

# **Disabled People and Direct Payments in the UK: preliminary analysis of key informant interviews**

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This summary presents a preliminary (anonymised) analysis of qualitative data from 21 key informant interviews, carried out between May and July 2004 for the ESRC-funded research project *Disabled People and Direct Payments: a UK Comparative Study*. Key informants from across the UK were selected on the basis of their knowledge or expertise in relation to direct payments, including representatives of disability organizations, the public sector, central government and its devolved regions, and key activists involved in the early development of direct payments practice and policy. Our preliminary review provided a picture of distinctly uneven regional implementation in UK direct payments policy (see phase one working papers). The key informant interviews constitute 'phase two' of the project, and will be significant in shaping our analytical framework for more detailed data collection with individual local authorities.

## **Executive Summary**

- Explanation of the uneven take-up of direct payments in the UK involves a number of interrelated factors.
- These include the presence of a strong disability advocacy base; adequate funding for policy development; the political culture of national, regional and local government; local markets for the supply of social care; the role of local champions within purchasing authorities; and the existence of appropriate infrastructure (specifically, but not exclusively, the existence of user-led direct payments support schemes).
- All of these aspects could be considered within the overarching concept of a local or regional opportunity structure for policy implementation.
- There are issues in terms of monitoring access and in ensuring equity between different user groups. Although this is improving in some respects, careful attention must be paid to patterns of implementation and initiatives intended to advance take-up by specific groups (both in terms of the impact for that group and the implications for other groups).
- Implementation for under-represented user groups does seem to be improving, and there is a keen awareness from those in support organizations of where the problems lie.
- There are concerns that marketisation and contracting may be impacting negatively on the quality and scope of support valued within an independent living philosophy.
- There are complex relationships of interdependency between central and devolved government, purchasing authorities, professionals, disabled people's organizations and support groups. The links between them, and the impact on take-up, quality and outcomes require close attention to ensure effective implementation of direct payments across the UK.

- Communications between purchasing authorities and support organizations are not always positive or beneficial, specifically where there is pressure to increase take-up amongst new user groups without adequate resourcing. This is particularly so in areas outside England.
- There is some support for more radical future policy development, including some advocacy for nationally funded direct payments.

## **Expectations of the 1996 Act**

In asking our key informants about their expectations of the 1996 Act, we received a range of views relating to the promotion of the rights and choices of disabled people, the integration of broader independent living goals into service provision and the development of social care markets. Expectations of the Act were mixed, with some seeing the potential to promote independent living outcomes and choice for disabled people, or legitimise and promote existing independent living schemes, while others had viewed the initial legislation with more scepticism.

I would be lying if I said I was surprised that things didn't happen very quickly. We were just used to the horrendous kind of inertia and lack of interest in local authorities, everywhere really, with some exceptions.

This was a theme which was reiterated in several of the Scottish interviews. There were evident frustrations by many of the activists by what was clearly seen as a 'wasted opportunity' between 1996 and June 2003, when policy became mandatory. This type of sentiment also came across from interviewees in Wales. Initial expectations were let down by what was seen as a lack of direction from local and central administrations:

My expectations were that it would kind of get off the ground...[but] there wasn't anything mandatory to do that...I suppose I was expecting the Assembly or Government to have a much stronger role in...monitoring whether local authorities were implementing it in their area.

Similarly in Northern Ireland, the 1996 Act had a very limited impact. Whilst some individuals had gained access to payments and were received positively, it was emphasised that many people had not really heard about them until the more recent policy drive. In exploring the reasons behind this, one policy planner suggested that there was a feeling that the legislation was 'imposed' from Britain and was therefore received with a high degree of reluctance. Hence, it was suggested that there was perhaps a feeling that policy had been devised in Westminster and then imported to Northern Ireland. Unlike elsewhere in the UK, there was no significant grassroots disability activism, or user-led support, for direct payments and therefore no real demand momentum to encourage take-up.

Several respondents talked more generally about problems in 'getting the message across', partly due to an initial lack of interest from within local authorities/trusts or to the fears of social workers threatened by a shift in service provision. General concerns were also expressed over restrictions in access for different user groups resulting from different local authority interpretations of the 1996 Act. Notably it was felt that the clause

stipulating that an individual's ability to manage the payment alone, or with assistance, set out in the original guidance (DoH, 1997) had resulted in the exclusion of many potential users labelled as having learning difficulties or mental health problems. As one respondent recalled, it was also acknowledged that locality made a real difference in gaining access to appropriate support:

I think it's a bit of a lottery really. I think it very much depends on where you live in terms of what people get from an indirect payment and what they get from a direct payment.

