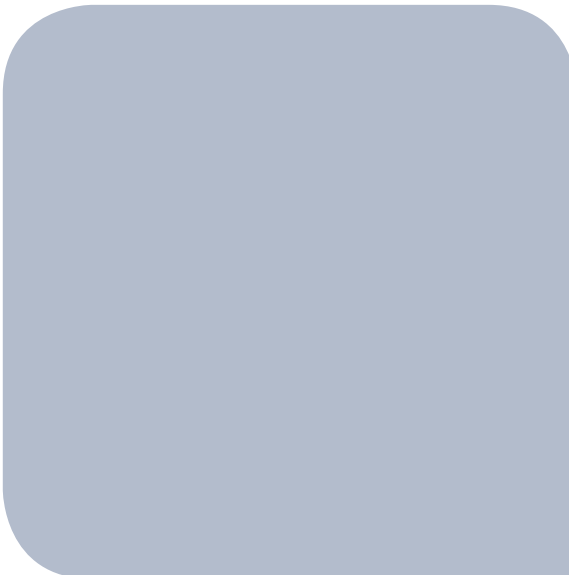
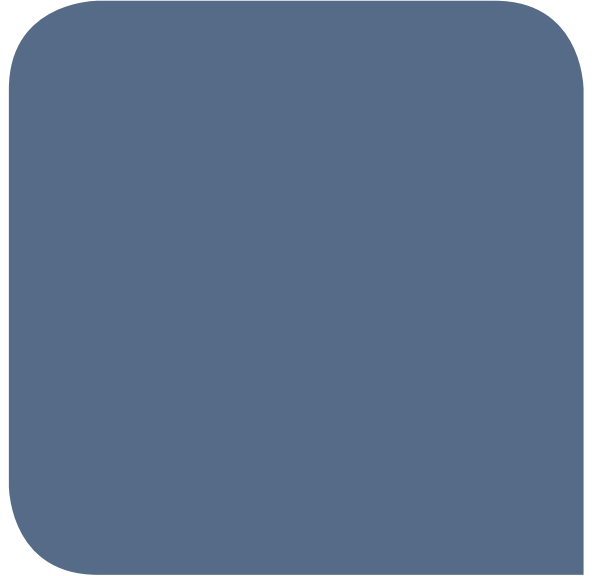


Contributing on equal terms: Service user involvement and the benefits system



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Michael Turner and Peter Beresford

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In addition, our thanks go to all those who have helped us to identify ways of taking this work forward effectively and who have helped make it happen, including Don Brand of the Social Care Institute for Excellence (SCIE), Roger Steel from Involve, members of the Shaping Our Lives Management Group and its National User Group and Fran Branfield, Shaping Our Lives' Manager. We have also benefited greatly from the help and expertise of Judy Scott and want to say a real thank-you to Claire Mills and Peter Jones at the Department of Health, and others who have worked with us to take forward the findings from this project.

And we would not want to forget to thank former minister for community Dr Stephen Ladyman MP for recognising the concerns of many service users and for setting off this project in the first place.

Finally, we would like to thank the Social Care institute for Excellence for the financial assistance they gave to this report, and particularly Jane Campbell, Nasa Begum and Amanda Edwards for their personal commitment.

Foreword

Jane Campbell
Chair, Social Care Institute for Excellence (SCIE)

Peter Beresford
Chair, Shaping Our Lives

This report arose out of discussions between the Minister for Community Stephen Ladyman and the wide range of service users attending the national launch in 2003 of the national user network of Shaping Our Lives. Conference participants highlighted difficulties in securing proper payment for the contributions people who use services make to reviewing, planning and developing services, even though their participation was a key element of government policy. There were particular problems for people receiving benefits, and practice varied around the country.

In response, Dr Ladyman confirmed he was sympathetic to the arguments being put forward, and asked Shaping Our Lives to help him by providing comprehensive information about the nature of the problems. This would assist him in raising the issues with ministers in other departments. SCIE offered to support Shaping Our Lives by funding a study of the difficulties that people and organisations had encountered and some of the ways they had tackled them.

This report is the result of that work. It draws on a thorough knowledge of the literature, and has involved a wide range of service users and other stakeholders in discussion about the issues involved in payment for participation. The outcome is a detailed exploration of the range of difficulties that arise for people using services and the organisations seeking their involvement.

It confirms that social care and health services value and want to make use of the input of people using their services. It also shows that the benefits system can at times be both inflexible and inconsistent in the way it operates. This leads, in some cases, to real anxieties for service users about whether participation threatens their benefits, and indeed to concerns for users and service organisations about the legality of some payment arrangements.

The report was commissioned by the Minister and submitted to him late in 2003. There was then a process of discussion with other government departments. It is clear that ministers have listened to the concerns being expressed by people using services. The Cabinet Office Strategy Unit's 2005 report *Improving the life chances of disabled people* includes a strong recommendation on the value of user participation, and a commitment that the Department of Health and the Department for Work and Pensions will issue guidance to health and social services authorities on good practice in paying service users, including those receiving benefits.

Some time has passed since Shaping Our Lives first produced the draft of this report. In association with other service users and professionals, it has used the time to try to begin the process of sharing the knowledge it gained from the project with more service users and other organisations. Shaping our Lives has talked about it at meetings

and conferences and discussed it with different government departments, ministers and officials.

During this process, we have learned two things, both of which make clear that, if anything, there is a growing need for a report like this to be published and its findings to be disseminated as widely as possible. First, there still seem to be some large obstacles in the way of achieving the kinds of changes that service users' experiences and comments suggest are important. Second, the issues first raised by service users in the summer of 2003 have become even more important. The pressure for user involvement has been growing rapidly – both from government and from service users and other citizens. For example, the requirement for user involvement in the new social work qualification highlights even more the need to resolve problems relating to participation and payment, and some social work educators worry that, unless this happens, that whole groundbreaking initiative may be undermined.

We have retained the original foreword with which we first sent this report to the Minister, Dr Stephen Ladyman. We hope it will serve as a helpful reminder that the report began as, and continues to be, part of an ongoing process of change for service users.

We see the present version of the report as a step in improving policy and practice in this field. In one sense, it represents a culmination of work and effort. In another though, it signals the beginning of a longer journey.

Underpinning this report is the goal of making it possible for service users and others who face exclusion and disadvantage to make their contribution to their localities, services and society on equal terms with others.

Service users are sometimes stereotyped as passive and dependent. Some critics would want people to believe that many are unwilling to contribute and are reluctant to accept responsibility. The people who contributed to this report show with passion how wrong this view is. We hope that, by making it more widely available, all that service users have to offer may become both more clearly evident and more achievable.

This edition of the report

The benefit rules and barriers to involvement have remained unaltered since this report was first presented to former Minister for Community Dr Stephen Ladyman. The benefit rates have been updated where appropriate, to reflect those made or altered in 2005. Where changes to organisational names have been made, for example, what was the Benefits Agency is now Jobcentre Plus, we have reflected this in the text. Footnotes have been added to assist the reader with understanding complex benefit rules.

Foreword to the 2003 version of this report

Peter Beresford
Chair, Shaping Our Lives

Dear Dr Ladyman,

In the past, long-term users of health and social care services were frequently written off as dependent and unemployable. They were not seen as having a contribution to make. This has changed as organisations of disabled people, mental health service users, people with learning difficulties, older people and others have highlighted the part that we as service users can play in improving public policies and services and by being active citizens in our neighbourhoods. Government has responded by encouraging the involvement of service users, stressing our right to social inclusion and working to make paid work an option and entitlement for people who use health and social care services.

But increasingly the long-term legacy of dividing people into 'dependent' and 'independent' – those seen as contributors and those seen as a cost on the community – has come back to haunt us. Service users and our organisations have most clearly highlighted this in relation to the benefits system. The government aim now is to offer people the choice of moving from enforced dependency on benefits to participating in society and getting a job – as of right. But as service users at the national launch of *Shaping Our Lives* in 2003 highlighted, too often the benefits system is working in the opposite direction – keeping people dependent, excluding and stigmatising them, rather than helping them to launch themselves back into their communities and, where appropriate, the world of work.

This report was commissioned by Dr Stephen Ladyman as Minister for Community and is offered to help him take forward discussion with government departments to help put right this very important problem. It's a big problem for service users, but we believe that it is a soluble one for government. *Shaping Our Lives* has sought to find out quickly what the problems really are from a wide range of key stakeholders, to inform this discussion and help take it forward with urgency.

The message that comes clearly from the research we have undertaken is that service users want to make their contribution, want to gain skills and the confidence to do so, want to act with integrity and honesty, but that sadly the old traditions and mindset of benefits and their organisation are not helping this to happen.

I commend this report of a user-controlled project to the Minister as chair of *Shaping Our Lives* and hope that he will find it helpful. We want to break the tradition of service users being seen as net 'takers' rather than 'givers'. As this report makes clear, service users are committed to making their contribution and sharing both the rights and responsibilities of their fellow citizens. But for this to work, there needs to be safe, secure, transparent and progressive arrangements in place for benefits, consistent with the new government philosophy committed to social inclusion, independent living and valuing the contribution of all.

Shaping Our Lives is committed to supporting the Minister in any way we can to take forward this work and to share developments with the wider constituency of service users.

Summary

Health and social care service users have highlighted increasing tension between service user and government commitments to get involved and contribute to local communities and the day-to-day working of the benefits system.

Shaping Our Lives, an independent user-controlled organisation that is core funded by the Department of Health, was asked by Dr Stephen Ladyman, former Minister for Community, to produce a report on the problems with paying people who receive benefits to take part in user involvement.

The Social Care Institute for Excellence provided financial support to undertake researching and writing the report.

Shaping Our Lives made contact with a wide range of service users to carry out this work. We emailed everyone who was at the launch of the Shaping Our Lives National User Network in June 2003 and everyone on the Shaping Our Lives database. The project also drew on material produced by service users and others, and related organisations with expertise and interest in this field were contacted.

