provides their care, when they provide it and how their needs are met (Spandler 2004). Priestley (2005) reported that generally DP appeared to be utilised by individuals to provide control and flexibility of care and allow a greater level of independent living. SCOPE reports the main reasons users chose DP were the control, choice and flexibility offered (2002). Indeed, some users report they felt DP were the only vehicle available to get the help they needed (Clark, Gough, and MacFarlane 2004).

**Difficulties and Drawbacks**

It was reported by some users that in times of high employment, they found it more difficult to recruit appropriate carers (Carmichael and Brown 2002); advert response rates were low, with few suitable candidates presenting for interview (Glendinning et al. 2000c). Users also recognised difficulties in recruitment could be borne out of the lower levels of pay on offer compared to those on offer for similar work with agencies and social services. Users with very specific needs e.g. required lifting or required oxygen worried about the training and experience carers may have and the impact this could have on their care (Glendinning et al. 2000a). Some users have difficulty with the distinction between health and social care made by some authorities. Users argue that often because of a health problem, personal or social needs may develop; however, the DP scheme does not allow for this crossover between health and social care needs (Glendinning et al. 2000a).

The levels of responsibility associated with DP were a cause of anxiety for some concerned about the paperwork required in terms of employing their personal assistant (Glendinning et al. 2000c). Spandler (2004, 194) suggests that the only common difficulties reported, by users, are those associated with ‘bureaucracy, paperwork and administration’. Older users of DP indicated meeting the audit and administration criteria and timescales could present a major difficulty (Clark, Gough, and MacFarlane 2004).

Users also have reported difficulties with prompt payment under this type of system, indicating they experienced late payments that had a knock on effect as they had to borrow money to pay the wages of their personal assistant (Carmichael and Brown 2002). Lastly, Priestley (2005) states that DP schemes often have many levels of checks or assessment, reporting a Trust in Northern...
Ireland indicated provision of a home care package required only one layer of assessment, whilst provision of DP could require up to five.

**Providers**

Pearson (2006) suggests limited funding for support schemes may restrict their effectiveness. Cutbacks in resources available for local authorities in the current economic climate may make it difficult for providers to offer reasonable rates of payments to those requiring assistance, therefore this may prevent them from offering DP at all (Fernández et al. 2007). SCIE (2009) agrees that cutbacks in resources may affect the provider’s ability to offer adequate payments for user-directed care.

Some argue users of DP are, by definition, dependent and in need of care, therefore it is unreasonable to expect them to take charge of their own care (Pearson 2006). If this belief is prevalent within the health and social care system, it may mean some of those eligible for DP are never offered it. SCIE (2009) indicates one of the reasons that social workers (SWs) do not offer DP as an option to disabled people may be due to their beliefs or attitudes about the risk for the user. They also suggest those working directly with people with disabilities may not be aware of all aspects of DP policy and, as such, are reluctant to offer this option to people within their jurisdiction.

**Uptake**

The NHS Confederation (2009) points to the responsibilities of social care providers to introduce the option of DP to those who are eligible; however, the rate of implementation has been poor (Fernández et al. 2007), despite government eagerness to increase the number of DP users, with the issue high on the health and social care agenda (Leece 2007). Davey et al. (2007) suggest there are barriers to DP uptake and implementation:

1. Concern or anxiety about managing DP among users and carers
2. Social services staff resistance to DP
3. Number of people available to take the role of carer

The SCIE (2009, 5) acknowledges the uptake of DP in the UK ’... by various groups of people who use services has been slow’, ... but state the uptake in England is more than twice that of other areas in the UK. They suggest this may be due to implementation of DP at a local level, with different policies and health care structures at work in Northern Ireland, Scotland and Wales. When the implementation of the DP scheme became mandatory, 88.7% of authorities in the UK were already offering DP to consumers (Riddell et al. 2006); however, the introduction of performance indicators and targets
appears to have increased DP uptake rates, yet these rates differ depending on country, region and locality within the UK (Priestley 2005).