## **Barriers to expansion**

In exploring the barriers at local level, all respondents from within the disability movement were critical of the lack of financial support to develop more user-led support and sustain the position of those organisations already performing this role.

...the Government says, 'okay so you should enable people to use it [direct payments]'...but you know there's just so much voluntary staff can do. Now your support workers will help people start...but if you're going to really support people on an on-going basis – which seems to be implied by the latest policy and practice guidance – well then you're going to have to start paying for it.

Another dominant theme was social worker resistance and this was picked up by interviewees in all areas of the UK. Sometimes information was not being passed on systematically throughout social work teams, thereby limiting access to new users. Resistance and the broader cultural change in service provision were also highlighted from a planning point perspective. Restrictive eligibility criteria and charging policies, put in place by local authorities/trusts, were strongly criticised.

There was also criticism of the devolved administrations for their failure to fund the policy expansion implemented over the last year. In Scotland in particular, several interviewees were disappointed with the absence of transitional monies from the Scottish Executive to allow local authorities to shift more of their services towards a direct payment model. Likewise in terms of the wider promotion of policy by central government, there was concern that the Department of Work and Pensions had used a high profile campaign to promote pension payments by direct debit confusingly under the banner of 'direct payments'.

In looking at why direct payments have expanded more quickly in some parts of the country than others, the link between strong user-led support and political commitment from local authorities/trusts was highlighted.

The impact of policy directives on take-up were addressed more specifically by two of the policy planners, suggesting that central reviews and guidance would act as a major stimulus to expanding take-up (e.g. in Northern Ireland). It was suggested that direct payments had developed more quickly in England specifically *because* of the shift to

mandatory implementation. Increased take-up was also attributed to the shift to include policy as a key performance indicator for councils.

## **Advantages and disadvantages of direct payments**

Overwhelmingly, for all interviewees, the advantages for disabled people of having a direct payment centred on similar goals or outcomes. As one user summarised, these focused on three main areas:

One in telling the personal assistant, to [be able to] make the decisions about who is going to come in and out of your home. Secondly it is about what sort of lifestyle you want...and thirdly I think is the flexibility of the whole thing about choosing everything and the control that gives you.

Comments also touched on wider issues in relation to direct payments and their impact on the social position of disabled people. For example:

I think direct payments have almost been a passport to actually being able to get other rights...it's all very well having a DDA but if you can't actually get access in the morning, then how can you...enjoy the kind of rights that are about employment or accessing particular services.

From the position of disabled people, the disadvantages of having a direct payment were viewed as limited. Indeed, one respondent remarked that she 'couldn't think of any'. However, issues were raised in relation to some of the difficulties surrounding the employer role and access to support networks.

[It's] the work involved, the responsibility of having to account for how you spend the money...The disadvantages of employing a personal assistance is particularly when someone is sick. That's probably the worst time when you're an employer.

Concerns were also raised about the financial accountability of the end user. Whilst it was acknowledged that accountability systems do need to be in place, local variation and intrusive practices adopted in some areas were highlighted.

For purchasing authorities, the perceived advantages were centred mainly on shifting responsibilities for support from care managers to individual users.

...if somebody achieves a level of independence that they didn't have before, then in the long run it ought to be less work for the local authority.

The promotion of direct payments was also identified as a means of developing 'social care markets' and creating more flexible support packages. Conflicting views emerged over the issue of cost efficiency. In some cases it was felt that over the longer-term, direct payments were likely to be less expensive than service provision.

There has got to be savings somewhere along the road or otherwise we shouldn't really be doing this. I'm not saying that's why we're doing it, it's because of the proper outcomes and flexibility, but...there's never anyone who says about costs.

However, respondents from within the disability movement emphasised the need to move away from the idea of direct payments as a 'cheaper option' (particularly where savings were not reinvested in support services).

Overall, it was clear from the interviews that the resources made available for support vary considerably across the UK and between local authorities/trusts. Nationally, the Direct Payments Development Fund has seen monies directed at voluntary sector organisations to facilitate the support role in England. In Wales funds have been targeted at local authorities rather than the voluntary sector. In Scotland, the establishment of DPS in 2001 - funded by the Executive – enabled a more direct focus on training and facilitating user led support. In Northern Ireland, responsibility for meeting support costs has been organised at Board level, rather than through the DHSSPS (to date, the CIL in Belfast has acted as the only funded support organisation with monies allocated from the Eastern Board, where the majority of DP users have been located).