Responses came from a wide range of individual service users, from organisations controlled by service users and from service providers who were concerned about the issue.

Main findings

These are the main findings of the report:

- Most service users and service providers believe that people should be paid to take part in user involvement. This recognises the value of their input. Service users also value the experience to taking part in user involvement.
- However, the rules on paying people who are receiving benefits are making service users payments difficult and sometimes impossible.
- These rules allow those receiving benefits to be paid a little, but people think that they should be changed so that they can be paid more.
- Some rules are not very clear. For example, some people believe that those receiving Income Support cannot be paid expenses, but others think that they can.
- Service users find it very difficult to talk to Jobcentre Plus about being paid, and it often takes a long time to sort things out. Service providers have similar problems when they try to deal with Jobcentre Plus.
- Some people found staff at Jobcentre Plus unhelpful and unfriendly. Others did not have this problem.
- People who are paid are very worried that they will lose their benefits. Even those who are not paid worry that, by taking part in meetings, they might be seen as being fit to work and, as a consequence, will lose their benefits.
- These problems are discouraging people from taking part in user involvement.
- There are also issues about whether paying people will mean they become employees and therefore responsible for paying taxes.

- Many service providers do pay service users for taking part in user involvement, but they are worried about whether they are doing it properly and whether they are breaking the law.
- The problems around paying people who take part in user involvement are connected to those that make it difficult for people to move from benefits into work.

Report recommendations

These are the recommendations of the report based on what service users and others say and their experience.

- The Government should recognise that its commitments to social inclusion, active citizenship and the increased involvement of health and social care service users in paid employment are being undermined by the operation of the benefits system.
- The benefits system urgently needs to be reviewed and changed to ensure that government commitments to user involvement and social inclusion are harmonised with the day-to-day operation of the benefits system.
- By getting involved in service user organisations and participating in local and national arrangements for involvement in public services, policy review and governance of public bodies, service users gain confidence and skills that help them return to employment. This needs to be recognised within the benefits system, and the importance of supporting such involvement should be acknowledged. Service-user participation needs to be seen as a help rather than a hindrance to people moving on to employment in the longer term.
- Service users should not be discouraged from getting involved because of the way the benefits system works.
- There needs to be specific and explicit recognition that taking part in user involvement does not mean that a person is fit for work.
- The increasingly recognised model of good practice is one in which service users who wish to be paid are paid for their involvement and expertise.
- The amount that people receiving benefits are allowed to earn should be increased, and there should be a more flexible system for assessing how much people earn.
- The levels of permitted earnings should be reviewed and revised.
- Discriminatory rules on earning should be addressed. Earning 'disregard' amounts for means-tested benefits should be raised to match 'permitted work' amounts.
- Permitted earnings should be assessed over a longer period. One year appears to be a more appropriate length of time during which earnings can be assessed.
- A system needs to be developed that will guarantee that taking part in user involvement will not lead to a review of benefits.
- Information on permitted earnings needs to be reviewed and clarified.
- The way in which Jobcentre Plus administers the rules for permitted earnings needs to be reviewed to ensure that they are consistently applied.
- Training needs to be provided to Jobcentre Plus staff to increase their understanding of employment issues to do with disability equality and, specifically, of the value and importance of work to do with user involvement.
- The whole issue of how employment law treats work undertaken as part of user involvement should be reviewed by the relevant government departments.

Introduction

This report was produced as a result of a Shaping Our Lives event in June 2003 to launch its National User Network. The event was a rare opportunity for service users from all over the country to share their views and concerns. More than 250 people took part, most of whom were service users.

The launch included a keynote speech by Dr Stephen Ladyman MP, then just eight days into his job as Under Secretary of State for Health and Minister for Community.

In the open session following his speech, Dr Ladyman heard a number of people relate how they had experienced problems with payments for participating in user involvement initiatives while receiving state benefits.

He commented on the strong concerns that were expressed in the conference hall, and responded by saying:

'If we want service-user involvement, there has to be a way of remuneration and of covering their expenses which has to be squared with the Benefits Agency' [now Jobcentre Plus].

'Can you, through Shaping Our Lives, prepare a paper explaining your experiences and the difficulties that you face? I promise that I will look into that and I will discuss it with ministers who work in the Department for Work and Pensions who are responsible for the Benefits Agency, and if there is a way that I can help, I will try and find it. It will help me if I had your first-hand collated experience through Shaping Our Lives so that I know exactly what I'm talking about when I go in and speak to the ministers.'

This request was met with an immediate promise of support for a project from the chair of the Social Care Institute for Excellence (SCIE), who also spoke at the launch. SCIE met this commitment with funding for the work that has been carried out by Shaping Our Lives.

This report aims to detail those experiences. It is based on material submitted by individual service users, service-user organisations, statutory and voluntary-sector service providers and academic institutions, as well as drawing on existing information. As well as receiving evidence, Shaping Our Lives carried out individual interviews and two focus group discussions with service users (see Appendix 1 for details).

The work was carried out over a very short space of time in order to match the urgency of the issue and to provide information quickly for the minister. The work was nonetheless carried out carefully and systematically.

Shaping Our Lives received a huge response to its call for information, confirming the impression given at the launch that this is an issue of key importance to service users. It has also reinforced the idea that the issue is considered greatly important by service providers and others involved policy and practice.

Many respondents, service users and service providers, stressed the need to address this issue in order for the government and local authorities to achieve their aims to engage service users as highlighted in policies like health, housing, social care and regeneration. User involvement has increasingly been required by government legislation and guidance.

User involvement needs to be based on a community/user-led approach that is flexible and responsive to the different needs of different users in different areas. At the same time, Shaping Our Lives' experience is that, to be effective and worthwhile, involvement needs to be underpinned by principles and good practice.

Addressing issues around payments to users who receive benefits will be a key part of the development of the foundations for proper and principled user involvement.

1 Defining involvement

In producing this report, we primarily set out to examine issues around payments to service users in relation to involvement and consultation initiatives to do with social and health care services and provision, although we found similar issues in other fields. This activity can take the form of participation in involvement/

consultation arranged via statutory and voluntary service providers, input into training and education (often through universities) and taking part in research carried out by service providers, service-user organisations and academic institutions.

Shaping Our Lives' focus is firmly on the perspectives of service users. However, several respondents highlighted the need to also consider carers in relation to the payment issue – in some instances, individual service users' financial situations are linked with the benefits paid to their family carers – and Shaping Our Lives acknowledges that there are shared concerns on this issue.

As has been said, while social and health care are the focus of this report, some respondents pointed to the many other spheres of involvement in public life – for example, serving as a councillor, serving on benefits tribunals and membership of public bodies – and these have a bearing on involvement in social and health care and are referred to where relevant in this report.

The issue of payment and the problems that occur in relation to the benefits system are also under discussion in relation to other areas of participation in public life.

In the urban regeneration field, *New Start* magazine started the Just Rewards campaign in July 2003 for fair payments for residents involved in regeneration projects. That campaign has noted similar problems with payments for people receiving benefits. It received support from the then Home Secretary, David Blunkett, although there has still been little progress from the Department for Work and Pensions.

The Engage Network is a coalition campaigning for the greater involvement of disabled people in public life. Its members include the British Council of Organisations of Disabled People, Disability Alliance, Scope and a number of disabled individuals involved in public life. In March 2003, it submitted evidence to the Public Administration Select Committee, highlighting many of the issues relating to payments to disabled people that are addressed in this report.

Members of the Engage Network are also involved with the Office of the Commissioner for Public Appointments' working group on increasing the involvement of disabled people.

2 The reasons for paying service users

While the principle of paying service users for their participation in user involvement initiatives has been gaining recognition in recent years, it is by no means a universal practice and there can even be variations in practice between different organisations in the same area.

This was a point noted by participants in the second focus group that we carried out. They said that they were paid for some work, but not all, and that rates vary significantly:

Social services have just started a two-tier system. If you go to meetings, you only get travel. You only get paid if you go to committee meetings. Then, on the other hand, you get paid by the health trust for going to their meeting.

Participant, focus group 2

Several people in this group were very critical of the levels of payment to service users, particularly in relation to the amount of time that people give to these activities –

I get paid £10 per meeting. Whether it's one hour or one day, I get paid £10.¹

Participant, focus group 2

I once gave a lecture to 50 second-year psychology students for two hours. At the end, the lecturer got me to sign a chitty and I was paid £56² – wonderful! I gave a similar lecture to medical students while I was under Section 2³ and didn't get paid anything. I've just attended a two-hour meeting this afternoon for which I was paid £10.

What I'm trying to say is that the value of the payment depends on the provider of the service, so at the college I got a lecturer's rate, in the hospital I was just treated as an inpatient, and [I] just received a nominal fee for the other meeting. The problem is that there is no consistency because of this bloody awful phrase 'market forces' and that means: if people can get away with just paying travel expenses, that's what they'll do. There's a difference between doing voluntary work and slave labour.

Participant, focus group 2

I go to two or three meetings a day and I've only just started getting any money and it works out at about £20 a week. Yet some days I'm out at nine o'clock and don't get home until six.⁴

Participant, focus group 2

One person in this group had had an opportunity to compare rates of payment with people from different areas:

I was at a meeting with users from different areas and we were talking about what we get paid for meetings. In one area, they got £45 for half a day plus expenses and childcare. For a full day, they get about £80.⁵ In my area, they've stopped all payments. There's no attendance fee and no expenses paid so people have just stopped going.

Participant, focus group 2

The last part of this comment – the statement that, in their area, payments had been stopped altogether – is particularly worrying.

Service users see this issue of payment as a priority and a key point in ensuring that user involvement is based on proper and principled practices. The above comments indicate that, not only have many areas yet to accept the principle of making payments, some areas that have accepted the principle are beginning to go back on it.

