

Choice or Chore?



Carers' experiences of direct payments

November 2008



Choice or chore?

"Direct payments is the best thing since sliced bread."

If you look after a disabled or elderly family member or friend you can't do it alone. You rely on being able to get some support so you can get a break. Some rely on family and friends to step in, those with money can buy services from a care agency but many families, especially those looking after someone with substantial care needs, rely on social care from their local council to provide them with the support and back up they need.

Over the past few years things have been changing in social care. The government is moving forward with what they call the 'personalisation agenda' – a major programme to change the way social care is delivered to disabled people, older people and carers. A new scheme called direct payments is giving cash directly to families to make their own care arrangements.

Choice or Chore looks specifically at carers experiences of these direct payment schemes. 3 out of 4 carers rate direct payments as better than the services they previously received from their council. Carers tell us that direct payments have brought the freedom, control and choice they have always wanted. Half of the carers surveyed said they had more free time since getting a direct payment.

Choice or Chore's positive message also comes with a warning that proper support must be in place to help carers manage direct payments. In many cases it is the carer who manages the direct payment. Administration and management of direct payments get added to a long list of responsibilities held by

carers. There is a risk that whilst benefiting the service user direct payments can leave the carer worse off as extra responsibilities eat into their precious free time.

Whilst giving choice and flexibility direct payments must never be a way for local authorities to wash their hands of families in need. Proper back up and support must continue and when a crisis happens local authorities must be ready and able to step in and take over. Yet this survey shows 79% of direct payment recipients have no contingency plans in place. Government has given extra money to local authorities to increase take up of direct payments and so local authorities and their staff must ensure proper help is there for carers to administer them.

Councils are setting stiff targets for the take-up of direct payments. Government is also planning to further expand 'personalisation' with the introduction of individual budgets, where money is pooled from different departments to give families a single cash payment. Many of the lessons drawn from this survey could also apply to plans for individual budgets, namely that local authorities must ensure that carers' needs are considered and that assumptions are not made about their willingness and ability to manage complex care packages on behalf of the person they care for.

Our survey was full of success stories. If problems can be overcome then it is clear that direct payments can give families control over their own care packages in a way that can change lives.



Case studies

X Lorraine...

Direct payments aren't working for us. Social services just want to hand over the money and walk away. My son has severe learning difficulties, autism and challenging behaviour. The main problem is there are no services to buy locally that can meet his needs.

Both me and my husband gave up work to care. He works 3 days a week and I work the other 2, but we would love to get a break where we could both take time off. This simply isn't an option unless we find staff with the high level of knowledge and expertise needed.

"It seems a cop out to simply hand over the money and leave us to it."

In the end we have to use the money to pay family and friends to help us out. Social Services are OK with this but it isn't a proper consistent care package for our son. It's irregular, ad-hoc and doesn't give us a break because they aren't qualified it means one of us must always be there as well.

It's just a non-starter for us. What happens if our son hurts someone? At least with Social Services the staff are trained and we have a large organisation to fall back on and the ultimate responsibility is not ours.

I'm sure it's a brilliant scheme for people with less complex needs than my son but for us it seems a convenient cop out for the LA, simply to hand over money and leave us to it.

✓ June...

"My mother isn't always comfortable with strangers providing the personal part of her care. Direct payments allow me to buy help around the house, which I couldn't previously access under our old care package. This allows me to care without the pressure of having to do all the cooking and cleaning as well. Often these domestic jobs just didn't get done, or I could only do them in a slapdash way. I work full time, but I can now also pay someone to look in on my mother to check she is OK whilst I'm at work. The key is flexibility - my mother's needs change and the services we buy with direct payments can change with them and fit around us.

Direct payments allow me to get some 'me' time and I am sure that my mother also feels the benefits - she relaxes more and she is not on the receiving end of my tired temper. The flexibility means that we can pay someone to support us going out shopping if she wants to.

"I no longer feel a failure."

Being a carer can change your relationship with the person you care for. Direct payments have allowed us to get back some of that mother/daughter relationship. I would not change providing care for my mum, but when you love someone you want to be all things to them. When you can't do this you feel a failure. I don't feel this way anymore. We spend quality time and her care is successful.