DP uptake rates show strong variations across user groups, with research conducted in England suggesting the uptake of DP remains low among those with mental health difficulties and learning disabilities, representing 4 and 11% of all recipients, respectively (Fernández et al. 2007). These findings are echoed by research that DP are allocated most often to those with physical disabilities, but least often to those with mental health issues (Davey et al. 2007). SCIE (2009) highlighted that UK local authorities were spending 15.5% of their care budgets on DP for those with physical disabilities, with much less allocated to other user groups: learning difficulties (1.1%), older people (0.8%) and mental health issues (0.4%). These discrepancies may exist due to the reluctance of SWs to offer DP to older people (Leece 2007) and those with cognitive difficulties (Ridley and Jones 2002).

Northern Ireland

Riddell et al. (2006) report that in 2003/2004, 2 local authorities in Northern Ireland had no DP users. They report in Northern Ireland there appears to be ‘a greater suspicion about DP, either from local politicians or from public sector trade unions’. This may lead to difficulties in accessing unbiased DP information in Northern Ireland. A lack of clear systems within social services regarding DP may act as a barrier, with no valid structure in place to access DP (SCOPE 2002).

However, more recent implementation drivers have been introduced in Northern Ireland alongside related legislation, and targets, which may have impacted positively on DP uptake. Priorities for Action published by Department of Health, Social Services and Public Safety for 2010/2011 in Northern Ireland (DHSSPS 2010, 25) states:

Direct Payments also play an important role in facilitating independent living as they offer service users flexibility, choice and control over the purchase and delivery of the social care services that best support them. Trusts should continue to promote the use of Direct Payments as an alternative to traditional social care provision.

The draft commissioning plan in Northern Ireland (Health and Social Care Board and Public Health Agency 2011) also set targets for uptake of DP stating that by 31 March 2012, the number of DP users across all Trusts should have reached 2100.

Aim

To evaluate the impact of DP on users receiving care or support at home and highlight potential barriers to uptake of DP in a large Health and Social Care Trust in Northern Ireland.
Design

A cross-sectional survey of people in receipt of DP in the Trust was completed.

Method

Sample

Due to the nature of DP, the vulnerable nature, and often, complex needs of recipients requiring care at home, informal carers may be best placed to comment on the scheme. Accordingly, for the purposes of this study, DP users were defined as those who were in receipt of DP or the informal carers who implement the budget on behalf of a service user. As the research aimed to discover the impact of DP on service users, participants were asked about their experiences of the DP programme and its impact on the user. Records indicated there were 317 DP users within the jurisdiction. An overall sample size of 30 users was proposed for the study (10% of all DP users in the Trust area). All DP users in the Trust’s jurisdiction were invited to take part in the study, with the sample drawn from those providing consent to participate on a ‘first come, first served’ basis.

Measures

A review of the literature revealed no standardised measure of DP user experience. Therefore, a semi-structured interview schedule guided by the existing literature was devised. Section 1 gathered information on the participants’ background including gender, age, user group, location and level of education. Section 2 allowed the participant to speak more extensively about their experiences and views on certain topics associated with DP, including benefits associated with the scheme, the challenges faced and the support services available. Section 3 included the instruction: ‘Below are a number of statements that you may agree or disagree with. Using the 1–5 scale shown, indicate your level of agreement with each item by circling the appropriate number’. The statements were scored on a Likert scale ranging from 1 — Strongly Agree to 5 — Strongly Disagree.

Procedure

Eligible participants were identified through a DP Liaison Officer who contacted the potential participants via post, sending each potential participant an information leaflet, consent form and a copy of the interview schedule to be used. Those wishing to take part in the study were asked to return their
Results

In Section 1 of the interview schedule participants provided background information, which is broken down as follows. Thirty respondents took part in the study (8 males and 22 females). The sample was made up of 2 DP users and 28 informal carers. The respondents were all aged over 18 years. Respondents also provided information on the gender of the DP user themselves (19 males and 11 females). 33.3% of the sample live in urban areas, whilst 66.7% live in rural locations. Forty per cent reported the service user belonged to the learning disability user grouping (See Table 1). Respondents all implement/manage the DP scheme. Twenty-nine respondents provided information on their education level. Four (13.8%) reported they had a primary school education, 8 (27.6%) were educated to a secondary level, whilst 17 (58.6%) had third-level education.