The complexities of paying people on benefits appear to be holding back progress on ensuring that payment becomes an accepted principle and practice. According to some respondents, this makes it easier for some organisations to be evasive about the principle of paying service users:

I think a lot of organisations steer clear of the payments issue and don't pay people because it's so difficult.

User-controlled organisation

It's about time this inequitable concept of partnership between service providers and users stopped. We have a partnership board which is very well attended by people with learning disabilities. They say they want a payment; they want to be seen as equal partners with everyone else working around the table. The board says they will look into making a payment but they have not found a solution in well over a year.

So there's a very mixed experience out there, but we have to ask: if the mental health forum pays, why don't the forums for other impairment grouping? We also have to ask: if some people do it, why don't all people do it? Why are some of us left out?

User-controlled organisation

We have found Jobcentre Plus approachable, but we have found the local trust have been loath to pay the minimum wage for advice work, until we challenged them upon this, and [they] scare individuals with talk of losing their entitlements rather than offering helpful information.

User-controlled organisation

The members of the focus group we carried out with people with learning difficulties have taken part in the activities of a wide range of committees: partnership board meetings, which are run by the council; sub-groups of the partnership board; day centre committee meetings; a quality action group; housing committee; and a committee for modernising day centres.

They were not paid for participating in these meetings. They had been paid for some work, including sitting on interview panels, but said that decisions about what they are and are not paid for seem to be arbitrary:

The council wants to pay us for some things, but they don't want to pay us for everything and I don't know how they decide.

Participant, focus group 1

You should get paid to go to the meetings. When I go to a meeting, I can't go to college.

Participant, focus group 1

It should be noted that some service users do not believe that payment is necessary for taking part in user involvement.

One respondent was particularly concerned that payment for involvement in initiatives carried out by service providers would deter people from undertaking unpaid roles in user-controlled organisations.

Another was concerned that payments would restrict user involvement to small groups of people:

Do not set up a system of payment whereby a clique of users monopolise and dictate to whom the money goes, and they then keep it in a secret enclave comprised of friends and family and depriving those genuine users who are, because of the structures, the only ones not able to get a take on it.

Such structures allow for undemocratic distribution of payments and thus leave out the chance for a broader range of users to have payment in return for their contribution. There needs to be selection processes and rotating positions and tasks. It will not be fair or proper if only one small clique of users are allowed to hog payments and ride on the backs of [grass]roots users.

User/survivor of mental health services

This highlights the importance of individual service users having a choice about payment and the efforts being made to include the widest range of people in arrangements for involvement, addressing issues of diversity. It also suggests that there may be a need to find out more about the effects of difficulties with benefits on people's preparedness to accept payment and therefore get involved.

Worry was also expressed about the potential costs of paying service users for their involvement, particularly in relation to the voluntary sector. One service provider said that funds should be available to pay service users and reimburse them for their expenses.

While not opposing payments, a participant in the second focus group was concerned that payments gave service providers an element of control over the involvement process:

When they want users there, they pay the £10. When it's a meeting where they don't want people there, they don't offer the money and people don't turn up and they can put through the policies that they want. The giving and withdrawing of the money gives them control.

Participant, focus group 2

Service users in the second focus group were also keen to stress that being paid was not the most important part of user involvement, and that being listened to and

having their views valued were their key concerns. Several people in the group said they wanted to get some credit for ideas that they put forward and which are taken up.

One participant gave this assessment of the general situation of user involvement and the payments issue:

The problem with user consultation ... is that the same people keep attending the meetings. For every person who attends a meeting, there are 10 or 15 or more who don't bother. The reason why they don't bother is because they can't see the value of it. They can't see that they can make any useful changes. Those of us who do attend these meetings become marked out and marginalised because we become known to the services.

The payment that we receive is a side issue. It's not the amount of money that matters, it's being listened to, being taken seriously and making some changes.

Participant, focus group 2

This person went on to say:

My experiences have led me to conclude that there's an endemic problem right across the services, that there is a tokenism associated with bringing in service users into services by saying: 'If you attend this meeting, we will pay you this amount of money.' This is encouraging people to attend meetings for the small amount of money that is on offer, rather than attending the meetings to bring their experiences to the meeting.

People who attend meetings should be rewarded on an equal basis. I was at a meeting this afternoon with three consultant psychiatrists who earn an average of £100,000 a year. They earn in a year what I have to live on in about eight years. Users are not being valued at the moment, perhaps because of the history of some of the confrontation that happens at the meetings. The 'them and us' approach needs to be broken down and that will only happen when people are remunerated accordingly. At the moment, some of the remuneration is not worth bothering with.

The point here is that service users should be properly valued in all ways, and that payment is an important part of this. It may be that it is an essential part, as the process of paying users gives clear recognition and financial value to their input.

The majority of service users do want to receive payment for their involvement and expertise. The case for payments was put strongly by several respondents:

The work that I do is community-based and probably saving the NHS and social services a fortune in salary. I don't think – and this is backed up by my GP – that I would be able to do the work as well [as I do] if I were paid a salary, but the chance of 'earning' a little payment, like for attending meetings where I go as a [mental health] service user, would not go amiss.

User/survivor of mental health services

At one stage, I was doing five or six meetings a week and just getting the odd £15.⁶ I think we should get paid. Just a small amount. Lots of people are on very good money.

Participant, focus group 2

I'm being paid the minimum wage for attending meetings where I am giving advice that has the potential to change people's lives and change policies. Frankly, it's pathetic. I'm 40 years old, I've been in the mental health system for 20 years, I've got a damn-sight more experience than a lot of the professionals I know.

Participant, focus group 2

If it wasn't for people like myself, a lot of the work helping others would not get done.

Disabled person

The services are getting consultancy on the cheap because they're not paying users.

Participant, focus group 2

[Payments] also underpin the 'value' of the knowledge and experience that disabled people like myself accrue over the years, which cannot be taught but is gained through 'life experience' ... There needs to be a degree of informed decision-making involved from people taking part in user consultation and involvement, and this in turn adds 'value' to the case for remuneration.

Disabled person

A service provider also made an important point about the benefits such organisations get from paying service users:

Service providers that pay users for training, interviewing, etc. have a right to expect things in return – for example, reliability, appropriate behaviour.

Payment of service users' expenses in relation to participation does seem to be almost universally accepted, although it does not appear to be universal practice – several respondents cited examples where expenses are not paid. Others pointed out that certain expenses associated with involvement often go unpaid, such as telephone calls and postage and stationery costs.

3 The benefits system and payments

The following are the basic rules about payments that apply to people receiving benefits.

People who are receiving benefits because of ill health or disability will be getting one or more of the following: Incapacity Benefit, Severe Disablement Allowance and/or Income Support (for incapacity). People who receive any of these benefits are not allowed to do any paid work except when it complies with the Permitted Work Rules.

These rules – introduced in 2002 to replace the ‘therapeutic earnings’ system – were intended to allow up to 16 hours of paid work a week in certain circumstances. However, when the Permitted Work Rules were created by the Department for Work and Pensions, they did not address a separate benefits rule that is applied to means-tested benefits. Means-tested benefits such as Income Support, Housing Benefit and Council Tax Benefit have an ‘earnings disregard’ that, for those receiving incapacity benefits, is only £20 a week.

So, although the Permitted Work Rules allow earnings of up to £78 a week,⁷ people who claim a means-tested benefit will have that benefit reduced, penny for penny, by any amount they receive over £20 a week (or £10 for people with a partner). About 80 per cent of people claiming incapacity benefits are thought to be claiming a means-tested benefit.

Additionally, people who receive incapacity benefits are subject to regular medical reviews of their entitlement. Misunderstandings can occur over service users’ involvement in initiatives carried out by service providers when Jobcentre Plus is not advised about the purpose of the scheme. People may have their incapacity status disallowed as a result of official error, even though they are following the Permitted Work Rules or are volunteering.

A full analysis of the rules, by a welfare rights specialist with particular experience of these issues, can be found in Appendix 2.

Benefit rules on earnings for people getting incapacity benefits are due to be changed in 2006, but no mention has been made of any plans to raise the ‘earnings disregard’ to match permitted work rates.

Service users highlighted a number of limitations that these rules and the way in which they are administered, place on their ability to take part in and accept payment for user involvement activities.

3.1 Rate of payment

The key concern from many respondents was the level of payment allowed under the Permitted Work Rules. Thus, for example:

I have negotiated with Jobcentre Plus that I am allowed to earn £66.00⁸ per week without it affecting my benefits. The problem with this is that I could do three things

this week and should be paid £200 but [will] only be able to take £66 of that £200. Then for the next two weeks I might do nothing. My point is, it would be better to be allowed to earn an agreed sum over the year – i.e. £3,432.⁹ Then, if we are more busy in some periods over the year than in others, we won't lose out so much.

Disabled person

I am a non-executive director on the board of a primary care trust – a remunerated position of over £5,000 per year. I am also in receipt of Incapacity Benefit, so not allowed to claim the remuneration.

The chair of the PCT has supported me in trying to resolve the issue and both the NHS Appointments Commission and Commissioner for Public Appointments have been approached.

However, as it became clear a universal solution was not imminent, I explored the possibility of 'therapeutic earnings'¹⁰ with my GP, and the Benefits Agency [now Jobcentre Plus] agreed I could claim £66.00 per week. Up until now I have continued with this arrangement but, with the demise of therapeutic earnings, will have to switch to the Permitted Work Rules, which I understand will only allow me to claim £20 per week, unless supervised by someone working for an agency seeking employment for disabled people.

Disabled person

I now have a post under the Permitted Work Rules for four hours a week. I do much more than four hours but can only benefit financially up to £20 a week because I am on Income Support.¹¹

User/survivor of mental health services

Services providers expressed similar frustrations and felt that their efforts to give users recognition and remuneration were being undermined by benefits rules:

It was impossible to pay them at the proper rate so we were limited to paying each person the maximum allowed so as to not affect their existing benefits in any way. This meant in effect that they each got paid different amounts for the same job.