Concern was expressed from those within the disability movement over what was generally viewed as an under resourcing of support roles – e.g. where local authority funds were tied up in block contracts budgets had not been made available to develop support. However in some parts of the UK, designated posts within social work departments, to support direct payment users and encourage take-up, were becoming more widespread. The funding of these roles and their organisational remit raises a number of on-going problems as there is no legislative requirement to financially support them.

I think they [local authorities] had hoped as we had...that there would be a sort of budgetary element of finance provided to get all this off the ground and allow support organisations to be funded and that has just not happened. We have been established a long time, we are the best known and we really struggle with finance.

## **Assessment**

All respondents acknowledged a link between assessment and budgetary rationing processes. Local authority personnel stated that it was impossible to separate these, while direct payment users were unsurprisingly more critical. Decisions about assessment and DP access were linked to the wider implications for services as a whole.

...as you get more and more cash payments, you've also committed money on a block payment basis. So if, for example, we have allocated 80 per cent of our resources through a block contract, either because of blocks in our in-house services or because we have to service a block

contract with an external service, that means we have only got 20 per cent of our resources to deliver as cash.

From a user perspective, the issue of unmet need was especially problematic. Access to payments was viewed as increasingly dependent on the views and approaches of individual practitioners, and some social workers are using their discretion to make judgements about who is an appropriate recipient. Care managers were identified as key gatekeepers in the assessment process (although examples were given of authorities which had developed strategies to ensure that direct payments were routinely offered as part of the assessment process). Many authorities had cumbersome systems that were not geared towards assessing the support required to live independently.

Assessment and access to a direct payment also raised issues surrounding inequity between different user groups (e.g. where DPs were only available to people with physical impairments and assessed as having very high support needs). Similarly, discretion in assessment affected eligibility for particular kinds of support.

I called on someone the other day who is currently getting assessed for direct payments and has just recently had a child about 6 months ago and was told quite categorically by the worker that they couldn't get any funding for their parental role, which is just wrong.

Complaints had also been made from local authorities in Scotland over the changes in administration practices required and many staff found direct payments to be much more difficult to administer than domiciliary services:

The problem at the moment is that local authorities are claiming it is much more work because they need to initiate procedures and the shortage of social work staff mitigates against them being able to do that. The evidence suggests that it would be less work for local authorities once people are more easily able to manage on their own.

It was suggested that support organisations play an important role in pre-assessment, ensuring that potential users are aware of the criteria being used. However, it was acknowledged that this requires adequate funding.

## **Labour force issues**

It was clear from the range of discussions that in some of the more traditional 'Old Labour' heartlands, opposition to direct payments from public sector unions had restricted their development. Councils in these areas appeared wary of offending the unions and saw their role as protecting public sector jobs.

It's about entrenched political, with a small and big 'P', culture really isn't it. A lot of commitment to centralised services and the whole impact on workers' rights and those kind of things which are more potent in some areas than others.

In one Scottish local authority Unison had instructed its members to stop processing direct payments.

Unison in Scotland published a paper on its website which sets out the debate around direct payments (Unison Scotland, 2004) identifying benefits as well as 'risks', but raises questions about the status disabled people as *employers* (their italics).

...the risk...is that if you shake up the services there won't be any services left to provide.

Union concerns also focused on the exploitation of personal assistants through low wages and limited employment rights, which has clearly impacted more strongly on female employers.

The whole process goes right against everything the union has been fighting for which is to professionalise the service and get people employed on proper contracts. The whole thing, like the home help service, has moved from casual labour to people being employed directly with proper employee rights...

Everyone agreed that there are problems with the labour market supply of personal assistants, across the UK, particularly where local service sector economies are buoyant. Many respondents made comparisons with employers like Tesco's, where workers on similar salaries would also receive more substantive support such as pension rights. However, there appeared to be a critical difference between how different local authorities are developing labour markets for direct payments (e.g. in the extent to which staff are recruited via agencies).

There's a shortage of people to meet the empowerment need shall we say, of disabled people. There are plenty of people will come along and work to how social services would provide care; i.e. doing things like coming in and telling a disabled person to get off the phone, and who are they speaking to as they shouldn't be on it. But there are not many PAs who understand the concept that you're the employer and they're the employee.