Thirteen respondents had been using the DP scheme for less than 2 years. Of the 17 using the scheme for longer than this, 5 had been using it for more than 4 years. Ten respondents had previous experience of traditional care received from the Trust, eight of these reported they preferred the DP scheme, one preferred a blend of DP and traditional care; and one did not answer this question.

Table 2 illustrates the responses to Section 3 of the interview schedule. One respondent offered no response to the statement ‘I find it difficult to keep up with the paperwork’, therefore there are only 29 responses for this.

Results indicate the majority of respondents see DP as a scheme that allows greater independence, control and flexibility of care. The majority also report they find it beneficial to choose their own carer, with all but one participant reporting they could choose a carer sensitive to all needs. All respondents

<table>
<thead>
<tr>
<th>Group</th>
<th>Frequency</th>
</tr>
</thead>
<tbody>
<tr>
<td>Physical disability</td>
<td>8</td>
</tr>
<tr>
<td>Learning disability</td>
<td>12</td>
</tr>
<tr>
<td>Mental health</td>
<td>2</td>
</tr>
<tr>
<td>Older adults (65+)</td>
<td>5</td>
</tr>
<tr>
<td>Children (&lt;18)</td>
<td>3</td>
</tr>
<tr>
<td>Total</td>
<td>30</td>
</tr>
</tbody>
</table>
reported they have a good relationship with the employed carer. There was a mixed response regarding the improvement of the quality of care under the scheme; this may be due to the fact that some respondents had no previous experience of other care services, so felt they could not comment on improved care under the DP scheme.

Eleven reported difficulty with the assessment process for the scheme, whilst some reported difficulties with paperwork and the responsibilities under the scheme; however, the majority again reported no problems in these areas. As can be seen in Table 2, some of the respondents highlighted issues of dissatisfaction around the level of support provided by the Trust (10 out of 30) and the DP scheme itself (4 out of 30).

The information gathered from Section 2 of the interview schedule is detailed below.

**Table 2.** Responses to 12 statements relating to DP scheme.

<table>
<thead>
<tr>
<th>Statement</th>
<th>SA</th>
<th>A</th>
<th>N</th>
<th>D</th>
<th>SD</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>I feel direct payments have given me a greater level of independence</td>
<td>10</td>
<td>17</td>
<td>0</td>
<td>2</td>
<td>1</td>
<td>30</td>
</tr>
<tr>
<td>I feel I have greater control over my care</td>
<td>12</td>
<td>16</td>
<td>1</td>
<td>0</td>
<td>1</td>
<td>30</td>
</tr>
<tr>
<td>I can create a more flexible care package which suits me</td>
<td>14</td>
<td>13</td>
<td>1</td>
<td>0</td>
<td>2</td>
<td>30</td>
</tr>
<tr>
<td>I find it beneficial to choose my carer personally</td>
<td>19</td>
<td>8</td>
<td>3</td>
<td>0</td>
<td>0</td>
<td>30</td>
</tr>
<tr>
<td>I have been able to chose a carer sensitive to my health, social, religious and cultural needs</td>
<td>13</td>
<td>16</td>
<td>1</td>
<td>0</td>
<td>0</td>
<td>30</td>
</tr>
<tr>
<td>I have a good relationship with my carer</td>
<td>17</td>
<td>13</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>30</td>
</tr>
<tr>
<td>The quality of care I receive has improved under the direct payments scheme</td>
<td>9</td>
<td>6</td>
<td>11</td>
<td>2</td>
<td>2</td>
<td>30</td>
</tr>
<tr>
<td>The direct payments assessment process was straightforward</td>
<td>3</td>
<td>14</td>
<td>2</td>
<td>7</td>
<td>4</td>
<td>30</td>
</tr>
<tr>
<td>I find it difficult to keep up with the paperwork</td>
<td>2</td>
<td>4</td>
<td>5</td>
<td>13</td>
<td>5</td>
<td>29</td>
</tr>
<tr>
<td>I find the responsibilities associated with direct payments can be a bit overwhelming</td>
<td>1</td>
<td>4</td>
<td>5</td>
<td>14</td>
<td>6</td>
<td>30</td>
</tr>
<tr>
<td>I am satisfied with the level of support provided by the Trust</td>
<td>4</td>
<td>12</td>
<td>4</td>
<td>7</td>
<td>3</td>
<td>30</td>
</tr>
<tr>
<td>I am satisfied with the direct payments scheme</td>
<td>11</td>
<td>13</td>
<td>2</td>
<td>3</td>
<td>1</td>
<td>30</td>
</tr>
</tbody>
</table>