The benefits of direct payments

We asked carers who had direct payments what they thought of them. It is encouraging that only 9% said their experience was negative. 38% had mixed feelings - they could see the benefit to the person they cared for but the paperwork and other issues had caused problems for them as a carer. Just over half reported that their overall experience of direct payments was positive and 57% would recommend the scheme to others.

It was clear that the flexibility and choice that direct payments allow can have a direct benefit to the quality of care received. Many carers felt they had better staff, the service was more reliable and in turn they had more free time.

73%

found that the care they purchased with the direct payment is better at meeting needs than their previous service

"Much as I love him, I have no interest in my husbands hobbies - now I don't have to be involved in them as his workers are. It gives him something to tell me about or if he wants can keep it private, something he hasn't had for a long time. direct payments suit us perfectly."

73%

said they can get services at a time when they need them

"It has been a life saving experience, being able to employ good quality, loyal staff who come at the times we want them and carry out the services we need."

49%

said they get better quality staff

"They are here for the full length of time and not rushing off to the next client. I am far more comfortable with them in the house. I feel sure my husband is better for the continuity of people we like. They treat husband as a person and not just a job."

49%

said they have better continuity of staff

"My husband careworkers have been with him for 7 years and have good conditions of service working for us. We treat them well and there is mutual respect. They are almost part of the family."

46%

can use the direct payment flexibly to pay for things that were not available from the council

"I used the direct payment to employ an agency to do domestic work so that I can 'enjoy' my caring role, looking after my 11 year old son."

48%

of all respondents reported that they have more free time since getting a direct payment

"The provision of direct payment for my son has made a huge impact on our family. We can now give dedicated time to our 2 other children, in the knowledge that our son is being well cared for. We can organise short notice evenings out as a couple, which was never possible before."



The process

Applying for a direct payment

Applying to get a direct payment can be problematic. 1 in 4 carers waited more than a year from making an enquiry to getting their payment set up. Whilst it took most respondents less than 6 months to set up the direct payment, this is still a long time when the need is great. Application processes must be simplified.

It is also important that full information is supplied that allows people to make informed choices. Local authorities have targets to meet on numbers of people getting direct payments and it is important that these do not result in people feeling rushed or forced into accepting direct payments.

- 48% said that having the direct payment was their own choice based on full information. However a worrying 5% felt that they were forced into having a direct payment without knowing enough.

"I was coerced into accepting direct payments to pay for one particular service for my son. It has been a nightmare from start to finish. It took months for the payments to get authorised, meaning I was seriously in arrears before we even got started."

Setting up the care package

When you get a direct payment there are two main routes. The first is for those who don't want the responsibility of becoming an employer and that is to employ a care agency.

Good practice: Ayrshire Independent Living Network

What does it provide for direct payment users?

- **Payroll Service:** works out tax, NI and staff wages, and the individual pay the employees themselves. They charge £20.50 per months from the direct payment for this support, regardless of the number of employees.
- **Training for direct payment users as employers/ in employment law:** can do training on a one to one basis and go to the persons home to do it, or they or source training from Scottish PA Employers' Network.
- **Support PA recruitment:** advertising, posters, interviewing support, enhanced disclosures, references, send out forms before interviews, source free interview premises, termination/offer letters.
- **Employment support:** provide contracts of employment, sorting out specific problems with members of staff as intermediaries in disputes, ensuring they have proper employers' liability insurance. AILN go to the carer's home, go through paperwork and talk them through it.
- **How much do users pay?** £20.50 a month for payroll, rest of the support listed above is free.
- **How do direct payment users hear about it?** Mostly referrals from LA or the local hospital.
- **How many people do they practically support?** Currently they provide payroll support to 140-170 users.
- **Structure & Staff:** registered as a charity, user-led, run by a committee of disabled people, many of whom are direct payment users. Employ a full time direct payment Support Worker and two part time Payroll Officers, a management committee and volunteers.



"Using an agency covers sickness and holidays. We also have very little in the way of paper work as the agency employs the staff."

Many on direct payments chose the second route - to arrange their own care and become an employer. This brings with it huge responsibilities to pay tax and have proper insurance. There should be proper support and help with these responsibilities (see box on Ayrshire on page 5). It is clear from **Choice or Chore** that without support this responsibility can overwhelm families.