In Wales, the low number of users (and the level of local labour supply?) has meant that, to date, there were few problems with the supply of personal assistants, although local authorities had expressed concerns about meeting demands in rural areas. Another issue raised by respondents in Wales related to the training of personal assistants (none were apparent in Wales).

Other problems related to the (police) checks and safeguards required to employ a personal assistant (e.g. involving a delay of several weeks in recruitment).

I think this is one of the areas where social work departments may want to protect their necks but you also do have to strike a balance with giving people a certain amount of independence.

## **The impact of activism on policy and practice**

Disabled people's organisations and their allies were perceived as crucial in moving direct payments onto the national policy agenda, through local activism, pilot projects and campaigns since the 1970s and 1980s. However, policy transfer to other user groups may also be perceived as obscuring the origins of direct payments in the historical claims of disabled people and their organisations (e.g. the inclusion of 'carers' and parents of disabled children from 2001 may give rise to tension with the ethos of choice and control by and for disabled people).

By and large direct payments are disabled people's ideas and they'll keep it going. The ideals of direct payments, being traditions, history; they reside within the users, not within the local authority...

I think that if it hadn't have been for disabled people's organisations throughout the country...the whole idea wouldn't have got to where it is... It's the disabled people's movement that has made it what it is.

There just wouldn't be direct payments if there hadn't been that movement...the disabled living movement, independent living movement, has been crucial.

However, this historical and political narrative is not always known by end users of direct payments, or the local and devolved authorities charged with administering them.

Up 'til now and until recently direct payments has been something which has come from disabled people and there is maybe a sense now that people receiving direct payments [see that it] is coming from either central government or coming from social work...you read things and you think these people don't understand where direct payment has come from.

While the take-up for direct payments in parts of England appears to have benefited from the systemic influence of disability organizations, have lower numbers of direct payment users. It was suggested that the lower numbers of users in Scotland, Wales and Northern Ireland were partly attributable to lower levels of regional activism. In contrast, England had a well formulated self-advocacy infrastructure, with several key organizations in place by the mid 1980s, creating networks and opportunities that may not have been available elsewhere.

Informants suggested that there had been more limited disability activism in Northern Ireland than elsewhere in the UK. This was attributed both to the wider political context and to the unique service structure (where disability services were historically located in Health Boards, now Trusts, rather than local authorities). In addition, the troubles in

Northern Ireland were thought to have channelled the energies of activists towards more immediate concerns and campaigns.

## **Local political conditions**

Some key informants acknowledged important connections with allies at various levels in local or national government. Some of these ‘local champions’ for direct payments (particularly in England) had worked directly with disability organizations to help push direct payments onto the policy agenda. However, it was clear that different localities had different histories, and that local political conditions made a difference to the opportunity structure within which disabled people’s organisations developed their claims to direct payments.

In the South there have been real advantages and I think those advantages are, I mean, this might sound right off the wall, but I was analysing the other day what I felt had made a difference and I think [it was] at the time of the GLC [Greater London Council] and times when we started to really come together in larger numbers to debate the issues.

In this sense, the political complexion and policy agendas of local government may be a factor in advancing or inhibiting direct payments as a mode of welfare production. Our data suggests that Conservative local authorities are more likely to have higher numbers of direct payments users, and to promote this option alongside public services. This may, suggest an ideological impetus towards welfare marketisation and ‘consumer choice’, or towards cuts in public service based on perceived cost benefits for Council Tax payers.

Regional policy histories and political cultures clearly play a part. Where the development of direct payments was viewed as a ‘bottom up’ policy process, arising from disabled people’s advocacy there appeared to be relatively strong commitment to the implementation of direct payments legislation. By contrast, lack of historical ownership in the policy process may result in a more sceptical view, as illustrated in this example from Northern Ireland:

Well you see unfortunately there are cultural issues and we got direct payments as a legal framework from day one. So we had it imposed on us. It was wonderful in England in that legislation had grown up naturally it was just a reflection of what people wanted and what was going on... we got this piece of legislation and were instructed to implement it and staff just saw it as a potential threat to their jobs.

For service users and public sector employees alike, there may be suspicions that direct payments are being offered in order to divest public responsibility and to reduce traditional forms of provision (as in the closing of day centres for example).