reported they have a good relationship with the employed carer. There was a mixed response regarding the improvement of the quality of care under the scheme; this may be due to the fact that some respondents had no previous experience of other care services, so felt they could not comment on improved care under the DP scheme.

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The information gathered from Section 2 of the interview schedule is detailed below.

**Information**

Half of the respondents’ report they learned about DP through a SW attached to the service user’s case. Some report it was explored as an option with the SW after a change in circumstances, e.g. patient hospitalisation, others report that the SW brought someone along with them to discuss DP as an option, for example a psychologist, a community nurse. The remaining participants heard about DP in a variety of ways, including having used the DP scheme elsewhere previously; accessing information online and making further enquiries; through
previous employment as a carer; through support groups; through staff who worked in the Trust; through reading leaflets; or through friends or parents.

The sample expressed differing degrees of satisfaction with the information they received about DP; some found it to be straightforward, posing no problems. Others had a few issues with the information, but reported it was generally ‘okay’. However, some found the information provided was not accessible (too technical), not sufficient or not clear around the scheme. Others were overwhelmed with the sheer volume of information received on entering the scheme. The difference in opinion across the sample may have varied as a function of the support provided with the information and the knowledge of the person providing the DP information. Those who reported receiving support and clear explanation in the early stages, appear to have felt the information provided was accessible:

I have a very good SW. I had a visit by the finance people before I started to do this. I had very good support.

In contrast, those with less positive experiences reported poorer delivery of initial information:

Certainly the first SW that came out, she was quite young, being fair to her, maybe she hadn’t been instructed in the use of Direct Payments and how it actually worked.

**Experiences of DP**

The majority of respondents report relatively positive experiences, highlighting the benefits for the user and the informal carer, the flexibility of the scheme and control over care. Many respondents report DP to be a good scheme which they have little or no trouble with. Some point to the flexibility of the care, being of utmost importance, fitting care around family life:

It’s been excellent in terms of, it wasn’t the case that we were going to buy in care at certain times of the day; it was more our family was going to dictate how that, and the amount of flexibility we were going to need.

Although experiences differ across the group, the scheme is viewed positively by most. Some did highlight negative experiences of the scheme, pointing to initial difficulties with banking, difficulties arising when trying to organise adequate carers and issues with associated paperwork. Despite reports of fairly positive experiences, it should be noted the scheme may pose issues for some users.

Respondents have different views on their main responsibilities under the scheme. Many of the respondents point to the importance of ensuring paperwork is kept up to date, with records made and stored, returns sent back, tax
and national insurance dealt with and payments made to employed carers. Others see the main responsibility of using the scheme to ensure the patient is cared for and their needs are met. Respondents recognise the role of the carer as key in the process, and indicate their responsibilities around recruiting the right personnel, payment of carers, working practices and monitoring of the carer and level of care provided.

Respondents had differing opinions on their role as an employer. These seem to vary based on the level of experience the individual has of the scheme, their professional background, their engagement of outside agencies and the number of carers they employed. Many respondents reported that they had no problem taking on this role and were managing well; others stated they were initially a bit uneasy or afraid, but as their experience of using the scheme grew, their anxiety around this decreased. Some reported the involvement of other specialised agencies or individuals, reduced their worry about being an employer. However, some still had concerns:

I don’t think anybody is a natural born employer and that may be something you don’t realise going into Direct Payments, that you do have responsibilities and duties as an employer.