- Most recipients had received some help with being an employer, only 24% did not receive any help with being an employer. More than one in five (21%) said that they received some basic training and information. A further 28% are getting regular and ongoing help. For most people (78%) who receive help, it is available for as long as they need it.

"The prospect of becoming an employer and negotiating all the administrative tasks involved in direct payments was daunting and has caused stress and pressure on my free time as a carer. I feel that I wasn't prepared effectively to manage direct payments. I suspect that a 3 hour training session would have equipped me adequately and avoided the increased pressure I felt as a carer."

For those who received help, this covered a wide range of areas. Most people (70%) received help with tax and National Insurance, but people also had support on sick pay (42%), disciplinary issues (26%), covering staff sickness and holidays (25%), staff training and development (21%).

There were several examples of carers who had not had support and this had led to stress and in some cases they had chosen to abandon direct payments.

"Grandad can't do the paper work so it's left to me, just another job on top of my busy schedule. Why can't it be simplified? I am going to pack in the direct payment. I just do not have time to fill in forms and I don't want any added stress."

Running the package

In giving a direct payment most Local Authorities pay a set hourly rate. In some areas care may be more expensive than the Local Authority will pay. Our survey showed that most people (70%) can buy at least the number of hours they are assessed as needing and 15% can actually buy more hours. But 15% face a shortfall in care. This is worrying as it means that any shortfall in care is likely to be met by the carer.

One of the advantages of direct payments is the flexibility to employ someone who is already known to the person needing care. This can be especially valuable with certain conditions such as mental illness, learning disability or dementia. However there are restrictions in the rules on employing family members who live in the same house.

- 74% employed a friend or someone already known to the person who receives care – 45% employed a family member. 65% believed the rules about who could be employed with a direct payment should be less restrictive so that close family members can be employed more easily.



"Direct payments are the best thing that could have happened to our family. My husband would not readily accept care workers, luckily our local authority accepted our employing a family member as he has complex needs. Prior to this I coped and struggled on, virtually alone, for 20 years with no input from Social Services. If direct payments had not been available for our family, I would still be going it alone."

53% of respondents said they had experienced problems recruiting staff. The biggest reason for this, cited by 62% of those who had experienced problems, was that it was hard to find suitably qualified staff. For those 20% who have experienced high staff turnover, the most common reason was that the rates of pay were too low. Other issues were that the careworker was only looking for a short term job or that they had learned new skills or been trained which they were able to use to get a better job.

Administration

Doing the administration of a direct payment will often fall to the carer and our survey found most carers spend at least some time each week on administration tasks. Mostly this was less than 5 hours but in some cases it was much more onerous.

Nearly nine out of ten (88%) respondents reported that they spend less than five hours per week on administration. However 10% spend between six and fifteen hours per week and two percent spend more than 21 hours per week. 21% of carers said that they have less free time since taking on a direct payment.

"I find rotas and timesheets and monitor sheets can take up my previous 'me' time which is very scare since it is only my sister and I who look after Mum and we both work."

In return for all this work just 4% of respondents reported that they get any financial compensation for their administrative role. 66% thought that carers should be paid for the time they spend on administering direct payments.

"I am given £3 for my administrative time per month which is clearly below the average wage! The vital role of the carer in direct payments needs to be recognised or more money given to employ an administrator."

Ongoing support and help

For most carers using direct payments leads to less contact with social services. This can be a positive thing.

"Best thing we ever did. We are in control and can control how Social Services gets involved. We have tended to shy away from support in the past and do it alone, fearing intrusion."

However others expressed fears that they were being left to get on with it. One of the most worrying findings was that 79% of direct payment recipients have not discussed emergency planning with their social worker (see box on page 8).



"You are left with worry of what to do and what will happen if you cannot find anyone when the staff is leaves. In my case, I will not be able to go to work, and if it continues for too long I may lose my job."

Promoting direct payments

Whilst the benefits of direct payments are clear 38% of respondents to our survey did not receive a direct payment. Some had never been offered one, some simply didn't want one. For some the condition of the person they care for is such that direct payments just aren't the best option.

However there are clearly some misconceptions about the problems. Of those who had been offered one but had turned it down, the majority (60%) did so because it sounded like it would take up too much time to manage. Yet our survey shows this isn't always the case. Nearly nine out of ten (88%) respondents reported that they spend less than five hours per week on administration and 48% of all respondents reported that they have more free time since getting a direct payment. This suggests that if families were given proper information about the amount of time it takes to manage a direct payment, more might take them up.