Service provider

This was the experience of the organiser of an urban regeneration project where the funder had agreed to pay local people to undertake consultation with the community:

Our plan was to train and recruit local people to undertake the consultation work, and the funder agreed to provide a budget based upon 200 volunteer hours at £7.50 per hour. Initially, we were jubilant at this, as it seemed to offer the prospect of getting some funding back into the community. Little did we know how difficult this would be.

We were aware that there would be issues regarding benefit entitlements, but we didn't anticipate how problematic it would be to help those in greatest need. In the end, the only people we could actually recruit were people who were not in receipt

of benefits – people who ran their own businesses, or were home-makers with partners with a reasonable income.

In practice, we found that other people on low incomes were prepared to get involved, even if not as employees, and we've used innovative ways to secure some community gain from the funding. We have paid actual expenses, and negotiated with the funder to make donations to nominated community groups and partnerships which broadly reflect the volunteer hours contributed by local people.

Service provider

3.2 Areas of confusion

Some of the experiences reported by service users indicate that there is considerable confusion about how to apply the rules on payments to people receiving benefits. This is not just among service users and service providers but also among staff at Jobcentre Plus, as this service user found:

I was receiving Income Support and some disability benefits. I also did occasional lecturing at a university. This was above what I was permitted to earn in a week, although it was generally only an hour's work. This caused such confusion at the benefits office as they weren't sure how to deal with this situation. Should I sign off and then sign on again? They advised me to do this, but that requires so much paper work that it just wasn't worth it. It was sorted in the end, but I had to make sure I only ever spoke to the same person at [Jobcentre Plus], otherwise they didn't know what to do with me.

Part of the problem may be that there are different rules for different benefits and different situations. In this example, people involved in the same piece of work received different payments because they received different benefits:

I run a 'Teenagers to Work' programme annually, which targets looked-after and disabled young people aged 16-18 years. Young people are paid as employees for a month to work on projects around being looked after. One disabled young person aged 17 on the programme ended up being paid £15 per week when others were paid £100. His mother claimed Income Support and had a higher-rate enhanced allowance for him due to disability. Advice at the time was that the mother had to stop claiming at the start of the programme and then claim again when he had completed the programme. This would mean a delay of a few weeks whilst benefit was sorted, but also risking the possibility that the young person would not be assessed this time round at the higher rate. Further advice from [Jobcentre Plus] was that we could not give gifts in kind as any adjudicator would consider these as cash equivalent. In the end, that young person decided to be paid the £15 he could earn without benefits being affected.

Service provider

Responses from several people and organisations indicated that there is confusion about whether expenses can or cannot be paid without affecting benefits. Some respondents believe that expenses are payable, while others have been told that they are not:

Information that I was given at a meeting we had with a welfare rights officer highlights the letter of the law regarding expenses and any person in receipt of Income Support or Sickness Benefit. Anyone on Income Support should, in theory, not eat sandwiches if they attend a conference because they are breaking the rules. This is called 'payment in kind'. I know a person now who will not accept lunch on representative work. I have studied the Welfare Rights CD-ROM and this is correct. I am not on means-tested benefits, so I can eat the sandwiches. What a farce, but true.

User/survivor of mental health services

I've just been to an NHS meeting and had to pay £10 to get to it and back. If I have more than one meeting in a week, I am going to be well out of pocket.

Disabled person

One service provider said that they understood that Jobcentre Plus treated travel expenses as income when they were paid for travel to a regular place of work. A briefing by the Disability Alliance says that there should not be a problem with paying expenses.¹²

3.3 Dealing with Jobcentre Plus

People receiving benefits are usually reluctant to break the rules associated with their payments and will generally seek the advice of Jobcentre Plus before doing something like accepting a payment.

This said, everybody in the second focus group said that they did not report payments that they received to Jobcentre Plus because they had found it too complicated when they did, and because it might draw attention to their situation. The system clearly pressured them into doing the wrong thing.

Many service users had had lengthy and difficult experiences of negotiating with Jobcentre Plus:

I was appointed as a Mental Health Act commissioner while I was still on benefits. I explained to [Jobcentre Plus] that this would involve me in working two days per month and earning £180. They said this did not fit into their rules and I must either stop claiming benefits or do this work unpaid. Even then, they would question whether I was still incapable of work and entitled to benefit if I was doing two days' voluntary work.

So they sent me a typed list of questions, which they appeared to have made up on the spot, and a standard but lengthy form to test my incapacity. I answered all these questions at length and eventually to their satisfaction, but I could very easily have decided that it really wasn't worth the hassle, and that it wasn't worth jeopardising my entitlement to benefit and decided not to take up being a Mental Health Act commissioner.

User/survivor of mental health services

I am a service user on Income Support due to an enduring mental health problem. I am only allowed to earn £10 a week before my benefits are affected. I have a job I do most weeks reading to a partially sighted lady. If I have any work for the trust, I have to not accept payment either from the lady or from the trust to do what is required by the benefits system.

I am supposed to fill in a form every time I have work. It's easier either not to get involved in the work for service users or do it voluntarily without declaring it – it's supposed to be declared even if it's voluntary. It would help not to have to fill in a form every time as the involvement work is only sporadic.

User/survivor of mental health services

I receive Incapacity Benefit and two early retirement pensions. I am actively involved in voluntary activities designed to help my fellow sufferers. These activities (hopefully) help my fellow sufferers and give my life some focus and purpose.

If I were to engage in activities that offered remuneration I would be required to obtain permission [in advance] from one pension provider and the Department for Work and Pensions.¹³ I would also be required to inform 'the tax-man'.

My mental health condition requires that I keep my life simple, and the above have deterred me from attempting any remunerative activities ... I am simply not 'up to' sorting this type of thing.

User/survivor of mental health services

I worked on a Department of Health committee that paid an attendance fee of £100 for full-day meetings and £50 for half days. I'd also done some work and then joined a committee for another organisation.

When the work finished after a year, I got in touch with the benefits office – I'd put it off because I wasn't looking forward to it. I was completely honest and they were as nice as they could be, but they said, 'The rules are the rules.' They weren't happy that I had left it so long, but I was very diplomatic and persuaded them this was the best way to do it – though they did say that they could have taken action against me for not going in sooner.

So I got a statement of what I'd been paid for the financial year and we're into the stage where they're working out how much I have to pay them back.

In other years, I've been paid under 'therapeutic earnings' by a charity, but up to the full amount, so I'm trying to persuade them to allow me to take the balance against what I pay back. I've also asked for expenses like telephone costs to count against this.

Disabled person

I was working on a service-user research and evaluation project, and my Income Support and Incapacity Benefit were withdrawn for six weeks. The only money that I had coming in was my Disability Living Allowance. The local welfare rights service helped me to appeal and my benefits were reinstated.

Not having benefits for six weeks had a detrimental effect on my mental health. I was told that I was fit to work and had to claim Jobseeker's Allowance.¹⁴ This was ludicrous because my doctor's opinion is that I may not ever be fit enough for work.

User/survivor of mental health services

This service user describes the process of trying to get Jobcentre Plus approval for payments for participating in a university-based project:

We started out wanting to make some arrangement whereby we could work together without feeling that what we were doing was somehow dodgy. It mattered to both of us. I started out by attempting to fill in a 'permitted work' form, which was difficult to understand. It also required me to name an employer for whom I would be working, which I wasn't. I couldn't say I was self-employed either. The easiest way to look at it was to say that I was volunteering on a project at a university and they were paying my expenses. That was true enough: they paid me £100 for work that went on for eight months and has required a lot of phone calls, emails, stationery, etc.

In the event, dealing with [Jobcentre Plus] required a huge amount of energy, especially as their inflexible system and often uninformed phone workers made the process of getting started much harder than it needed to be. I got so distressed I nearly gave up, but I had good support from the person at the university and the employment support worker I went to see (both of whom are professional advice workers). If I'd only been interested in the money, the project would certainly never have got off the ground.

User/survivor of mental health services

Others report similar experiences:

We continue to have issues around the Permitted Work Rules, which allow users to earn either £20 or £67.50¹⁵ for 15 hours' work on top of their disability benefits. At least that is what our local [Jobcentre Plus] says via their disability advisers, who I have liaised with closely. Several organisations locally are employing users under this scheme, but all the money earned is taken away from the users' Income Support top up, or from their Housing Benefit, so it is virtually useless.

User-controlled organisation

I've worked with several research projects led by people on benefit and this has been a continuing (and stupid) difficulty. Each local benefit officer can exercise their own discretion – don't have to take any notice of their predecessor or their neighbour officer in the next patch.

Academic

For service users, the experience of dealing with Jobcentre Plus can be difficult and demoralising:

It upsets me to talk about it. I do some part-time work and I've been reported for doing it, and they said I've been getting a lot of money but that is a lie. I only get a

very little bit. The welfare rights adviser has been dealing with it and he says I am allowed to earn up to £20 a week. They had threatened to take me to court about this. All the trouble has put me off. It was like a nightmare – I had all my benefits stopped.

Participant, focus group 1

I am in correspondence with my local [Jobcentre Plus office] because I was honest enough (some say stupid enough) to notify them that I had earned the princely sum of around £300 in a year! They wanted to know how many hours and when and who for some work I did 20 months ago, at home without a stop clock! or at meetings as a service user.

Once they had confirmed, presumably, and after having misunderstood a very clear letter which said I had worked for 20 hours in total and earned £100 in three of their weeks, they sent me forms for 'permitted work' and also another one for 'voluntary work'. [I'd] filled in one of the latter a few years ago (in a moment of honest pique!), and I [had been] given the all clear. My work had not substantially changed so I had no reason to think I needed to fill in another. My memory is not good, and my filing system is worse, so I had difficulty remembering what I had put the first time. It has been a lot of hassle.