You have to take the mindset that your home is a workplace and that can be a bit of a disadvantage.

Some respondents reported no drawbacks with the scheme. However, for others, a lack of knowledge and support provided were key drawbacks:

Lack of support … If you choose Direct Payments you are left to work it all out yourself.

Many reported no issues in keeping paperwork and returns up to date, with some stating that receiving initial support in this area helped them feel more capable. Others point to support being available, allowing them to ask questions and get clarification when dealing with the paperwork and returns.

The (rep) that came out here and went over all the paperwork left me wee copies and things and any queries over the first couple of returns, I didn’t want to do anything wrong, I just rang or called in with her at the office.

A number of respondents stated that external agencies, mostly, took care of this aspect, whilst others had their own system for dealing with the paperwork. Some suggested that due to other commitments, sometimes the paperwork slipped their mind. The majority report they have no difficulties with banking or finance arrangements. A few had issues setting up a second bank account, difficulty in payments coming into the account and discrepancies in payments. An issue arose for one user when the DP were originally awarded, with a long delay between the agreement of DP provision and the implementation
of the scheme, leaving them to fund the care required in the interim. One respondent reported difficulty getting the required information from the Trust.

Many report they had no difficulties with recruitment because they either employed a family member, knew of someone with the necessary skills, got recommendations by word of mouth or went through an agency. Others had advertised to recruit appropriate personnel. However, for a few people, recruiting was difficult:

We were left very much on our own. (Patient) has very complex needs and we were just getting used to that ourselves. It was just going to the job centre, putting in the ads, getting the replies and seeing who was suitable and trying to get references to decide if this was somebody you wanted in your house ... We have very good carers now, but it didn't always work out, some of the people ... would take the role, go for the training and drop out at the last minute which was very frustrating.

A number of respondents reported they knew what DP could be used for as they received clear information on this, whilst others were a little unsure and wanted clarification. Some felt they have had no clear guidance on this. A few respondents identify dealing with the Trust was challenging:

There seems to be a block on what package is allowed. I don’t think any assessment there has ever broached the 24/7 care that (patient) needs. When they come out to do the assessment, they go away and write their own assessment then which was nothing to do with what was said here.

One respondent reported issues with the assessment process. Others identify other challenges including difficulty in recruiting carers in rural areas; finding replacement staff; police checks preventing carers from starting care role immediately, leaving the user without care in the interim.

The majority reported the flexibility of the scheme and the control over care were key benefits. Some pointed to patient benefits under the scheme:

I think it’s great I was able to pick someone for (patient) who I knew (patient) would really relate to, for (patient) to spend time with. The things that (patient’s) done, got to do, over the last few weeks because of (carer) it’s amazing.

Others highlight the benefits for the informal carer:

For us, it’s a godsend that we get a bit of a break ... it just gives us a bit of freedom, we can get away and do our own thing for a while.

Whilst some highlight that DP allow the patient to be looked after at home:

If we didn’t have this we couldn’t keep (patient) at home; we’d have to hand (patient) over to someone.
Advice and Recommendations

In general, the advice given, for future users, was positive and practical. A number of the respondents offered enthusiastic recommendations suggesting people should take the scheme on, having no hesitation in recommending it:

I would advise that I find it’s a much better system for care, the flexibility that you have, just the control you have over hours.

Others pointed out some issues the individual may need to consider prior to entering the scheme:

The first thing is for a service user, if you are not capable of managing this yourself ... do you have friends or family that would help you manage it? If you are not able to manage that I would suggest that go the route of pay an agency directly for your care or accept domiciliary in-house care from the Trust.

Others gave more specific advice or suggestions such as keeping accurate and timely records and getting an external agency involved to handle elements of payroll. One respondent warned against entering the scheme as the necessary support was not available.

