English Authority B

Background

This authority had 250 direct payment users and another 112 who were moving through the system at the time of the study. It had a full-time direct payments co-ordinator in place since 2001.

Management perspective

The current status of direct payments in the local authority

The assistant director believed that direct payments offered more choice and flexibility which in turn offered an alternative form of care provision based on how people wanted their care provided.

Accountability and monitoring

While the assessment process was the same for all groups for direct payments, it was evident that some user groups required additional support, asked whether there would be a more stringent assessment for groups such as mental health and learning difficulties the director replied that all assessments took into account the support networks around individuals and that this was not restricted to direct payments, however, there might be an added amount of caution in relation to the additional responsibilities that direct payments brought with them to ensure that individuals were obtaining the best ‘care’ available for them.

Future plans and wider issues

There was a planned movement of the support for direct payments to an ‘in house’ support system which would bring perceived advantages to the authority. This was to be set up using the social services team already in place headed up by the direct payments co-ordinator and a new post would be created which focused on independent living issues. This in-house support system would replace the external support organisation that was currently in place.

It was believed that direct payments could extend in the future to allow individuals to purchase services from other authority areas, but was the interviewee was not sure how that would work out. However, he believed that such a system could give people additional choices and would ensure that services that were worthy and valuable would stay in place whilst other service providers who were not producing worthy services would not survive.

Key issues were to expand and extend direct payment take up.

Practitioners’ views

Background and initial reactions to direct payments
Those that attended the focus group were unaware of any direct payments in place in the mid nineties or in the early days of 2000, but felt that direct payments were promoted positively and would be especially attractive to younger people.

I mean a lot of people, young people, didn’t want to actually go into our day care centres. It wasn’t appropriate for them; so direct payment was another way of looking at alternatives to the basic day care. So that was quite a big positive.

The direct payments co-ordinator had been in place since 2001 and appeared to be key to those present at the focus grouping in the understanding of direct payments and in keeping up with any new legislation or changes that were coming through from the Department of Health.

I started in end of 2002 beginning of 2003 and the direct payments coordinator was in the post then, so once I found out about the direct payments coordinator was really useful as my point of reference to send me all the legislation, send me all the paperwork through, tell us what to do and as part of my induction I went to spend half a day with her.

For another the direct payments coordinator was crucial in the early stages and he would accompany her on home visits to understand about direct payments, how they worked and what the key issues were. These examples go someway towards proving the crucial role of a direct payments coordinator for the success of direct payments for staff confidence levels in administering direct payments.

There was also a strong push towards direct payments from the authority and from upper management, so much so that there appeared to be an over exaggeration on direct payments to the exclusion of other available services in the initial stages.

I think in the initial stages the assessments that were coming through were sometimes inappropriate because they were moving away from home care and going towards direct payments for a lot of the families. So a lot of the assessments have had to be reassessed later on because people [were] accessing direct payments at a level that’s not appropriate because there are other things, and that’s been a hiccup. But I think initially that was the problem because people had just said, Right we’re moving away from this, we’re going towards this and that’s what you need to do.

It was also evident that children’s homecare services had been replaced by direct payments, leaving families with little choice, as one care manager said for them ‘it was direct payments or nothing’. However the initial telephone interview with the direct payment co-ordinator (early 2005) revealed that the
children’s team for personal care was small and as workers left it was not viable to keep it running.

**Workloads**

Many social workers and care managers have said that direct payments create additional paperwork and are likely to add to workloads because of the more frequent reviews for direct payments (in comparison to directly provided services), or alternatively when the direct payment user encounters a problem with staffing, sickness or recruitment. Those present at the focus group felt that there was an increasing level of paperwork overall and that this was also the case in relation to direct payments.

> It’s a hell of a lot of extra paperwork. This is one of the main issues in credit at the moment. We don’t talk about paperwork because there’s that much; it just comes out of every corner. There’s more and more paperwork …

(Children’s social worker)

However, this did not appear to be the case in mental health, we were told that in mental health there was no paperwork if someone was applying for a direct payment compared to directly provided services. This was because the lead in the direct payments team for mental health would automatically deal with the application and the processing required.

> It’s easier on direct payments [name] would just take over- the direct payment is identified and the care co-ordinator would ring [name]- She just takes over- although the client co-ordinator usually deals with other service commissioning and that might be a down side for the client because they don’t have as much contact with the care co-ordinator through direct payments. But direct payments are an easier option for our workloads because it’s all taken from us.

(Mental health care manager)

It appeared that there were different routes regarding the setting up of the direct payment and the workloads for different teams. At the same time the absence of paperwork is contradicted by other factors relating to direct payments for mental health users. These included the bi-focused promotion of services at source and the direct payment.

> But we’ve also got two opposing policies one is that we use our existing services and the other policy is that we push direct payments

(Mental health care manager)

Interviewers asked if as direct payments offered more options and took more time whether the authority had recognised this and increased any package of remuneration for social workers or care managers because of it. Focus group participants said that the extra workloads weren’t recognised but they did get a letter every year telling them how grateful the authority was for their hard work.
You still get your allocated amount of cases every week, so it doesn’t matter, you know, the bit of paper they write thank you for doing so well and that’s been hard to fit that work in the 37 hours a week.

(care manager)
And we’re supposed to just be looking at low-level cases service provision and reviewing it every six months. We have on average – well I’ve got about 39 cases and if they blow up then you’re kind of thinking, Oh prioritise, which bit goes in first? When it’s smooth it’s … it works quite well because across the year you’re supposedly taking them out and reviewing them every six months.

(care manager)
Overall workloads appeared stretched for some, although case loads varied by team, region and seniority.