User/survivor of mental health services

There is no clarity on this payments matter: all is fragmented and, in my case, quite threatening ... The risk of losing benefits and the knock-on effect it might have on other concessionary payments (exemption of council tax/concessionary bus pass, etc.) means I attend presentations and conferences believing I am running unnecessary risks of forfeiting my basic entitlements ...

User/survivor of mental health services

We do not currently pay our service users for their involvement in the project, despite the fact that they are contributing to strategy meetings alongside health and social services professionals. We have looked at the issue of paying service users for their involvement in the project, but as you know, this is a minefield as all our service users are on benefits which they are not in a position to jeopardise ...

Also, because any work done is both sporadic and dependent upon the state of the participants' health on a given day, it is unwise for our service users to jeopardise their current benefits as, once taken away, these would take considerable time to reinstate, creating financial difficulties in the meantime.

User-controlled organisation

A service user group highlighted particular problems faced by people with learning difficulties when dealing with the authorities:

Some users are better equipped to argue that they should be allowed 'therapeutic earnings' [now 'permitted work'] for the work they're doing or that they are only working for the time that is allowed. Someone with a learning difficulty is more likely to just say they were working and they were paid, and once you say something like that, it's hard to re-argue it.

User-controlled organisation

Where service users have experienced positive outcomes and found that they can be paid, the process has often been a difficult one that has highlighted the lack of clarity on the issue.

For instance, a service user who was appointed as lay representative to one of the new social-care quality agencies was very concerned that the payment that accompanied the three-day-per-month position would lead to the loss of Incapacity Benefit. This situation was made worse by the fact that, when their term in the position concluded, the person would have been treated under new rules when reapplying.

Working two or three days a month is allowed under the Permitted Work Rules, but in this case, the amount being paid exceeded allowed income. On this occasion, an adjudication officer ruled that payments were allowed, with Incapacity Benefit being withheld for the days when other payment was received. The legislation cited was Social Services (Incapacity for Work) (General) Regulations 1995, regulations 16, 17, 19 and 20 and Social Security Contributions and Benefits Act 1992, Section 30A.

The person concerned noted:

I was very pleased with this resolution and was impressed that my local [Jobcentre Plus] office was at all times as helpful as they could be. I had not expected to receive the full amount of Incapacity Benefit while I was receiving remuneration and felt that the solution reached was very fair.

None of my disabled colleagues (some of whom are very familiar with benefits legislation) were aware that this was possible. Information on [what was] the Benefits website does not make this clear, neither is it ever included in information provided by organisations for disabled people – e.g. the Multiple Sclerosis Society. This would be because they are not aware of the situation.

Disabled person

Lack of awareness of these rules was evident in the response of another person who appeared well informed about benefits rules but had been told that payments for public appointments would exceed allowed income, meaning:

While I have the skills to take up a public appointment, I cannot because of the earnings rules.¹⁶

User/survivor of mental health services

3.4 Staff attitudes

Several people reported having had very negative experiences when dealing with Jobcentre Plus staff:

The attitudes of [Jobcentre Plus] staff are appalling ... as well as obstructive. I want no contact with them at all if I can possibly help it. They attempt to humiliate and to destroy people ... that is no exaggeration, if anything it is an understatement.

User/survivor of mental health services

Even if they are completely honest and up front with [Jobcentre Plus], service users are treated with mistrust and suspicion. One service user regularly has his benefits book suspended for only receiving expenses arising from his voluntary work. Another service user took on some occasional bank work and again did everything to inform the [Jobcentre Plus office] about the work involved, only to find that, a few weeks later, their benefit was suspended and they were under investigation.

User-controlled organisation

Others reported more positive experiences:

I have found Department for Work and Pensions¹⁷ staff to be helpful at all times. I do understand that they have a duty to 'look after' the monies that they issue, and must have rules for this.

User/survivor of mental health services

The people were as nice as they could be but were constrained by the system.

Disabled person

The people with learning difficulties who took part in the focus group thought that more help should be available from social workers, but complained that they did not have access to one. They said that they received good help from the welfare rights adviser at the local disability organisation.

3.5 Fear of losing benefits through review

It is clear from the responses received that, for service users, one of the biggest concerns about receiving payments is potential loss of their benefits and the associated processes of review and investigation. The prospect of having to reapply for their benefits compounds these fears – particularly as reapplying will mean that new rules that may not have affected a person as an existing recipient could come into play and have detrimental effects on them.

This means that, while many organisations have been making efforts to establish systems for payments that meet the requirements of the benefits system, many service users remain sceptical about their situation and what will happen if they accept payments:

Because of all the hassle, and because I feared for the safety of my benefit, I decided to abandon any idea of any variety of 'permitted work', and just stick with voluntary work. I have said I only do two hours per day.

User/survivor of mental health services

It is disheartening to hear of some people getting paid who feel relaxed and happy about it when others such as myself feel under pressure on this score and, in addition, are not paid. Instead we are having to live with the knowledge that the Work and Pensions snoops might pounce at any time with their reason for snooping being because I stuck my neck out to try to help and support the initiatives that involve using experts by experience.

User/survivor of mental health services

I do worry about my involvement with the mental health service meetings in case someone decides I am too well to remain on Incapacity Benefit and Disability Living Allowance.

User/survivor of mental health services

Service providers also reported that the situation can remain difficult because users expect that payments will cause them problems, even when the payments are entirely legitimate.

A lot of feedback has suggested that most people will only want expenses to be claimed back. They are too worried about benefits being affected if they are paid for their involvement, even if we keep the payments below the weekly limit of £20. I have had close links with our [Jobcentre Plus] office and think we can make it as simple and safeguarded as possible, but it is very hard to reassure people.

Service provider

People recovered enough to think about a return to (part-time) work face a dilemma:

If I stay well, I can afford to stop benefits, but if I get unwell by trying too much (which often happens), I risk losing benefits, and having all the hassle of setting them up again.

User/survivor of mental health services

I ran a user-focused monitoring project a couple of years ago. All those who took part were mental health service users. They had the choice of doing the work as volunteers or being paid. Some chose to do it as volunteers because they were so afraid they would lose their Income Support, Disability Living Allowance or Housing Benefit. Others chose to be paid, and I had to devise a very complex system and write to each of their GPs to agree that the short-term work would be therapeutic. However, it caused great stress, especially around the issue of Disability Living Allowance where people were very concerned that they might in future be either reassessed or have their Disability Living Allowance stopped.

Service provider

This last quote illustrates just how great the fear is and how harshly people have been treated. While Disability Living Allowance is not income related, there are concerns (set out in a briefing by the Disability Alliance) that participation can be seen as showing a change in the person's health/impairment, and therefore leading to a review of the allowance.

People's fears particularly focus on the possibility of a review of their benefits. Some had had particular experiences on which their fears were based:

My GP has just received a questionnaire to ask if I am still unwell and entitled to benefits. I am told that this is routine and not related to starting the voluntary work. However, the message it sends me is that, if I dare to seek out a new life for myself, and become a well manic-depressive, I am a fraud. Could they not say that they would love to hear me speak for myself, have a place in the world, not be a burden, and that they would like to help in any way they can?

User/survivor of mental health services

Service providers also recognised the impact of people's fears of having their benefits reviewed:

Service users are also worried that their involvement will automatically trigger a system for their benefits case to be reviewed. I work with people who have mental health needs, and in order to avoid anxiety about these issues, they seem to be opting for non-payment as the least stressful option.¹⁸

Service provider

People's fears about being reviewed result from the way such reviews are conducted and what they have heard about other people's experiences.

Where reviews do take place, people are subject to a 'fit for work' test, and taking part in user involvement, even on a voluntary basis, can trigger such a review:

Numerous people I know have been told that, if they do voluntary work, they are not classed as available for work, and because of this attitude, people have refused to be a volunteer.¹⁹

Service user

With regard to taking part in user involvement initiatives, even if it is unpaid, I am still not sure if this is permissible because by definition 'disabled' could mean you are not well enough to participate in this. The whole area opens a minefield of ifs and buts, and the implications could have undesirable effects to your right to satisfy the criteria for benefits.

Disabled person

They force you back into work when you're not well and not ready. They think that, if you're fit enough to go to these meetings, you're fit enough to go to work.

Participant, focus group 2

One service-user organisation pointed out the contradictions in relation to this test:

There is grave concern about the work test and the way that people are deemed 'fit for work'. Service users get invited to high-level meetings [because] they are ill and, therefore, by implication 'unfit to work'. However, another agency perceives that ability to attend such meetings as making them 'fit for work'.

User-controlled organisation

However, a participant in the second focus group was able to give a clear, concise explanation of the differences between user involvement and having a job, which should satisfy concerns about this issue:

You can go to meetings because it's flexible. It might be that you go to a meeting and don't do anything else for the rest of the day, or even the next day, and that's how you keep well. If you were working regularly, you couldn't do that.

Participant, focus group 2

A service-user organisation put the issue into a wider context:

Ultimately the major concern is the issue of 'fitness for work'. The truth is that disabled people can 'work' given the necessary support and flexible employment. This, in turn, prompts further questions of society – if we think work is important, what needs to be done to make it more possible?

User-controlled organisation

Others also pointed out that the restrictions on payments were indicative of the wider limits of the benefits system, which defines people too simply in terms of being able or not able to work.

[Jobcentre Plus] has no understanding of the recovery process: how I could be able to start a demanding piece of academic and empathic work (which is doing a lot to help me feel stronger in myself) but also be vulnerable, prone to emotional storms and a great deal of distress ...

[Jobcentre Plus]'s definition of a service user is that someone is 'incapable'. They use this word in its most absolute sense and don't acknowledge that we are able to, and must develop, a much more loving and positive view of ourselves.

User/survivor of mental health services

The system is set up to deal with people who are either disabled or are capable of working – either one or the other with no flexibility for anything in between. 'Therapeutic earnings' [now Permitted Work Rules] is a little sop in between, but it doesn't really allow for the reality of most people's lives.