The real fear behind it was that they needed to make challenging decisions about shutting down traditional services and transferring the resources, and they didn’t do that.

In summary, the data suggests that the uneven regional development of disabled people's collective advocacy for direct payments, together with the particularities of local or regional political culture, impacts on the policy process and opportunity structure for implementing direct payments legislation.

## **Support schemes and the marketisation of social care**

Our preliminary data suggested that the presence of direct payment support schemes run by user led organizations was directly correlated with higher numbers of reported direct payment receipts. This view was shared by our key informants

Take up of direct payments has been better in areas with support schemes and strong organisations of disabled people

However, this association is mediated in practice by issues of funding, market competition, and relationships with the purchasing authority. While disability-led organisations have been the primary players in areas with the highest take-up, there is evidence of a shift towards other types of support organizations. There are concerns that some purchasing authorities are contracting support from organisations that may be less than adequate in serving disabled people as direct payments users. In addition, the effectiveness of schemes may be influenced by differences in resource investment between regions. For example, while English regions were able to bid for two rounds of development funds from the Department of Health, there has been much less implementation funding outside England.

There was general agreement that user-led support organizations were more beneficial to disabled users of direct payments, providing peer advocacy as well as specialist information that might not otherwise be available.

If you don't have people like us around to support you through the whole process you actually have no idea what is around.

.. if the commitment from the top is not there, then you won't have... a good support service... having a very strong organisation of disabled people locally is important, one way or another.

Support organizations run by disabled people were credited with a better understanding of key issues and allowed opportunities for effective peer support. The importance attributed to effective local support schemes underlines the difficulties in localities or regions where such initiatives were less well developed

I think one the disappointment to me is the fact that so few of the support schemes in Wales are actually run by disabled people.

They're practically non-existent in Northern Ireland there's only the CIL [Centre for Integrated/Independent Living] taking on a support organisation role here and no Development Fund money in Northern Ireland and the voluntary sector interest just hasn't been there. And because we didn't have a strong disability movement here lobbying for

Direct Payments, that didn't come up through community groups or voluntary sector.

The extension to new user groups and the targeting of specific groups by some authorities created problems for over-stretched support schemes that were not receiving the additional resources to operate effectively. Where high expectations are coupled with restricted funding, market pressures may impact on the viability of good user-led support schemes. Some user-led support schemes have been left with little option but to withdraw from tenders that fail to specify adequate support for disabled people. This may be one factor that influences some purchasing authorities to begin contracting with non-user-led support schemes for direct payments support schemes.

Local authorities just see how cheaply they can do it...And what happens then is that disabled people are not stupid and they have said 'No, you are taking us for a ride we are not going to do it'.

...in certain cases the best value process etc and contracting is leading to cheap, cheap options really, for providing a direct payments support service. So the local authorities are contracting with an organisation, that is...it's not a local organisation run by disabled people.

There are some extremely entrepreneurial and aggressive voluntary organisations in Northern Ireland who will see another opportunity and move in...

For those organisations that do enter into contracts or service level agreements, there may be a real shortfall between the quality of support required to meet disabled people's needs as direct payments users over the longer term and the actual level of service funded through the contractual specification. The process of contracting and marketisation was thought to be leading organisations that offer support within a more holistic independent living ethos towards an uncertain future, with potentially negative impact on the growth of direct payments to disabled people in some areas.

## **Access and Equality**

Perceptions of low take-up by particular user groups were often grounded in experiential knowledge rather than statistical evidence. However, there was widespread agreement that take-up amongst black and minority ethnic communities, mental health systems users and those labelled as having learning difficulties was lower than for other eligible groups:

It's still on the whole people with physical impairments, younger people...  
Very few people still with learning difficulties, mental health needs, very few from ethnic minorities...

Concerns about equity in relation to ethnicity were evident in most of the interviews carried out, in line with issues raised in the research literature on direct payment patterns.

First all I think there are a huge group of local authorities who are not reaching the ethnic groups anyway, for any kind of service or any support. So when it comes to direct payments, and to be fair it is not just the local authorities that haven't got the expertise or the time, I think it is our own disability groups. These groups are not clued up enough.

Disability organizations were clear that improvements would require a greater level of 'outreach' to ethnic minority groups (e.g. NCIL has been active in promoting minority ethnic issues for some time). However, organizations seeking to employ development workers in this area may find they are limited by funding.