Training

There was some reference to training in the initial section on initial reactions to direct payments that detailed direct payments coordinator’s work which appeared to be hands on, being available as a point of contact as well as keeping everyone up-to-date with any changes around direct payments.

We’ve just learnt as we’ve gone along. You’ll have talks. The people that set it up [support organisation?] have been and talked to us but that’s the most we’ve had, so you just learn as you go along so it’s all about how to use it appropriately

Once again, in mental health there appeared to be a different route towards training. Here there was a lead for mental health in place and what was referred to as the coordinators team.

We’ve had some open forums which the direct payments coordinator ran about 18 months ago –then when [name] was taken on as lead for mental health we had some informal training. She set up the strategic group for direct payments-it was informal, we used that as a feedback forum and could always ask her questions – we used that as training she did presentations and things so we used that as a feedback forum.

(mental health care manager)
While there do not appear to be any regular training sessions, it seems that induction and informal training goes on continuously, in addition the representatives from support and the direct payments co-ordinator are available for questions and contact if any issues arise around direct payments.

Major fears for Practitioners

There were fears that the changes in the eligibility criteria of Fair Access to Care from the original four points of low, moderate, substantial and critical to two which covered substantial and critical needs would limit access for some
groups who might benefit from a direct payment. In learning difficulties for example:

As of April 1 the council won’t meet anyone’s identified needs if it’s moderate or low. Up until April 1 the council will meet everyone’s needs, so if it was just a couple of hours direct payments for social interaction then they will get it, but now the council are going to move the goal post, so anything in moderate and low won’t be met. Even though there is a clear need, what this is going to say is we don’t have the resources.

The change in the eligibility criteria was considered a potential problem for mental health users. A care manager from the mental health services team told us:

A concern of mine is the change in the eligibility criteria- we’re now looking at high complex needs –I’m concerned that these people would not manage I know its worked out in others areas OK but I do feel for mental health it wouldn’t necessarily work–

The change in eligibility criteria had been put in place because of resource issues at the authority and was one of the strategies used by other authorities. A further issue was the length of time it was taking to get packages running. At one time there had been a wait of 12 to 18 months for some selected people waiting to go on direct payments. This was related to cost issues and changes in service provision rather than the support organisation’s process, but never the less it had impacted on those wanting a direct payment.

They’ve had a blip when we … twelve months ago it was taking twelve months to get somebody onto direct payments. That’s the worse-case scenario. We’d assess somebody and it was twelve months, but it’d all to do [with]… LD service had this huge overspend so they just stopped everything.

(Learning difficulties transition)

And we had everyone going from homecare, which was completely abolished to … over to direct payments and a lot of the personal care cases, and they just didn’t have the capacity to take it all on and set it all up so there were families that when I started a year and a half ago have only just been set up and running… Children’s services … it’s probably a misuse of direct payments. They just decided, you know, they don’t care, we’re scrapping children’s homecare- you will have direct payments

(Childrens care manager)…

Potential direct payment users were being advised to use any waiting time to set up bank accounts and get as much in place as they could in order to speed the process.

Use of direct payments
Direct payments were welcomed for the additional range of options that they offered for service users and for the autonomy and flexibility that they could provide. Issues here were also related to prioritising those with the highest needs, in this authority, (as in others) the processing through panels was dependent on perceived priority of applications at that time. It also appeared that the outcome of different applications would vary by different teams according to alternative services that might be available, at the same time there was evidence of the flexibility of direct payments in providing alternative options for service users.

I think you’re just unsure sometimes, you think well I’ll just go for it and see what comes of it really…because you may get new ideas, it’s like going to the pub for pub lunches or something like that. I’ve had one for rugby, watching netball matches, because she used to play netball, she likes to go and watch that. Oh many a thing…Going swimming. Garden centres, personal shopping, which I think is a good one, you know shopping - you think shopping – it’s not that kind of shopping, it’s like when it’s running up to Christmas and things like that.

(Childrens social worker)

Those attending the focus group believed that it was sometimes easier to get direct payments in place for those in the 18 to 20 age grouping

I think they tend to push those things more because like a young person, 18, 19, 20, they still have a life, they still want to do the normal things in life. We sort of like tend to push those things and it’s not often it gets turned down.

However, this may also have been due to the relative lack of services in place for these age groups in relation to social interaction and the rejection of traditional service provision by younger people or their families. For example the traditional day centre option for learning difficulties appeared to be rejected by some leading to new options that could be satisfied through direct payments.

You know, it’s very different, you can tell the difference in physical disabilities to LD. Core services for us is day care and respite, and it’s … we’re still in big day centres and lots of families say I don’t want that. That’s not what I want for my son or daughter. So we’ll then say fine, let’s look at direct payments in conjunction with ILF, and we can put together a very creative package. This authority love ILF because it doesn’t cost them, so throwing £250 into the direct payments pot, and ILF are throwing in another £300, you’re well away. So direct payments from this authority, when it’s in conjunction, and a lot of transition cases I do are around ILF and direct payments in conjunction…so if somebody wants to go swimming or do a … they’re lucky to get four hours but we’re creative, we’ll assess needs for personal support, but they don’t use it for that, they use it to go out.

(Learning difficulties transition)
In this example flexibility is evident in the way the direct payment is assessed (i.e. for personal care but used for social activity) and in the way it is pushed through the system via ILF (if possible) for a positive outcome at panel.

**Charging Policies and direct payments**

There was some evidence of charging policies acting as a deterrent to direct payment take-up especially in the children’s team, although this factor is unlikely to be restricted to this team in this particular authority (or indeed in other authorities). As we know there is a financial assessment for all social care costs in the majority of authorities with charges based on income, yet it was only at this authority that detailed explanations revealed the true costings that were in action, the affects on potential direct payments user and the effects on the processing of applications through panel.