Disabled person

HIV is a very complex disability, and the benefits system does not appear to take the problems into account. For example, someone who is HIV positive may have periods of good health followed by periods of extremely poor and debilitating health, and also there can be problems of side-effects of medication.

Despite this, there appears to be a climate where government appears to want to get people to come off benefits without paying any attention to the problems they may have, especially if they have been out of work for long periods due to sickness.

Disabled person

One participant in the focus group with people with learning difficulties had reached the conclusion that:

You're trapped if you work and you're trapped if you don't.

Participant, focus group 1

A participant in the second focus group recounted his experience of the life-threatening effect of going back to work too soon and the difficulty of getting back on to benefits:

Four years ago, I went back to work with a user group. I had a flexible routine – I came in very early because it was easier to get a taxi and went home at about three o'clock. But after working for about 18 months, it had knackered me out and I had a heart attack because of that.

Getting back on benefits was difficult. They pissed me about for a few months but then my union helped.

Service users also report experiences where local Jobcentre Plus services themselves do not have accurate information about the rules. As a result, staff may wrongly think that service users are breaking them and threaten to remove benefits from them.

There are also variations in local practice, as this person found:

If you do something and declare it, then it seems to be down to the particular office because they've got no guidelines that are binding on everybody. It even varies in a particular office.

Participant, focus group 2

Service user organisations have found it very helpful to make contact – often in association with local welfare rights workers and other organisations – with local Jobcentre Plus staff and establish relationships with them. They then work together to ensure that arrangements work correctly and smoothly and ensure that the benefits of individual service users are not unnecessarily put at risk.

3.6 Fear of losing benefits through accusations of fraud

Following on from the fears discussed in the previous section, three participants in the second focus group identified a particular and very strong fear of being wrongly accused of fraud:

People have terrible anxieties about these issues. You're put in a position where you feel you're doing something wrong. You're breaking the rules by taking this token payment which is really bugger all. You're put through all that anxiety – should I do it or shouldn't I? If I do it, will I get found out? Am I being dishonest?

Then you walk down the street with all the posters up about fraud and the adverts on the television. It all feeds into your head and that's the real problem. If you're already suffering from anxiety and depression, it's just going to make you worse. You end up thinking: why am I doing this when it's making me feel worse than I was before? It's not just unfair and criminalises people – putting you in a position where you could be committing fraud just by accepting a £10 payment. More seriously than that, it does your head in with worry.

Participant, focus group 2

The reason why I will never declare any payments that I get is because I know that, if it all goes pear shaped and they decide that they are going to investigate me, the first thing that they will do is stop paying me everything until they resolve the issue.

It wouldn't just be a week or 10 days; it would be three or four months with all the financial implications that that has.

Getting payment and being found out opens a big can of worms because you're not just talking about Income Support, you're talking about Housing Benefit, Council Tax Benefit and everything. It would be catastrophic.

Participant, focus group 2

People who claim benefits do not volunteer information. It's one of the first things that you learn when you use the system. You do not tell them anything unless they specifically ask for it. If you can be economical with the truth, which in the case of my £10 payment means not letting them know that I've had it, that's what I do. The legal framework means that you have to lie to protect your income. Even if you earn just £5 and someone at the benefits office finds out, they could theoretically launch a fraud investigation [with] someone following you around and monitoring your movements.

Participant, focus group 2

Of course, not declaring the payments means that people may still be accused of fraud.

4 The impact of these issues on user involvement

Many of the comments detailed in chapter 4 go a long way towards illustrating the impact that benefits rules have on individuals. In addition to this, the rules have an impact on the efficiency and effectiveness of user involvement more generally.

All of these problems create an environment where there is a temptation for some to receive remuneration but not to declare it to the benefits agency. This creates tensions and suspicions within service-user groups which then undermines the work.

User-controlled organisation

People are clearly being put off becoming involved because of the problems that they believe it will create:

The disruption totally put me off service-user involvement so I resigned. I am very wary about getting involved in permitted work in the future. I feel that I have been discouraged and penalised. I will turn down any more offers to do service-user work because I don't want to risk losing my benefits again. After all the mental distress I was caused, I wasn't even offered an apology by my benefits office.

User/survivor of mental health services

I was offered an interview for a non-executive directorship. They really wanted someone with user experience on the board, but what is the point of me going to an interview if, for £5,000 a year, I would completely lose all my benefits? My Incapacity Benefit with Income Support, my wife's Invalid Care Allowance, and the mortgage payments, Council Tax Benefit and free prescriptions. There's absolutely no point for £5,000 a year. There is no mechanism to compensate for that loss. I'm quite angry when I think about this – it would have been good for me and good for them because I had the skills and experience that they needed, but I'm being denied that opportunity because the benefits system doesn't allow me to do a little bit from time to time.

Disabled person

A worker from an urban regeneration project gave these observations on the effect of the restrictions imposed by the benefits system:

On reflection, it seemed such a shame that the people we had most wanted to help, some of the poorest members of our communities, were specifically excluded from the opportunity to earn some much-needed cash, leaving other people to benefit who were not in the same degree of need. The problem with this view is that it misses the point that we actually needed local people to do this consultation work, because they are the experts, they have the local knowledge of who meets where and when, and have views on how they would like the future to unfold.

If we want people to become active citizens, and to gain experience of the discipline and challenges of work, I am convinced that we should offer remuneration and incentives. Instead of a stark divide between working for a living and receiving benefits, could we not have a system that blurs these distinctions and applies incentives to reward community work and active citizenship, whilst maintaining the benefits safety net?

Service provider

5 Issues around employment law and tax

The payment of service users opens up a wide range of issues in relation to employment rights, employment law, income tax and the national minimum wage.

One service provider had been advised to treat people taking part in involvement initiatives as 'sessional employees'. Service providers expressed a range of concerns around this:

The immediate problem being reported was that paying people technically made them employees of the local authority or whatever, and there were some human resources departments who were getting het up about all the employers' liabilities that entailed. To be honest, I couldn't see the real problem with the local authorities taking on those responsibilities.

Service provider

In the past, social services has paid token payments. This was stopped in response to an awareness of the implications of new legislation and on advice of legal services. The National Minimum Wage Act 1998 that came into effect [on] 1 April 1999 increased protection for employees. As a result of this, it used the term 'workers' and is inclusive legislation that employers and workers/employees cannot opt out of. Almost everyone, with some exceptions, who does work for an organisation can be classed as a worker, which in law is seen as an employer/employee relationship.

Volunteers who make a genuine gift of their time and skills are an exception, as are elected members of organisations. Organisations are free to pay volunteers' actual expenses or reasonable estimated expenses incurred. Using clever forms of wording will not avoid the implications of the Act. For example, a self-employed consultant would only be legally accepted as such if they had payments from a number of organisations.

We have explored a number of options that are legal, bearing in mind the Minimum Wage Act. However, this isn't the only area where the Minimum Wage Act is making itself felt – for example, sheltered employment, volunteers, etc.

A major problem this causes for us is that service users are, therefore, employees of [the] council and are therefore not independent. There are also the wider human resources implications that need to be addressed.

Service provider

Such human resources implications could include holiday entitlement and employers' liability insurance.

One respondent pointed out that if users are in this position, they are no longer independent, so the basis of their involvement becomes questionable:

If they're employees, they can be directed to toe the line.

Service provider

The situation regarding the application of the minimum wage is not clear. One service provider said that it paid participants in consultations a nominal fee of £15 and that it had been advised that the minimum wage would not apply.²⁰

Employment issues also trigger issues around taxation:

In my experience, universities engaging service users as lecturers will deduct income tax automatically from pay, irrespective of whether the person comes within the scope of income tax, though one way round this is to get the university to pay the full amount to an organisation, who would pass the money on to the person who earned it.

User/survivor of mental health services

In my past job as assistant director of finance, I was involved with the payment of service users and carers. The practice was that recipients had to sign a declaration that they would inform the Inland Revenue of any earnings that they received. However, when I contacted the local Inland Revenue office, they said that this was not sufficient and that such payments had to go through payroll. This created untold problems for us, as you can imagine, but given that our colleagues in another part of the organisation had been subject to an Inland Revenue inspection some years earlier and were fined a substantial amount of money for making payments to people who the Inland Revenue considered should be on the payroll, and that we had contacted the Inland Revenue, we had to abide by their ruling.

Service provider

However, as with benefits, there seems to be some confusion here. A user-controlled organisation reported raising the issue with the Inland Revenue and being told that they just needed a report of how much each person had been paid in each financial year and a signed declaration from each person to state that this was the only income they received apart from their benefits.

The tax problem can have an impact on the ability of some service users to participate. An older person who took part in a university research project describes what happened:

All of us had income tax and in some cases National Insurance, deducted. In one case, the Inland Revenue carried on the one-off payment as income for the following year. Our other costs – telephone calls, parking fees, etc. – were not taken into account. At the moment, one of our members is contacting the Inland Revenue about a payment for attending a seminar. I realise that this is a grey area, one does expect to pay income tax if eligible, but when the costs outweigh the benefits, it is disheartening, and some people cannot afford to be involved with participatory projects.

Older person

It appears that the position of service users in relation to government support for disabled people at work is confused. Within the bureaucratic web of contradictions in which people find themselves entangled, they are treated as employed by JobCentre Plus staff but not accepted as employed by their own Access to Work scheme. (The

scheme provides equipment and other support that disabled people need to carry out a job.)

This person describes the situation:

Remuneration in respect of this kind of appointment is considered as salary by [Jobcentre Plus]. At the same time, it is not considered as employment by legislation governing Access to Work in [Jobcentre Plus].

This meant that not only would my income be reduced, but also I would receive no assistance with the purchase of the items essential for the nature of the post.²¹

Disabled person

6 How users are being paid now

A number of the service providers that contributed to this report are paying service users for their participation in various ways. Some are very concerned about the legal position of the payments that they are making.