There was little reference to issues of gender balance, although there was a belief that more women than men took up direct payments. One interviewee suggested that this might be accounted for in terms of women's greater investment in relevant social capital and information networks.

I think on balance I would say more women, and I think the reason for that is that there are more women who go to places where they might hear about direct payments. Women go to day centres more often than men do and they go to older people's luncheon clubs, the kind of places where people congregate where they might just pick up the literature.

Conversely, similar take-up patterns could equally be explained by the relative lack of support received by women within family networks:

... I would say there's probably more women on direct payments than men... it's interesting and a very, very sad sociological observation to be made for the fact that there's more women on direct payments than men... because to be blunt, women get abandoned more quickly and that's very sad.

Factors associated with ethnicity and gender, as with social class (which was not raised in the interviews) cut across patterns of access and equity between different direct payment user groups yet are not always routinely monitored.

User groups were more clearly defined in terms of impairment labelling and chronological age. For example, many key informants reported that adults with physical impairments were still the most likely to be accessing a direct payment. However, it was also clear that efforts to include other groups, initially excluded, were having an effect. These included carers, those labelled as having learning difficulties, mental health service users, older people and 16 and 17 year olds. This could be perceived as either a positive or negative effect:

I think in areas where direct payments or indirect payments have been around for a long time, I think a lot of authorities went down the pilot route, starting with physical and sensory impairments, then decided that they might have to get other people on board. So their support has become thinner because they have had to stretch it further and I think people with physical and sensory impairments are now becoming bottom of the pile. I

think people with learning difficulties are having much more effort put into them. I am not saying what is right or wrong. I am just telling you the facts. I think there is also a lot of work being done around older people but I think the people that are coming out top of the list are carers. They are the ones who are accessing direct payments faster than anyone else.

In England at least, there was some suspicion that the spread of direct payments to carers might increasingly move disabled people back towards relationships of dependency, rather than forward towards user control and flexibility.

There is no logic for carers needs to be met by direct payments, I don't think there is a need for that... The whole purpose of direct payments is surely to enable somebody to live independently and that... I just think that skews the whole relationship. There is no reason why support for carers couldn't come from central government through the social security system.

There was certainly some impetus from purchasing authorities to increase take-up by carers and other new user groups.

...direct payments is now much wider than the original proponents that really moved it on in the early nineties, mid nineties, into becoming a legal delivery, because now that particular group of people [disabled adults with physical and sensory impairments?] are part of essential users and very specific to direct payments, but they're not the main part. They're actually if anything going to be the minor part and what we've got to do is make sure that learning disabilities people, older people and their carers, and carers themselves, who aren't in groups, also make access.

People with learning difficulties and mental health service users, although increasing their take-up, are still amongst the smallest user groups and those working on direct payments in disability organisations showed a keen awareness of the access barriers they faced. There was some evidence of improvement as a consequence of inclusion drives for these groups.

In terms of learning difficulties I think there has been a big shift in the last year or two. They are really beginning to come on board now... and I think I am being a little bit cynical now, but I think it is all about some local authorities wanting to get their Brownie points. There is pressure from Government and, because there is pressure, the inspections are putting a lot of emphasis on direct payments [for this group].

But in relation to mental health service users:

I think they are getting a very poor deal, basically because they are mainly served by the health professionals. And of course some people in the mental health system can't get them because they are ruled out by the

legislation. But I would say the greater issue is that the health professionals are not willing to take it on or ignorant.

In common with access for mental health service users and those with perceived learning difficulties, many of the key informants felt that equity in access for older people lagged well behind policy recommendations.

I think the older people's team, although they all have had training, I think there is much more of a [reluctance?]. You know, older people can't manage, they don't want it, they are tired of managing things themselves. You know all the negative things that we know about really.

I think that the care managers who deal with older people are, generally speaking, somewhat less open to it and the same goes for people with learning difficulties, and mental health service users.

To summarise, the key informant interviews revealed perceptions of inequity in accessing direct payments (between different identified users groups) that are broadly in line with published data. There are some concerns about the impact on disabled people of widening eligibility. However, implementation for under-represented user groups does seem to be improving, and there is a keen awareness of where the problems lie amongst those in support organizations.

## **Monitoring equity**

There was little evidence of the use of systematic or targeted monitoring to address issues of equity in direct payments implementation. In-depth analysis of direct payment take-up patterns at the purchasing authority level is generally lacking. Some English Local Authorities are undertaking monitoring, through performance system questionnaires, in an effort to target equity issues in particular localities.