If the direct payment is an alternative to day care … and the day care and the direct payments is used between 9 to 5 Monday to Friday, then we could put on the financial assessment charges day care and that’s £4.10 per day maximum charge, or £2.85. …the money we recoup is pitiful. But if we then say charge as direct payments as an alternative to homecare, which has got charging policy direct, then the charge is £7.50. Or if direct payments is an alternative to an assessed need for respite, then we’ll charge them £10.50 roughly for a night’s respite. So it makes such a difference, and particularly with children’s services – I’m desperate, I’m desperate, I can’t cope – and then we say, certainly, [you] pay £7.50. They say I’ll cope. And they change their attitude.

(childrens care manager)

At the same time, it also appeared that the bigger the contribution an individual or family member was charged the more likely it was that the direct payment application would go through at panel.

At the moment the direct payment for a PA is £7.76 an hour, when you get to adult … or get to transition age, turn 18, [its] applicable to pay a service charge because they’re claiming capacity, we charge £7.50 an hour. I think we’ve got two parents out at … that have continued because we pay them £46 a week, we charge them £37!

(learning difficulties transition)

More often than not with direct payment, because the service charge is £7.50 an hour, it’s more cost effective and cheaper to the Authority to approve direct payments because of the service charge. So all these little packages that children services [are essential for weekend] support, in adult services, when you tell the parents that if they have four hours at £7.76 it’s £35 - you’re going to pay £30, we’re going to pay the, I think it’s £4.62. So the panel will say yes. They don’t say no.

**Assessments and checks**

As noted eligibility criteria was changing as of April 2006 to substantial and critical need only. Home care and personal care no longer existed in
children’s services; all had been replaced by direct payments. While the assessment process for direct payments was deemed to be exactly the same as that for directly provided services, there was a fourteen page document outlining risk assessments (adapted for particular teams) which could sometimes skew outcomes for direct payments.

It appeared that risk assessment was divided between ‘risk appliances’ and P.A.s. However, interviewees were insistent that the risk assessment outcomes were not a factor in denying a direct payment.

The risk assessment would be different. Risk assessment [is the time risk and complicated. I get everyone to sign up] – so the GP, the health practitioners, everyone’s involved that if we’re managing high risk everyone is in agreement that [the strategy] in the care plan that we’ve implemented has got risk, but everyone is in agreement that if anything did go wrong there’s nobody saying well Norman said it was going to happen. We all agreed that [he said those things] and we all agree to take them collectively. So how the care package is met, whether it’s by direct payment doesn’t sort of impact on them.

(learning difficulties transition)

Reviews of direct payment users were carried out periodically, from the focus group discussions it appeared that although children’s services team have the opportunity to be reactive to changes in circumstances, (for example in approving additional hours or crisis management on the same or next day), direct payment packages were rarely increased for adults. The situation for adults had caused numerous complaints to the authority and it was not clear from the discussion what the strategy was regarding changing circumstances for adults.

In contrast where a direct payment was being used inappropriately or in some cases not being used at all over a period of several months there appeared to be no hesitation in ‘pulling it out’ or ending the direct payment according to the discussions. The reasons given for the ending of direct payments in this way were numerous and ranged from people who had left monies in the bank over a number of months and apparently managed without it, to those who decided (but seemingly hadn’t told anyone) that they could not manage the employment issues. In these cases the authority had decided that the direct payment wasn’t needed or that alternatives should be offered. However, it would have been beneficial to hear about strategies or negotiations that might have occurred in such circumstances, as it stands the transcript of the discussion presents a picture of simply removing the direct payment.

**Why people might not want/get a direct payment**

For some teams, low incomes appeared to be the key initial barrier to obtaining direct payments. This was especially severe where direct payments were the only alternative, for example in children’s services, where the setting up of a bank account and the potential problems attached to a low income could effectively negate access to direct payments.
Some families have credit problems where they can’t get a bank account set up and, on the other hand, you’ve got families that are struggling with the concept of being the employer so therefore choose not to take on the responsibility and then there’s nothing else. And those are the families that need the support more, and we’re finding that they have been not discriminated against because it’s there for them, but it’s harder for them to access.

(childrens care manager)

In addition, the restrictions being encountered in setting up initial bank accounts for some potential users reflect a class and impairment bias, and a further potential barrier to acquiring direct payments.

They’re [the support organisation] trying to bring in the building society, trying to get people to go through the building society and work it that way, but it just doesn’t work very easily, you know. And these families that can’t get a bank account are the ones that would struggle to even run it if they could, so these families are without a service and they’re the ones that need it more than the “middle class” families that have got 2.4 children and everything’s smooth and they’ve got money rolling in.

(childrens care manager)

For those with perceived learning difficulties there were additional problems. The lead practitioner of the learning difficulties transition team said:

[It’s a ] Big, big issue. Have you got a passport? Well no. Lots of families don’t. Can you sign your name? No. Have you got a utility bill? No. You can’t have an account. And there’s, you know, these were a big issue for direct payments. ..and it’s still an issue. A lot of time we recommend to families to go get a passport for your son or daughter whether you’re going abroad or not because that will give you some sort of eligibility to get an account.

(learning difficulties transition)

These examples provide evidence of the problems of direct payments for particular impairment groups which are compounded for lower income groups. As noted the support organisation and direct payments team were currently attempting to make the process easier via the use of building societies. This is unlikely to be a problem that is restricted to this authority.

Availability of P.As
There was an admitted problem in finding P.A.s as in other case study areas. This slowed the process of the direct payment, finding P.A.s was more acute in affluent areas and in rural areas. For example in some areas there wasn’t a bus service. In the more affluent areas the lack of P.A.s could push up the hourly rate in order to recruit.