One provider described making payments of £15 each time a service user attended a meeting:

We give service-user delegates a nominal remuneration of £15 per involvement and expenses (travel, phone calls, care for relatives whilst at meetings, etc.). As long as they have one involvement per week, this falls within the £20 limit for Income Support and Housing and Council Tax Benefits ... I believe Housing Benefit, employer's insurance, occupational pension schemes and Permitted Work Rules must also be considered – neglecting these areas of benefits would be detrimental to service-user delegates. We do advise service-user delegates to declare their involvement to the Department for Work and Pensions.

Service provider

Another had a system based on a 'flat rate' payment for expenses:

We have been 'paying' people a flat rate of 'expenses' which have always been paid in cash on the day. The amounts we have been able to pay have usually been in the order of £20-30 per session.²²

Service provider

A number of people described how their organisation made payments to a service-user organisation which then passed on the payment to individual service users:

We send representatives to the mental health voluntary sector group. They get paid through our organisation because the group always had the commitment to make a payment. The forum sends it directly to us and tells us why. We then offer it back to the service user, minus a small administration fee. The service user can also opt to use it as income generated for the organisation.²³

We also send representatives to the local strategic partnership, but we have to invoice them for a payment and that's a right pain in the butt because we cannot keep track of our representatives, the meetings they attend, and then they ask for a payment we haven't received.

User-controlled organisation

We get the money for people who go to service-user meetings paid to us. It goes into our account, then we pass it on to them. What we say is that this is a grant as our constitution allows us to give grants to people for items or equipment that they need or to help to improve their quality of life. So we give it to the people and say that they can use it for these things, but we try to make sure people do not think about it as payment because this causes problems with the Inland Revenue and people's benefits.²⁴

User-controlled organisation

A number of local authorities are making payments by giving participants in consultation meetings gift vouchers. One council cited advice from the Department for Work and Pensions that people would not be expected to declare vouchers that they have been given unless the value went above the threshold for paying National Insurance. Others had been advised that vouchers would be treated in the same way as cash payments.²⁵

One worker from a young people's project in a local authority described the use of gift vouchers:

I currently reward young people in this situation with gift vouchers up to £15 per week whilst also covering their expenses. This can feel like exploitation. Providing it is not regular work/commitment, they should be able to be paid what others would expect – at least in line with minimum wage. [Jobcentre Plus] take any other form of payment as a cash payment, so we cannot consider paying a young person with a gift they may want, to get around this. Some flexibility on this may help so that some items are not seen as cash and hence deducted from benefits.

Service provider

The search for acceptable alternatives lead one council to look at paying service users through credits in its Local Exchange Trading System, which involves services trading their time. However, the council has been told by the Department for Work and Pensions that such credits should not be more than the equivalent of £100 in value in any one year.

One of the organisations making cash payments had some concerns about the legality of their actions:

Participants have been asked to sign in receipt of the money but have not been asked to provide travel or other receipts. It is not, however, an ideal solution, not least because it is a covert rather than open approach to the issue of payment. Another possible drawback may be the difficulty of reimbursing genuine expenses on top, leading potentially to some disparity between people, although this situation has not yet arisen. So far, we have not been challenged about this practice.

Service provider

Others have also expressed concerns about the legality of the ways that they are paying people. Respondents made various comments about this, such as:

I guess I am slightly hesitant to go into too much detail here, as we've probably run roughshod over some benefits regulation or another!

Service provider

I know of organisations who are employing a few users on permitted work and skating on thin ice as regards how they pay them and declaration of payments.

User-controlled organisation

People do think of it as payment. Although we try to make it clear to people that it's a grant, they do think of it as a payment ... It becomes a game of words, with

me saying one thing because I'm aware of tax and benefits rules and the people themselves thinking that they've done the work and been paid for it ... There's a danger that they could get into problems with [Jobcentre Plus] if they say the wrong thing.

User-controlled organisation

I have seen various forms of payment ranging from service users queuing at the end of a meeting for a £10 note, to universities paying lecture fees to an organisation to be divided as the organisation saw fit. There have been some cases where no money changes hands but the individual will be 'treated' to lunch. We needed to set up a system of payment for user-focused monitoring only to be told by the Welfare Rights Unit that there was no truly legal way to do it.

Service provider

One service user with experience of the £10-note-at-the-end-of-the-meeting method observed that it is far from satisfactory:

The other thing about this £10 is the way that they pay it. The way that they do it is not very dignified. You queue up to get the money with everyone looking on – the professionals and the psychiatrists just look at you.

Participant, focus group 2

Finding workable solutions to paying users in a way that is legal and meets the requirements of the benefits system appears to be a difficult job:

Locally, we too have been looking at this issue. A group has been working for the last 18 months to try and find a solution. A decision has been reached that we employ service users on a bank contract. Initially this will be piloted in three service areas: training; recruitment and selection; and research. While the solution we have come up with is not ideal, we now have made progress with a method that is at least legal and auditable.

Service provider

There are also major issues here for statutory organisations such as health trusts. Although they have a 'duty of care' to service users, they may actually be unintentionally putting their welfare at risk by not checking carefully enough that the work they involve users in or the payments they make to them are not jeopardising their entitlement to receive certain benefits. Furthermore, it may not always be possible for them to be certain that what they are doing is actually correct.

While the 'duty of care' may lie with the organisation, it is likely to be the individual service user who suffers in such situations. It is therefore important that service agencies accurately establish the problems and issues that may be encountered, provide this information to service users, make sure that service users' benefits status is not put at risk and see that they get involved on the basis of fully informed consent.

We found one example of a service provider that appears to be completely disregarding this duty of care, as well as making it very difficult for people to claim their payments:

Our user group used to manage the payments. We used to get £15 each time we attended a meeting. But now our worker's been cut and we're not getting paid. The trust has said it will pay us, but to get this, you've got this bloody big form to fill in that nobody can understand. They say the benefits issue is up to us – they are taking no responsibility for benefits. It's up to us if we declare it or not – if we don't declare it and get found out, we're on our own, which is a load of rubbish.

Participant, focus group 2

7 The value of user involvement to individuals

The value of user involvement in policy and practice has already been mentioned. A number of respondents were also keen to point out the individual benefits of these activities:

The work I do here helps me to maintain a sense of balance and self-worth ... I try to maintain some balance and being involved helps me to do that. I am sure that there are times when I am OK because of my involvement. If I was penalised and had to stop, I know that my mental state would suffer.

User/survivor of mental health services

Due to experiences and background, some care leavers will struggle to find and sustain employment or college. Their involvement in user-led work and participatory projects helps to build their confidence until they reach a stage when they can realistically work full time and sustain this. Young people get pressurised into finding work when they are not ready.

Service provider

People ... are doing very valuable work but are unable to get full-time work – probably because of the prejudice around their disability, not because they cannot work – and they have the opportunity to earn this money. The benefit of that goes beyond the money, it's a real value to them in the way that they feel about themselves – it really builds people's self-esteem to know that they are working and they are being paid like everybody else. They feel that they're there like everyone else and being paid like everybody else. I know the other side of this, when they're volunteers and sitting with people from the health authority or the council who are being paid very well, then they feel like second-class citizens and they do not feel as valuable as the other people around the table who are doing the same thing.

User-controlled organisation

Service-user involvement is the way that some people begin their journey of recovery, gaining valuable skills and confidence along the way.

User-controlled organisation

I couldn't do a job, but I really enjoy the work that I can manage.

Disabled person

Those connected with user involvement can see these benefits and how they particularly contribute to increasing people's employment potential. However, the general experience seems to be that policy and practice at Jobcentre Plus and the Department for Work and Pensions is unresponsive to this point of view.

The current situation is not acceptable. The permitted work scheme should work fully, allowing users to build up stamina for work, through user involvement, etc. and getting the little bit of money they are earning without fear or favour.

User-controlled organisation

The system isn't geared up to dealing with this type of work. The people that I saw at the benefits office were not decision-makers and had to refer everything on. The whole situation is not set up for this sort of thing – the people at the benefits office had never come across anything like this before and they were completely unsure of what to do.

Disabled person

8 Respondents' recommendations

Many of the people who took part in the focus groups had ideas about how the situation can be improved. The most succinct recommendation we received was:

Stop it, sort it out once and for all, and if you have to redesign the benefits system to make it happen, then do it 'cos it just ain't fair.

User-controlled organisation

People who took part in the second focus group identified the need for a clear lead to be taken by central government on the issues around benefits and the general principle of paying users:

The staff in the mental health trusts should talk to the government about this because it's government policy to involve users in care ... The government hasn't thought about this. They're wanting user involvement in mental health, in health, in housing ... user involvement in this, that and the other, but they haven't thought about what happens to our benefits.

Participant, focus group 2

The government wants user involvement, but there are no guidelines laid down, there's nothing about payment. If local authorities wanted user involvement, they wouldn't treat us tokenistically. I think they know they should be paying us properly, but they're scared because of the benefits issue.

Participant, focus group 2

On the limits to the amount people are allowed to earn while receiving benefits, there were suggestions that the amounts allowable should be increased:

I would suggest an increase to £90 per week as this is the level at which National Insurance becomes payable. These days £90 per week is not a lot of money in comparison with the average earnings.

Service user

Several people suggested that the way in which earnings are assessed should be more flexible and be carried out over a longer period of time:

There should be a far more flexible approach. For example, people on benefits should have their income assessed over a year rather than just over a week or a month. So if you are allowed to earn money over that sort of period, you could earn more in one go without worrying.

People get to the point where they're earning near or just over the threshold so they lose all their benefit, but they only have a little bit more money than when they had their benefits. That really stops people taking on paid work. It's hard if you're working, it can be very stressful, especially if you have not worked before. So you might think: what's the point of it? If you give people a larger amount to work with over a year it might help give people the incentive to work and get back into the community.