A number of respondents indicated they are happy with the scheme as it exists, and believe it should not be altered. Some identified issues around the paperwork, with some requesting it be simplified. Others offered suggestions for simple support measures such as reminders of key dates via a text message or email. Some suggested some resources to guide them through how the paperwork should be completed would be helpful:

If they had a disc or something that you could load onto the computer that shows you exactly what it is you have to do, I think that would help a lot.

Some respondents point to the provision of timely information regarding changes and Trust feedback on forms submitted as areas that could be improved. One respondent suggested the scheme could be improved by providing clear, concise information and possible templates to employers e.g. standardised contract, employee rights, holiday entitlements and terms of dismissal. Some respondents see the lack of public awareness of the scheme as a matter that needs to be addressed:

The Trust publicly acknowledging that it’s choosing to offer it in circumstances where the person is capable of managing it. The Trust has to offer it.

A few pointed out that sometimes they were left without a carer, if one person left and they had to take the time to recruit another. They suggest perhaps a list of approved carers in the local area would help.
Discussion

This study was designed to examine the impact of DP on service users; highlight associated benefits, difficulties and issues; and ensure recommendations to drive change in the scheme were put forward by those who use the scheme and would be most affected by these changes. Overall, the results suggest that for the majority of respondents, the experience of DP has been positive. Users report a greater sense of independence with DP, which may be related to the reported benefits of DP.

Maglajlic (2000) argued that DP fit within the new wave of consumer-directed care, and as such respondents should feel they have greater control over their own care. Indeed, one of the key benefits identified by users in this sample was a greater level of control in relation to their care. The current sample of DP scheme users reported control over selection of their carer, the carer schedule and the type of care delivered. Respondents were happy to have greater continuity of care, with their care provided by the same person (or people) on a regular basis, instead of having a dependency on more traditional care services delivered by different people over time, and at a time that ties in with the carer’s working schedule, rather than with user needs. These findings appear to be consistent with previous work, suggesting service users have more independence under the scheme, with control over the quality of their care (Hasler, Campbell, and Zarb 1999; Ungerson 2004).

Among the sample, this element of control appears to reduce some of the anxiety around user care, as not only do the users know what to expect from their employed carer, but also they can build up a relationship over time. The informal carers report they have peace of mind, knowing that the employed carer has been through a police check, is capable of providing the care needed and the extent to which they can rely on the carer.

SCOPE (2002) highlighted that users of DP seemed to select the scheme as it was one that offered the user choice and flexibility. Among this sample, the flexibility of the scheme appears to be beneficial for both the user and the informal carer. The flexibility to use the hours allocated, in line with user needs, providing care at a time suitable for the user was reported to be beneficial and also key to allowing greater independence. It was reported DP allowed the user the flexibility to build the care around their day-to-day lives, rather than have their lives built around the care. The flexibility of the scheme meant that scheme users could schedule their care at times when it was most needed, allowing family life to function alongside the care, with user and family needs paramount in the design of the delivery of the care package. Priestley (2005) reports this flexibility is key in leading to more independent living for users. DP allowed users in this sample to employ an individual who may be more sensitive to user needs e.g. employing carers from the users’ own peer group to care for them. This could account for the fact all respondents have a good relationship with their carer and all, with one
exception, report the carer is sensitive to social, religious and cultural needs of the user.

However, issues such as recruitment or sourcing of appropriate carers and contracts of employment were salient issues for this sample. Indeed, these issues appear as concerns for users within the literature, with various researchers highlighting concerns around vulnerable users recruiting and employing carers, difficulties with the recruitment process and the interest and availability of appropriate personnel (Glendinning et al. 2000; Carmichael and Brown 2002; Ungerson 2004). While this may suggest a reluctance or fear for many to become an employer under the scheme, conversely, among the sample, the role of being an employer did not appear to be daunting for some, especially those who had involved an agency to deal with the care or the paperwork; or those who had a background that provided them with insight into aspects of employment.