It’s wealthy housing and I always, whenever it’s the posh area, he’s got families in [place name] I’ve never been able to recruit at £7.76, I’ve always had to take it to pay at least £10 an hour.
One mental health care manager told us that one potential P.A had asked for fifteen pound an hour. This had been refused leading the potential direct payment user to return to directly provided services through homecare, another had been waiting eight months for a direct payment to be put in place because of the lack of P.A.s. The waiting times were considered to be an acute problem for mental health users because they were more likely to want a service in place ‘there and then’ and might have little patience with the process.

The lack of available P.A.s has also affected the authorities costing of packages and led them to set up brokerage system, interviewees commented that this process diluted the value of the choice and flexibility of direct payments, but was necessary due to the lack of available P.A.s

With a brokerage system the authority would commission an agency for X hours at a reduced hourly rate allowing capacity for direct payment users to obtain agency assistance, however, it was noted that the brokerage system was not the same as a direct payment because individuals did not have any control over who or when people came, as a result the control and flexibility element of the direct payment was superseded by the strategy that was to be put in place to ensure that direct payment users had available staffing levels from the agencies leading to a contradictory situation.

**Sickness cover**
This can be provided through agency cover but there were plans to set up a list of available P.A.s to be ‘on call’ (see future plans).

**Relationship of direct payments to core services and groups for whom direct payments work best**
There are no childrens’ homecare services in this authority, these are now served by direct payments but do not constitute a choice because as the care managers present observed it was direct payments or nothing. No clear division from focus groups and interviews as to particular groups who are better served by direct payments.

**Funding and the process of direct payments**
Funding for direct payments and for services overall was perceived as ‘very tight’ with the further disadvantage of a reduction in funding in the coming financial year. For mental health there were further problems whereby teams were expected to use services already in place while promoting direct payments.

The mental health care manager said

> I feel sad that direct payments haven’t taken off like they should have done because it’s an excellent idea, but a limiting budget … I would like direct payments to be a budget on its own. Its coming out of our budget- so if we get some for direct payments or 24 hour care- its almost like direct payments are being tagged on to my budget-yet
when we sit on funding panel and somebody wants a package of 2000 pounds a week- or 6 pound for direct payments the priority goes to higher need, now we have the substantial criteria- so a lot of the ones [direct payment applications] that are coming through are not deemed high need

care manager mental health

However, the focus group revealed that very few packages were purely direct payments with the majority being mixed packages and very few individuals receiving direct payments exclusively (e.g. 3/39 and 4/90). Funding of the direct payments was easier to get through when there was an ILF element as was the case elsewhere.

Training for P.A.s

There were no examples of training in place for P.A.s. from the focus group. Participants thought that there should be some training available and identified the potential problems of the lack of training.

Yes, I think that needs to be brought in from children’s definitely. More so than adults because the child goes through all the healthcare and all the education provision and all the work that they do to get, particularly autistic children, to a level where they’re integrated into society and they’re coping well and everything’s working fine; they go out with a PA with no knowledge, no experience - just a friend of the family or a college student who’s, you know, just waning a bit of extra money, and all that work’s undone within a few hours.

care manager mental health

It was noted that NVQs and particular awards were relevant in securing positions in agencies, but did not apply to direct payment P.A.s. At the same time there was an awareness that training by the authority could back-fire when the P.A.s simply moved through the system to agencies where the pay scales were higher rather than remaining available to direct payment users. Focus group participants said that a set of P.A.s had recently set up their own agency in this authority because they had realised the potential incomes from running an agency.

Future Plans and issues

As noted, there were plans to set up a group of P.A.s who had experience and had undergone police checks to provide cover especially in children’s services when a P.A was off sick or if there was a problem. There were also concerns regarding the lead on mental health on the direct payments team. The overall team was highly praised for the work that they did.

[The] direct payments team is absolutely excellent. I can’t fault [name’s] team at all… One thing I’m concerned about is [lead on mental health direct payments] post might be coming to a head because she’s not on a permanent contract she’s on a fixed term contract but direct payment’s are a government objective and [she] needs to be supported. I don’t know if they’re renewing it, they’re trying to get it
renewed but nobodies holding out much hope because of the money situation... and I think that might have an effect on direct payments from our point of view (care manager mental health)

This comment sums up the findings from all telephone interviews and case studies that direct payments are more successful in authorities with full-time designated direct payment leads in place. However, issues related to direct payment leads for different teams have not been raised until now—it is logical that leaders for teams would also be crucial in aiding the direct payment process for staff and for applicants.

### Service users' views

#### Initial awareness of direct payments

None of the direct payment users in our focus group had heard about direct payments via their social workers. One direct payment user was initially on a service users committee in the authority to assess how direct payments were going to be implemented, however until joining the committee he had not heard of direct payments and was using ILF and directly provided services at the time.

Another had heard about direct payments through her own activities on committees and mental health steering groups

> Well I suppose I heard about it initially because I’m sort of in the loop of committee’s and stuff. So I suppose that’s how I initially found out about it, when you [Richard] were on the Direct Payment Steering Group. So it sounded like, I thought well I could put myself up as a candidate. So I suppose that’s how I sort of accessed it,

Another user, Sally, had been living in supported accommodation, her mother and assistant at that time had chased the option of a direct payment for her.