We, for example, we have a question on our system here that says: Did you ask, did you have a direct discussion with the user about the potential of direct payments? And they have to fill that in, but that's the monitoring and performance aspect that would need to drive that.

One alternative to 'numbers monitoring' is to track individuals through the assessment process (from an offer of, or request for, information to decisions and outcomes). In combination with statistical monitoring, this may facilitate a better understanding of the local factors that influence people considering a direct payments option, and those who advise them. Such an approach would assist in determining whether and why different people are electing for established service provision in preference to the direct payment option.

What we actually do is we have our budget implementation group, so that's actually applications for direct payments and the impact on budgets and also why people are not taking up direct payments.

There were sometimes real concerns that numerical analysis could not provide the ‘bigger picture’.

I’m very uncomfortable about talking in terms of numbers...if we go down the route of numerical targets for DPs is that you put Trusts in the position of where that is the target, not the provision of services...I’ve argued against them in other areas of community care. To me they don’t tell you anything.

National monitoring systems require purchasing authorities to report numbers of direct payments receipts in terms of named user groups (although the reporting schemes differ between England and Wales, Scotland and Northern Ireland). Consequently, overall numerical data for different groups should be collected on a routine basis, and these may be translated into specific implementation targets.

We would, and I think most authorities now will have, targets for each different client group and there will be equalities in terms of racial minorities within that. And of course we carry out monitoring for different types of client groups, for learning disabilities, physical disabilities, old people and children, young people. So it’s all monitored in some such way and generally speaking people have to perform a range for that.

The interview data suggests that there is a basic level of equity monitoring, and some ad hoc targeted data collection, within purchasing authorities and some support organisations. There are also likely to be examples of good practice. However, there are also concerns about the robustness of local systems for monitoring user choice that rely on reporting by the same frontline staff responsible for assessments of need, and some scepticism about over-reliance on statistical returns at the expense of more detailed evaluations of process and individual decision making.

### **Future Directions: choice, flexibility and control**

This final section provides an overview of key informants’ thoughts on future directions for direct payments, on improvements that could be made, and on whether direct payments should be funded centrally or locally.

... the outcome is seen by the disabled people as being choice, control, flexibility, all those issues. If you can achieve the same ends in a different way with far less bureaucracy, far less paper work, far less individual having to adopt so much individual responsibility, then why not go for it?

Well, there’s vouchers obviously, voucher systems or credit systems, anything I suppose that offers a bit more user choice and control. The two obvious ones that I’ve always thought about is to offer vouchers and say, you know, you can use this on X providers within whatever period of time, or you offer call on credit in the block contract sense.

Others suggested that there ought to be greater flexibility, with the choice to ‘try out’ direct payments, and return to their original service plan if this proved too arduous or did not work as they expected.

...having a space to explore, to have the comfort zone, not being coerced into something they don’t want to do... I’ve often said that in my opinion the road to independent living through a direct payment or whatever should be like a motorway. You go on that motorway and you stop at the services that you feel you are comfortable in, and then if you are not too happy there you can move on, there’s another bit at the top of the motorway, a roundabout, and you can come back down and stop at the service you want, with the knowledge...

A suggested variation on this was a ‘trial period’ in which the user could test a range of authority provided options and those from other agencies to identify the best packages available locally.

The adequacy of service provision and local market structures were a recurring theme, with many key informants aware of existing or potential problems in meeting local demands for PAs and services. It was a challenge that key informants felt could be faced through improvements in local infrastructures, better financing, better communications between purchasing authorities and support groups, and the development of creative strategies in new forms of multi-stakeholder systems.

One way round this is for those support organisations to perhaps set up something like a stakeholders forum...where all stakeholders can meet and learn where direct payments came from, and also of the development of them, and try and take that back to their own group.

The stakeholder forum could ensure that the history of direct payments remains embedded in widened implementation, and would allow disability organizations to retain their identity and traditions while working with other user groups.

There were suggestions that the self-management of direct payments might be better construed in terms of a business plan than a ‘care’ plan. Others believed that the commissioning role should move from the purchasing authority to the individual, again allowing users more control and, potentially, overcoming some of the problems created by ‘block contracting’ of services.