None the less, the scheme is not without its challenges. Although the majority of users reported satisfaction with the support from the Trust, others highlight this as a problem for them, requesting provision of more current information, regular updates on changes and clarification on certain issues. However, it appears these are issues for many providers, with the research suggesting the key role of providers in offering users appropriate levels of support to improve satisfaction with the scheme (Pearson 2006; SCIE 2009). A lack of clear, concise information available for users was a complaint among the sample, with many suggesting they would like to receive current and timely information on changes in rates of pay, details on what exactly the DP can be used for and information relating to employment and employment legislation. This need for further information and advice for scheme users also arises in the literature (Glendinning et al. 2000; NHS Confederation 2009).

It appears, for some among the sample, that the challenges associated with the scheme often arose at the initial set-up stage. Difficulties understanding the scheme at this stage, for example due to a lack of information or a lack of explanation, may have meant some found using DP more difficult than it should have been. Findings like these among other scheme users may have been the reason why those offering DP have requested training to allow them to be more informed when offering DP to potential users (Maglajlic 2000). As suggested by the research (Spandler 2004), some in the sample highlighted the issue of paperwork and administration as a challenge; however, the responses from the sample suggested better levels of support and information provided initially appears to lead to better compliance. The literature suggests difficulties may exist in Northern Ireland in relation to promotion of DP (SCOPE 2002; Riddell et al. 2006). Some of the respondents in the sample report that the key issues for uptake in Northern Ireland may relate to a lack of public awareness of the DP scheme.

It appears, in general, DP have led to improved care for users, with the majority of people happy to recommend the scheme to others. It may be important to note that one theme that kept recurring among the sample was
the ability to care for the user in their own home, not having to choose to place them into a care home or ask social services to step in as the situation had become too difficult.

**Implications for Social Work Practice**

The findings highlight the benefits of the DP scheme; however, it is clear that it is not without its challenges. In the light of the current push towards consumer-directed care and care in the community, the key messages from the service users may help shape social work practice in relation to DP provision, and interestingly all revolve around communication, support and provision of information. The research indicates a number of areas, for consideration, which it is hoped would ensure increased uptake of the scheme, better implementation and compliance from service users, and overall improved service provision. The following recommendations may provide a key starting point for SWs introducing, or considering suitability of the DP scheme for their client, and recognising the needs of service users as they implement the scheme themselves:

- Additional support would be most beneficial at the set-up stage (with new scheme users).
- DP scheme users may benefit from ongoing support from the Trust and other related organisations (e.g. HMRC).
- Scheme managers may require further training to ensure they are comfortable with and knowledgeable about the scheme and how it should be implemented.
- Provide users with current and timely information.
- Allow user access to a registered list of approved carers in their local area who could step in on a short-term basis to provide care.
- It may be helpful to consider the provision of a central information point within the Trust for DP users.
- Create a public awareness of the scheme, e.g. through advertising.

**Limitations**

The research was conducted among a small number of participants, therefore the views presented may not reflect those of all scheme users. Also, the recruitment of participants was dependent on participant consent. Therefore, although a number of DP users were contacted to take part in the study, only those who replied to the Trust consenting to take part in the research were involved. This led to a large number of respondents being recruited from one area (47%) and left other areas in the Trust jurisdiction possibly under-represented. Again, as only those consenting to take part in the research could be
involved, and although respondents from all user groupings were included, the study did not allow unique barriers to uptake and implementations among individual user groups e.g. mental health or older adults to be explored in depth.

Conclusion

For the majority of the sample, the scheme offers a flexible care option that is controlled by the user, to deliver a user-specified, tailored programme of care that could not be facilitated under any other current care provision offered by the Trust. However, the scheme is not a perfect one and as with any scheme reliant on people for its implementation, there are apparent issues. A lack of standardisation of information, support and advice offered appears to create a difference of opinion about user experience. It may be the case that the implementation of the recommendations listed above could help to eliminate a number of the challenges reported, whilst ensuring the areas of the scheme which function effectively and bring benefits to the user remain largely unchanged.

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References


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