Gill was a mental health user who had educated herself about direct payments and formed clear opinions on the barriers that might have been in place for her and other mental health users:

> I suppose initially I read up about it myself. I think one of the key things for mental health is because it’s an invisible disability, and because it covers such a broad spectrum, and I can only speak for myself personally, in some respects that like because my condition fluctuates wildly, and the nature of it is that I can end up with an entirely set of different symptoms every three months. Because obviously you have to have an assessment for Direct Payments, therefore you’re assessed with a certain set of symptoms and needs, and three months later it changes.
All of the direct payments users that were present believed that they would have asked for more hours if they had had a fuller understanding of direct payments and had some peer support in identifying their particular wants and needs. Richard who had first heard of direct payments when invited to attend the service users committee to discuss direct payments said that initially there was not a support service to help with the paperwork or employment issues that arose in connection with direct payments.

I know when I first started [direct payments], I was pretty much on my own, because there was no support service. I had to do all my own paperwork... Like putting applications in, putting it all together, and putting job descriptions in, and doing all my own payroll. It were not easy at that time

However, Richard had had some experience of issues around employing P.A.s through using the independent Living Fund monies. He felt that this was an advantage to him, but in a similar situation he and others present felt that those without those skills would have been reluctant to take up direct payments.

There was some discussion of the limitations imposed on accessing direct payments by the Fair Access to Care (FACS) policies within this authority (and others). In particular, the ways in which the shift towards ‘critical’ and substantial impairments or illness were now in place as a screening device replacing the previous four point criteria to access social ‘care’. It was believed that this shift in the eligibility or in the newer gate keeping processes effectively limited the numbers of those eligible for both direct payments and directly provided services. This factor has been raised in other case study authorities from assistant director level through to direct payment user level. It remains an important issue when considering the effectiveness of direct payments to increase independence and must be considered a further barrier to disabled peoples’ access to direct payments.

Financial assessment

A further issue for mental health users was that they were to be financially assessed from April 2006

So from April this year, they’re going to be financially assessing people, with adult mental health for the first time ever. And your DLA is included, as I understand it, your Daily Care components are included in that financial assessment. So you’ve got to learn, I suppose in some ways it’s like learning the tricks of the trade. So it’s quite, you know it’s quite complex and you sort of think well how am I supposed to substantiate how I use my care component, because it changes month to month?
This was not mentioned in the focus groups with practitioners and serves as another salient reminder of the systems crisis regarding resourcing and in the ways that charging can effectively limit access to direct payments.

**Use of direct Payments**

Two of the direct payment users used their direct payment to employ P.A.s, the third to access alternative therapies. One user, Sally, was using her P.A to accompany her to college to do art classes, but this was not a set routine and would only occur once a fortnight. Activities appeared to be quite flexible and would include swimming, dancing or bowling.

The P.A was employed for 12 hours a week and Sally suggested that wherever she wanted to go or whatever she wanted to do she told Kelly (her P.A) and that’s how the direct payment worked. There were no set times and outings could cover day time or evening time depending on what Sally decided to do. In addition, if the hourly time was more in one week it could be taken off the following weeks direct payment hours. Richard had 5 P.A.s two of whom were full-time. Richard’s schedule was a busy one.

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Like this week, I’ll start at 10, this morning, until 6, because I’ve got a lot of engagements today. And tomorrow I’m doing the training session. And then on Wednesday I’ve got a meeting 4 while 8, so Fiona will start at 11. So I can get all my paperwork and the wages on Thursday. Then on Thursday we’ve got a meeting at [place name]. And then Friday, we’ve got a day off. I’ve got three other PA’s, they only do small number of hours, because they’re really students.
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Richard said that because each week was different in terms of the tasks and meetings he needed to attend; writing up rotas was sometimes difficult and time consuming for him.

Gill used her direct payment to access alternative therapies, as noted she was reluctant to employ a P.A because of the stress of employment issues, advertising and so on. She also felt that mental health users might face additional issues in employing a P.A.

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I think with mental health, it’s going to be so variable, the kind of thing that people want. I think there’s just loads of issues like capacity matching need, getting the right person.
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There was a related issue concerned with the notion of improvement versus maintenance and the notion that direct payments were used to develop independence and therefore improvements in quality of life and well-being.

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I think with mental health, there’s this thing, this recovery idea that because you’re getting care input, because I think there is the thing of maintenance versus improvement. And for me, I have a Direct Payment, as far as I’m concerned, for maintenance, not necessarily just about- it’s not just about improvement. And also, I think there can
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be a pressure to, I feel, to some extent, to be honest, a pressure, that if I’m getting a Direct Payment then if I’m getting it I should be improving. Whereas I feel I’m just getting it to maintain my existence as I am now.

All of those present felt that meeting with other direct payment users before the assessment process would have helped them to identify some of the issues they have since discovered in relation to direct payments, the hours they need and what to avoid in order to get the best value from the direct payment.

**Training information for service users**

None from the authority, but the mental health group were putting together a piece on mental health users accessing direct payments and what they could expect, including the processes and barriers that were perceived to be in place for mental health users accessing direct payments.

**Paperwork**

Each of the users used different methods of accountability when auditing their own payments and employment issues. Sally said ‘I like doing Direct Payments. And I do the paperwork with Carla, my support worker’. One of the support workers was present and said ‘There’s this big file that Sally keeps very well organised. She files all her bank statements. I just check the cheque stubs and the bank statements’. In all the paperwork was said to take up around ten to fifteen minutes a week.

For Richard employing 5 P.A.s, the process was more complicated.

The way I do it, at the moment, my PA’s are all classed as self-employed. So I do all my own payroll, and I go to the bank each week, with my senior PA. And when I get home I instruct my PA how much to put in each envelope, and they sign a receipt book. And then every three months I’ve got to bring my timesheet here [to the support organisation base]. I mean I know it is a big step. I know I was pretty scared.