Contingency planning – when things go wrong

Kate Keays

“ A couple of years ago, I suddenly developed a serious health problem and had to undergo major surgery requiring two weeks in hospital, a minimum of three months without any caring responsibilities and anything from six months to a year for a full recovery. The local authority realised that the cheapest way to keep my husband at home was through extending the Direct Payments budget to replace the extra care that I would usually be providing.

Following my surgery there was no way I could step in and provide back up care so we only agreed for Mitch to stay in the family home, on the basis of a guarantee that Social Services would back us up if the Direct Payments system failed. The guarantee was given but it proved to be a promise that the system couldn't support on the ground.

When things inevitably broke down through unforeseen PA absences, I had no choice but to put myself at serious risk and undertake tasks in clear contradiction to medical advice. I was terrified of injuring myself but what could I do? I was forced to break numerous health and safety guidelines in a very serious way. It was such a tortuous and distressing time for the whole family.

If local authorities and government are going to push Direct Payments they must give carers the same level of support and protection that a paid employee would receive. They must do more to develop realistic and reliable contingency plans to meet the unforeseen.”

Sadly, in September 2008 Kate's husband Mitch passed away suddenly. Kate has kindly agreed for us to use her story and the video footage.

See Kate's video diary at www.youtube.com/CarersUK



Conclusion

With local councils setting targets for take-up, it is clear direct payments are here to stay. There is no doubt from the evidence in our survey that they have the potential to deliver choice and flexibility that can bring significant improvements to quality of life.

In the rush to promote direct payments and the move toward individual budgets it is important that carers don't get forgotten. In many cases it is the carer who will be managing the direct payment. Councils must ensure carers' needs are considered too and that families do not get saddled with inappropriate levels of administrative and managerial work, on top of already heavy caring responsibilities. It's also important that after direct payments are awarded that support and back up should continue. Carers need to know they have someone there if things fall apart. Contingency planning needs to be given much greater priority.

It is clear that the responsibilities of becoming an employer and problems such as finding suitable staff, act as a deterrent to some families in accessing direct payments. More should be done to promote good practice. Carers who have already made it work can be a valuable asset as 57% said they would recommend it to other carers.

Direct payments have the potential to make a really positive change to the way social care is delivered but care must be taken to ensure they are truly a choice and are not seen as a chore for carers.

Direct payments: 8 lessons for local authorities

Carers' experiences of direct payments depend on how well their local authority supports them. Here are some of our key findings that could help local authorities improve their service for carers.

1. Speed up the application process

Cut waiting times and simplify the assessment process. 1 in 4 carers waited more than a year from making an enquiry to getting their payment set up.

2. Make it a real choice

Direct payments are not right for every care situation and no one should feel pressured into accepting them. This is enshrined in government guidance and councils should follow it.

3. Provide employment support

Local authorities should commission, and signpost direct payment users onto, third party support organisations who can manage functions like payroll. It is essential that good practice is shared between local authorities (see 'good practice' box on page 5).



4. Make sure all costs are covered

1 in 5 direct payment users were unable to buy all the hours that they had been assessed as needing. Local authorities must monitor direct payments to ensure that the cash awarded is sufficient to cover assessed hours. They should make sure that factors like high travel expenses in rural areas are taken into account.

5. Allow families to employ family members

45% were employing a family member and comments from carers were clear how much this was valued. Whilst some local authorities have a relaxed approach to the rules around exceptional circumstances, others interpret them more strictly.

6. Don't back off, back up

Local authorities should have appropriate back up and contingency plans in place before a carer is required to manage the direct payment independently. Families should not be abandoned but should be reassured through regular contact.

7. Value carers' administrative support

Local authorities need to do more to financially recognise the administrative burden on carers. They should implement a fair rate of administrative compensation for time spent on administration such as payroll. They should also give carers training on managing direct payments at the earliest opportunity.

8. Keep commissioning highly specialist services

Families miss out on vital support because they cannot find the right specialist services to buy with their direct payments. Even with a direct payment, local authorities still have responsibility for ensuring the needs are met so they must continue to commission and provide specialist services.

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Publication code: UK4044

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