So what you do is, you have somebody who helps you work out your own kind of business plan for want of a better word. Instead of a care plan why don’t we have a business plan? This is what I need to be able to develop my life in these ways. I need so much money and then you get help in negotiating that with the local authority, and you get funding and then you get the support in using that funding ...and you buy that in from wherever you want. Hopefully again there will be lots of different places, not just one CIL, but there may be lots of CILs that specialise in different areas. And you can put that in according to what particular types of support you might need. In the longer term I can see that...

We need to move the commissioning role from the local authority to the individual, so that the authority is giving them the money and they are commissioning their own services and choosing from a range of services that give them more kind of flexible choices. That's going to change the culture isn't it because it's not going to be local authorities doing block contracts with big organisations to deliver such and such a service? .So that is quite a big challenge for the big service providers to start to provide things to individuals rather than to local authorities. I think that will be one of the challenges to see whether that happens because if it doesn't happen I do think it's not going to really take off.

Further issues were raised around joined-up thinking, both geographically and over time, to ensure consistency and equity (e.g. in moving from one area to another, or in support from one year to another). These are serious inconsistencies that require remedies if direct payments are to gain the coverage envisaged by policy makers – and, more importantly, if potential users are to maintain trust the direct payment option.

It's peculiar to where you happen to reside... And if you move areas... it tends to have to be re-assessed, re-discussed and re-negotiated. If you move counties there is no guarantee that you would not lose it altogether... you might move to another local authority who say, well, actually we provide ongoing support in a different way. So there's no continuity geographically at all. And tragically I would also say there's no continuity in terms of years, you can't guarantee that the support you have this year will be the same as the support you have next year.

Concerns over change and continuity (both geographically and across the life course) might be addressed by a greater portability of direct payments by users within a national market (and a European market?).

If you came with a direct payment in your hand then it might just ease that transition because you control so much more of your world... You get it at birth and it follows you through your history and it goes up or down as your needs change. It saves you having these dialogues with different agencies to cross the boundaries, preschool to school, school to adulthood, adulthood to older age...

The problem of geographical consistency might be addressed if direct payments were centrally funded, developing a national framework that was consistent across the UK. However for some key informants, the prospect of central funding raised a different set of advantages and disadvantages. Many drew on early experience of the Independent Living Fund (ILF) prior to 1993. As a result there were mixed feelings around direct funding, management and implementation at the central, rather than local level. In the main, financial, legal and accountability considerations were thought to be problematic when considering centralization. Other considerations involved the ability of central governments to reduce or otherwise control monies, raising fears that direct payments could go the way of some previous disability benefits since the 1980s (being reduced,

changed or subject to tougher eligibility tests on the basis of national swings in political mood). On the other hand, central funding, if properly monitored, could lead to greater injections of cash, addressing some of the current equity problems associated with the vagaries of local politics and local budgets.

Those who believed direct payment funding could be centralized were clear that strong networks of local support remained essential to the end user.

The question of central funding seemed to replay many of the ongoing interview themes (financial and accountability issues, the importance of local networks of support, problems with assessments and eligibility criteria, low user groups and the tensions that had arisen due to differential opportunity structures in each country or area).

Another issue was that of eligibility criteria: whether these would alter if centralization was in place, who would be responsible for assessment, and how this would be applied. However, the ad hoc local and regional growth of direct payment infrastructure left some key informants convinced that central funding was the best way to go within the ethos that direct payments should be a national 'right' for disabled people.

I think ultimately it should be funded centrally. I think it's part of the reason it has been so difficult to implement is the nonsense of the way it is structured at the moment. It's a mixture of a charitable provision and local assessment, which just leaves too much to chance in terms of getting a good deal or a bad deal. I can't really see any reason... It will take a lot of work... but I can't really see any reason why it couldn't be done as a single centralised source of funding as a right. So that it has more in common with the benefits system than with either the ILF or social work assessments, but that is obviously a massive change.

...I can see the advantages in having a central and a national scheme as opposed to a local, something that's more locally available, that is maybe more responsive to the local factors, and perhaps less systems. I suppose there are pros and cons on both sides really.

While some see the present framework as chaotic, others are satisfied that many, if not all, of the aims of disabled people in the early days of direct payments have been advanced by direct payments implementation. However, there are real concerns that implementation remains both patchy and insecure. There are inequities between different regions and localities, and between different user groups. The expansion to non-disabled user groups, the framework of contracting, and the increasing marketisation of social care also threaten to undermine some of the foundations of independent living, from which direct payments as a concept initially sprang.