For Gill, because of the use of her direct payment to pay for an additional service, things were slightly different ‘I suppose you’ve got to actually keep receipts for everything I’ve got to make sure I keep the receipts and a bank statement and things like that’.

There did not appear to be any problems with monitoring and each of the direct payment users understood the reasoning behind monitoring.

**Representation**

There was some irritation that the panel that meets to discuss direct payment applications does not include any service users or direct payment users.
I think one of the big things that annoys me is that when the panel meets there’s no service users on it. Because initially I was asked, and a friend of mine, we were asked if we wanted to be on the panel. And this person sort of obviously hadn’t checked the facts out properly. So it turned out a service user couldn’t be on the panel, because of confidentiality issues. But I don’t see why people who use the service or people with disabilities shouldn’t be on the panel. They should be on the panel. It shouldn’t be just down to professionals making the decisions.

It is not clear who gave the incorrect information regarding input to the committee, but this example raises important points in relation to wider representation at the panel level in a time many local authorities profess to welcome service users input at the local level.

**Employment issues**

**Availability of P.A.s**

As noted just two users were employing P.A.s. Richard was employing five P.A.s of those two were full-time and three were students who were part-time. Richard has placed advertisements in the local paper and at the Local University where he teaches on the social work course. However, he also placed an advertisement at the job centre and had no response- the advert in the job centre had been in place for eight years. In additional Richard felt that it was difficult to find people with the right attitude. He said that they would avoid eye contact with him and speak directly to his P.A. ‘Because I’ve got a speech impairment and funny movements, they automatically think I’ve got a learning disability’

Sally thought that it was relatively easy to get her P.A. in place

> When I first did Direct Payments, I’ve asked Kelly from the theatre to support me and she said she would.

One issue that caused concern for Richard was sickness cover

**Sickness cover**

Although all authorities are required to provide back-up though agency cover if a direct payment user is left without a P.A, for Richard, being without available back-up was a frightening prospect, especially if impairment effects were particularly bad:

> the big issue for me is getting emergency cover when PA’s are off... at the moment, we’ve got no system in place, so I just go in with the PA’s or my dad. But it’s not easy at times. They let you down at last minute. Especially when you’re in bed, and you can only press re-dial on your phone. That's something I need to sort out.
Sally had a larger network of support around her and felt that sickness cover was not a problem because she would just ring the organisation that provides her support which was connected to Supporting People. However, while this group would provide somebody to allow Sally to get to the bowling alley, only the P.A provided through direct payments would be able to go into the bowling alley and actually do bowling with Sally. As such although Sally had support it was of a different type than that provided by direct payments meaning that direct payments provided more of a social input for activities that Sally might want to do.

**Why someone might not want/get a direct payment**

From the direct payment users perspective reasons that someone might not want a direct payment were linked to the stress of employing somebody or a group of P.A.s and issues around sickness cover. In additional one user felt that the Fair Access to Care eligibility criteria would limit those who might want a direct payment and those who would benefit from a direct payment in contrast to the past.

However, it was the focus group with service users who were not direct payment users that identified other reasons that people might reject the direct payment option. The non-direct payment users’ focus groups were held at a day centre dealing mainly with mental health users, but covering a range of multiple impairment groups, five people agreed to talk to us. Of the five service users none had been told about direct payments.

**Non direct Payment users**

All said that the idea of ‘vegetating at home’ was disabling for them and that although someone might come in and assist them with activities when at home all the time this would lead to isolation rather than independence. Two of those present were support workers to other people at the centre and all took up different activities including photography and web design. The time that each person in the focus group had been attending the centre ranged from 3 months to 10 years. As noted all were convinced that going to the day centre was a form of independence not available to them simply through assistance in the home because independence had a wider application than being able to physically do things, or being assisted by a personal assistant.

There’s a lot of this so called… This independence which is really isolation. And you get nothing out of it. Oh if they help you all to do everything for yourself. But people never see anybody. People never go anywhere. People don’t make friends. And it isn’t independence at all. its - it’s the way they [government and social services]look at independence, as if you’re on your own and you are coping. You are now better. Which is not the case- You could be coping in isolation. .. And you get depression from people who are not listening to you. And you get depression because - you think people don’t care.

When direct payments were first mentioned there was some confusion with direct debits with several people saying that they already had their money paid into the bank. Those present were asked what they might do if they had
100 pounds to organise their own support and assistance as opposed to going to the day centre. There were many perceived drawbacks mainly with the notion of the individualisation of the system, for example

We’ve been going back - we are now in the modern Victoria times where the ladies, the dowger would get a paid assistant to accompany [them]. No!- It does not work! Its about time people realised that people are either molly coddled too much here or not bothered about. The ones who are molly coddled are the ones that know how to get it. Because the system that we started off with- that was supposed to help the ones that didn’t have, and the ones that could have helped themselves. And everything that was supposed to be done to help people has gone by the wayside. And any government we’re getting in now, is just passing the buck to the wonderful people who do charities- And if somebody doesn’t give to that charity or the other one, everything falls apart.

The service user said that she had been overseas for twenty years and found that governments there had a different approach whereby disabled people would be employed in a factory or company because there wasn’t any social security. When we again asked people in the focus group if they were given a hundred pounds to spend on employing a P.A, or for particular services what they would do, the same woman said:

You can give me a hundred pound. Who am I going to employ for me? Who do I want? All I need really is I don’t want to sit in my flat and do nothing. And I’m able to do lots of things. And the thing that, the thing that hurt most which I think would hurt lots of other people. When I came back here, I only had ordinary manual skills. I was away for twenty years. I didn’t have a little piece of paper to say I could do it. And when I wanted to get a normal job even …the pay was so stupid that I had to; I worked out I’d have to work ten hours a day seven days a week, at nearly a pension able age, to earn the same as what I was getting on the Social Security. I couldn’t go to it, and if I paid bus fares out of it, I’d have no money for food. And that frightened me so much because I was independent over there.

Another felt that people would be given cash and might be tempted to abuse it. He had initially refused to contact social services or social security after an accident and as a result had mounting debts over this period.

I worked up to the accident, I worked all my life, and you know. And when I had my accident, after that, I was more like the old fashion school, because I were brought up a lot the old fashion way. I never went to the Government at first for anything. And then when I were really getting depressed, me doctor got in touch with the X Unit And then they started getting things rolling there. But, I’d - actually built up a big debt of, because I was buying things that I needed… So, this sort of situation where you were on about the money. I probably wouldn’t end up trying to sort something out. I’ve been trying to sort my debt off
but mine’s going to keep going and going for a long time because I’ve got such a massive debt.

This service user was also clear that advice from social services could be misplaced. An example he gave was that he was unsteady on his feet and had recently had a number of falls in the house. In the first instance he was assessed for a stair lift, one person told him that he couldn’t have one because of his size and weight and then a second said that he could. It was also suggested that he move out of his house to a bungalow.

He says, “Can you get one for your size”. He says. “We can build a platform”. I think. Well she says I can’t. And then the - there some of them that don’t want to give you it. And then there’s others. And you just trying to get along. I mean, I have a lot of falls because they wanted to move me to a bungalow, but I’m happy where I am. I know people, next door and things, and they’re real good people. And I’ve lived there a long time now. So, I’m used to that area. And that’s my house as far as I’m concerned.

Some of those present had accessed the photography option at the centre. A further issue concerned the community at the day centre which appeared to be very strong. As such the day centre was much preferred to a class outside that could have been accessed through a direct payment.

It helps me in a way of you’ve got so many different people with different disabilities. But sort of interact with each other. Where outside, a lot of people don’t want to know you or anything. But in here you can learn things off each other as well. I mean like I like my photography. If I know - if somebody says well what can you do with this? If I know about it And we all learn off each other. You know you learn different things- Also with the learning ability. I mean I’m a slow learning on some things and that. And as I say I have trouble with me hands also- But, what it is, you can learn at your old speed… here, we all seem to pull together. And if anybody who wants to have photography, they can use them, to learn bits about photography. And I’ve bring things in as I say, me own things. So they can learn from it. You know?

Two members of the focus group had frequently helped each other with photography. They concluded that the day centre and the activities they participated in were more useful than a direct payment might be and that there was a community at the centre that each felt comfortable with. All felt that this would be something they’d loose with a direct payment.

Because we’re all in the same boat. We - we can be ourselves. Out in the wild world, you can’t be - there’s - there’s too much stigma still. I mean I - I went a conference on Monday, about the stigma attached to mental health and that.

If a direct payment was used to access a college to learn more about photography, it was felt that the tutor or the other students might not
understand, that there might not be physical access or that they would loose their friendships at the day centre. Ironically, a different form of isolation was created through the comfort of familiarity, but it was clearly one that all those present were happy with. The day centre was described as ‘a central position’, ‘a place for meeting’, ‘learning from and teaching others’ and ‘a place where everybody could be their selves’.

We are human beings. We’re, we are community and we are social animals just the same as every other one. Being in our little boxes, and not being able to get out or being frightened to get out because you - you don’t know what - because of the certain ways. Does not do anybody any good- you - everybody needs a central position. Everybody needs the main wigwam or the main thing. Everybody must come together somewhere.

Asked what they would do if they couldn’t come to the day centre one participant said that he and some others thought that they would set up something like the present day centre for people to go to.

We ended up looking for funding to start up our own centre. But, we don’t want to run it like they run [previous centre]. We want to run it a bit like this Day Centre is, and that’s to help people, to come to terms and also to find work. Not to just come in for a cup of coffee and that. But to go find work. Or find places where they can go for jobs, where they’re not persecuted or stigmatised.

Feelings around employing somebody as a personal assistant were also unfavourable in general with none of the focus group participants identifying any particular advantages in comparison to attendance at the day centre. One participant identified the difficulties of being an employer and questioned the relevance of a P.A and what they might be able to do

So, them having be, you know the dowager and her helper [direct payment user and P.A], which would be very nice. Well I mean you might get fed up of that one. What do we do, if we don’t like that one? Not employ that one and get somebody else? It doesn’t - it doesn’t help. And that one person might fill one of the needs; they do very well with it. But the other needs. I mean can this lady helper take me-at the moment for instance I need a dancing partner- I mean I’ve love a dancing partner. She can’t do that!

But I think there’s a hundred pound to go and get your own helper or your individual person to be with you on that kind of thing. Like having a care worker. Your money would go for a care person plus another one in the afternoon, so many days a week to keep you going. But that would - you know and perhaps even take you out. It’s all right for a individual who wants that. ..

Another said he thought that more would be achieved, for him, through attending the day centre than would be possible through employing a P.A.
I’ve got to achieve even more because this way we can - we all need to combine, you know, pass each other information. Look after each other’s for each other. Try and learn each other things, you know.

One participant said that direct payments was ‘passing the buck’ and another added that it was isolating as well. When we asked if company and sharing was the most important thing we were told it was, moreover

It’s the most important. You could give us a thousand pounds, but it wouldn’t buy these people [wouldn’t work] towards something like this.

There was a lot of criticism of the government and the way that social services were run including the closing of centres.

It’s like they’ve passed the buck each and every time...each new Government that comes along-They’ve got rid of that. They’ve got rid of this. They got rid of the care homes. The general care homes that everybody had for when they were old. You - you could go into a proper care home that was nationally funded ...And our tax system even in the older days was far higher than anybody else’s in the world because we had a national health system - it was supposed to look after us. Now it’s a waste of the money on every thing under the sun, literally. And not put back into the people. What we give they should have put back into what we wanted. Not to what they thought we wanted.

(original emphasis)

When it was suggested that there were choices between different ways to provide assistance and support, one of which was direct payments, and that it should be offered in an assessment process as a choice, one person said.

‘We do have a choice. But the other choice is just to be isolated’.

Another said

So this is fine for me. And to try and do it the other way, I can well, you know it - its panicking in a way because here it works and it - we can learn each other and you - you do learn things and everything. But the other way, you’re up - you’re more or less on your own. You’re isolated. You’re aren’t....

‘,,You’re not part of anything...’. Was added quickly by someone else

The discussion was summed up by this statement describing how best to spend the mythical 100 pounds per person.

Say right, let’s open at- in every town a unit like this where we can come and we can congregate with one another. Because we are the lucky ones what’s here.
It was very clear that the service users identified the perceived individualising aspects of direct payments as something that would remove the independence and status they felt through attendance at the centre where they felt safer and more valued than elsewhere.

### Support organization

#### The role and remit of the support organisation

#### Services for users

The support organisation helps with the advertising and assists in finding P.A.s for potential direct payment users. In addition, they talk attend interviews, help to set up a bank accounts, do financial monitoring, tax and national insurance. They have also helped with the setting up of a learning difficulties forum for parents. The support organisation are involved in the induction process for all new staff

#### Relationship with the local authority: change from independent support organisation to in-house support

As noted, the authority was not offering the support organisation a renewed contract, but planned to move the direct payment support in-house. At present the direct payments coordinator manages the direct payments team within social services and this role is to be extended with the creation of a new post for an independent living advisor. It is not clear if existing support organisation staff will be re-employed in the new in-house service. Practitioner focus groups suggested that they would be, but direct payment users two of whom were on various committees were not convinced that this was the case.

There were mixed views on the move to in-house support from practitioners within the authority and from direct payment users. The practitioners felt that the move would be a beneficial one. Although the cost benefit to the authority didn’t appear to be the priority, it was a clear advantage. The practitioners did not perceive any conflict of interest in having the support service in-house, at the same time it did not appear clear to the practitioners why this action was being taken

> I mean in-house it gets monitored from within and you … well I’d like to know why. You know, they must know why they’re doing it…

For direct payment users the issues different, they felt that the support being moved in-house was ‘disappointing’ and could in some instances put some people off direct payments because they may chose the direct payments option because it was ‘a break away’ from social services. Some participants believed that there would be a conflict of interests. However, one participant felt that the complaints procedure might be easier because ‘in some paradoxical way there will be more accountability’. Some said that issues of
confidentially and confidence might potentially be undermined by the new arrangement.

Because I’ve got a stigma around mental health, I would feel personally, quite wary, even if they were a nice person, telling somebody employed by the authority, you know the details of my—because I get paranoia and lots of things, that a lot of people could potentially could misunderstand. And I’d feel quite wary about where that would end up in the authority; you know what I mean, in terms of writing things down and confidentiality issues… It reinforces an ‘us and them’ situation. So I worry in terms of the stigma.

While the simplistic view might be that the authority were saving money through this particular route one direct payments user suggested a potential longer term approach could be an underlying cause of the changeover.

I think there’s some politics involved in it as well isn’t there…And I think there’s a tension between central government perhaps wanting (and I still think the Direct Payments is a bit of a Trojan horse for dismantling the old service of Social Care, that’s just my conspiracy theory), but I think the Council’s realised potentially if the government office and the DOH are going to be pushing Direct Payments, and then as an extension of that, individual budgets, then I think they’re sort of realising the potential, that knock on effect that can have on their structures and their income and expenditure, and the services they deliver.

Union Representative

The union representative was also a care co-ordinator for the learning difficulties team as well as an advocate for the learning difficulties group. She gave an example of one man who had encountered constant problems with direct payments including people not turning up for interviews or not turning up to offer assistance once they had been appointed. The experience of this particular case may have coloured what were particularly strong views on the inadequacy of direct payments as a valid form of ‘care’.

The union representative perceived a range of negative issues related to direct payments, some of which had been raised at a national UNISON conference earlier in the year. The conference had a two session slot allocated to the discussion of direct payments at which there was representation from union officers and disabled people. The groups present accepted the flexibility and choice that came with direct payments, but key issues were raised by those who were described as ‘working on the ground’. While national officers and disabled people present saw direct payments in terms of greater control for the people using them practitioners suggested that direct payments represented ‘a lack of control by the vast majority of users’ this was because of a perceived lack of care and responsibility by authorities including the recruitment of unqualified and low paid staff.
Direct payments were described as ‘the emperor’s new clothes’ and ‘a patch-up or cover-up of what the L.A. should be providing’. Direct payments were perceived as an example of ‘L.A.s doing it on the cheap’ when there were in-house staff who were experienced and qualified. As a result of the perceived pitfalls in the system of direct payments there was ‘no democratic control’ and no ‘backup’ when things went wrong.

It was strongly suggested that what was described as ‘quality care’ should be provided and be provided by ‘a well resourced local authority team’. Direct payments as an alternative to the traditional day centre services were also thought to be inadequate because direct payments offered ‘no interaction, no organised programmes and no support for people’ Moreover, ‘unless dp workers (P.A.s) get paid fairly and have adequate support and supervision, then care agencies will continue to profit’ The union representative believed that the system of direct payments should be seriously reviewed.