User-controlled organisation

There was also the suggestion that participation in user-involvement activities needs to be treated differently from other forms of work:

There are two main ways of helping people who receive benefits on the basis of incapacity or disablement:

- Such work should not trigger a review of entitlement to benefits – i.e. it's not indicative of lack of incapacity to work or disability. Indeed it's likely to be confirmation of it.
- For means-tested benefits, an extra 'disregard' should be introduced for public involvement work, perhaps at a rate appropriate to one day's work.

User/survivor of mental health services

There should be standardised rates for different things that are then 'disregarded' by [Jobcentre Plus], so long as it does not exceed a certain number of hours over a set period.

Service provider

The payments issue needs to be placed in the context of the general rules about benefits for people working/returning to work:

The problem as we see it is this transition – how to establish a safety net that allows individuals to try out employment opportunities in a safe environment where they are not scared to lose their benefits. Some individuals may need several attempts at employment before they are strong enough to succeed and to flourish.

Service provider

Participants in the second focus group felt that, for some service users, the level of user involvement that they ended up having to take on was such that they were almost doing a job. People suggested that it should be possible to organise some involvement in such a way that it actually becomes a job and is paid as such.

One respondent suggested that a benefits system like that used in Norway would address the issues about participation, through a system of rules that is more suited to the general employment situation of disabled people. His understanding of the equivalent of Incapacity Benefit in Norway was that a person is allowed to earn a set amount every year while receiving the full allowance. In addition, people can decide on the level of their impairment – 100, 75, 50 or 25 per cent – and receive the appropriate proportion of benefit and be allowed to earn proportionally more. The system is based on self-assessment, with some checks, and people are allowed to move up and down the scale as they choose.

Other suggestions for change were for there to be training in disability equality and distress awareness for Jobcentre Plus staff.

The people with learning difficulties who took part in the focus group thought that more help and support about benefits should be available from social workers, but complained that they did not have access to them. They said that they received good help from the welfare rights adviser at the local disability organisation.

There was also a call to ensure that appropriate welfare rights advice is available to people who take part in user involvement.

In the second focus group, there was a suggestion that service users need a union to represent their interests. This was based on the groups' experience of refusing to participate in consultation meetings:

Our group stopped going to meetings and the services got in a real flap. They're started asking why we didn't come; they offered us whatever we wanted. I suggest that's what everybody does until they're taken seriously. Stop going to meetings; stop being a user representative until we're doing it on our terms.

Participant, focus group 2

9 Conclusions and recommendations

The current situation around payments to service users may require people and organisations to act illegally. Individuals are treated unfairly, being required to work without reward (often immediately alongside others who are being well paid) and/or being penalised when they are paid. As a result, people are being forced into a situation where they have to be dishonest and untruthful.

This report shows that moving to a situation that is legal, decent, honest and truthful involves addressing a range of issues. Some of these are complex and will require legislative change. Others could be dealt with more easily and quickly.

Recommendations

These are the recommendations of the report based on what service users and others say and their experience.

- The Government should recognise that its commitments to social inclusion, active citizenship and the increased involvement of health and social care service users in paid employment are being undermined by the operation of the benefits system.
- The benefits system urgently needs to be reviewed and changed to ensure that government commitments to user involvement and social inclusion are harmonised with the day-to-day operation of the benefits system.
- By getting involved in service user organisations and participating in local and national arrangements for involvement in public services, policy review and governance of public bodies, service users gain confidence and skills that help them return to employment. This needs to be recognised within the benefits system, and the importance of supporting such involvement should be acknowledged. Service-user participation needs to be seen as a help rather than a hindrance to people moving on to employment in the longer term.
- Service users should not be discouraged from getting involved because of the way the benefits system works.
- There needs to be specific and explicit recognition that taking part in user involvement does not mean that a person is fit for work.
- The increasingly recognised model of good practice is one in which service users who wish to be paid are paid for their involvement and expertise.
- The amount that people receiving benefits are allowed to earn should be increased, and there should be a more flexible system for assessing how much people earn.
- The levels of permitted earnings should be reviewed and revised.
- Discriminatory rules on earning should be addressed. Earning 'disregard' amounts for means-tested benefits should be raised to match 'permitted work' amounts.
- Permitted earnings should be assessed over a longer period. One year appears to be a more appropriate length of time during which earnings can be assessed.
- A system needs to be developed that will guarantee that taking part in user involvement will not lead to a review of benefits.
- Information on permitted earnings needs to be reviewed and clarified.
- The way in which Jobcentre Plus administers the rules for permitted earnings needs to be reviewed to ensure that they are consistently applied.

- Training needs to be provided to Jobcentre Plus staff to increase their understanding of employment issues to do with disability equality and, specifically, of the value and importance of work to do with user involvement.
- The whole issue of how employment law treats work undertaken as part of user involvement should be reviewed by the relevant government departments.

Bibliography

Citizens Advice Bureau (2004) 'Out of the picture: CAB evidence on mental health and social exclusion London' (available at http://www.citizensadvice.org.uk/macnn/index/campaigns/social_policy/evidence_reports/er_healthcomcare/out-of-the-picture, accessed 28 July 2005).

Department for Work and Pensions (2002) 'Permitted work: Procedural information for disability organisations' (available at http://www.dwp.gov.uk/publications/dwp/2002/disability/guide_nov02.pdf, accessed 28 July 2005).

Department for Work and Pensions (2003) 'Incapacity in doubt' in *Decision Makers Guide*, vol. 3, chapter 13, pp 13514 -13516 (available at <http://www.dwp.gov.uk/publications/dwp/dmg/index.asp>, accessed 28 July 2005).

Disability Alliance (2003) 'Pathways to work: Helping people into employment – response from Disability Alliance (R36)' (available at <http://www.disabilityalliance.org/r36.pdf>, accessed 28 July 2005).

Disability Rights Commission (2003) 'DRC response to the Department for Work and Pensions consultation document "Pathways to work: Helping people"' (available at www.drc-gb.org/publicationsandreports/campaigndetails.asp?section=emp&id=204, accessed 28 July 2005).

Dorsett, R., Finlayson, L., Ford, R., Marsh, A., White, M., & Zarb, G. (1998) 'Leaving incapacity benefit', Research Report No. 86, London: Department for Work and Pensions.

LSDA (2003) 'The welfare system and post 16 learning: breaking down the barriers', London: Learning and Skills Development Agency.

Public Accounts Committee (2004), 'Twelfth Report' (available at <http://www.publications.parliament.uk/pa/cm200304/cmselect/cmpublicacc/406/40602.htm>, accessed 29 July 2005).

Public Accounts Committee (2004), 'Sixteenth Report', (available at <http://www.publications.parliament.uk/pa/cm200304/cmselect/cmpublicacc/120/12002.htm>, accessed 29 July 2005).

Scott, J. (2003) *A Fair Day's Pay*, London: Mental Health Foundation.

Scott, J. (2003) 'Benefit Protection', *Community Care*, 22 September.

Seebohm, P. and Scott, J. (2004) 'Addressing disincentives to work associated with the welfare benefits system in the UK and abroad' (available at <http://www.sepbg.co.uk/downloads/disincentives.pdf>, accessed 29 July 2005).

Select Committee on Public Administration (2003), 4th Report, 'Government by appointment: Opening up the patronage state' (169: Benefit losses among people with disabilities; and 170: Recommendations for an urgent review of the rules on incapacity and income-related disability benefits) (available at <http://www.publications.parliament.uk/pa/cm200203/cmselect/cmpublicadm/165/16509.htm#a35>, accessed on 29 July 2005).

Social Exclusion Unit (2004) 'Barriers to employment: the benefit system' in *Mental Health and Social Exclusion* (available from www.socialexclusionunit.gov.uk/page.asp?id=257, accessed 29 July 2005).

Wallcraft, J. (draft in press) 'The Place of Recovery', in S. Ramon and J. Williams (eds) *Mental health at the crossroads: The promise of the psychosocial approach* Abingdon: Ashgate.

Appendix 1: How we did the work

A number of people started to contact Shaping Our Lives immediately after the launch in 2003 of the national user network, knowing that this work on user involvement, payment and benefits was starting. We also sent out an email to the organisations on the Shaping Our Lives database, asking them to send in their experiences and views on the issue.

The request was also sent out by Involve (formerly Consumers in NHS Research), the national organisation set up by NHS Research and Development to support public and user involvement in health, social-care and public health research. Involve has already produced its own guidelines, which highlight the need for payment for user involvement in research and evaluation (Steel, R. [2003], *A guide to paying members of the public actively involved in research*, Eastleigh: Involve).

Our request was also posted on the Disability Research email list run by the Disability Research Unit at the University of Leeds. We are also aware that people posted the request on a number of other internet forums.

We received 52 responses by email and eight by post.

The responses break down into the following categories:

- 19 individual service users
- 14 service-user organisations
- 23 service providers (including councils, NHS departments and voluntary organisations)
- one academic organisation
- two carers
- one other (consultant).

The emphasis on using email does mean that many service users who might have contributed were not aware of the project. While this is obviously a regrettable limitation on the project, the constraints of time and resources meant that the use of email was the most effective way to obtain information.

In addition to the direct submissions, follow-up interviews were carried out by telephone/email with five respondents.

Two focus groups were set up. One comprised people with learning difficulties from a self-advocacy organisation. Nine people took part in this: five women and four men. The group included two black people.

The other focus group consisted of mental health service users. Again, nine people took part: five women and four men. This group also included two black people.

The project was carried out by Michael Turner, a disabled writer, consultant and researcher who was a part-time worker for Shaping Our Lives from its beginning in 1996 until 2002. As well as working with Shaping Our Lives, he has worked with the

Social Care Institute for Excellence, the International Disability Equality Agency at De Montfort University, the Audit Commission/Joint Review Team, Greater London Action on Disability, the Department for International Development, the London Borough of Lewisham and Medway Council.

Appendix 2: Commentary and explanations of people's experiences

This commentary and the footnotes clarifying benefit rules have both been provided by a welfare rights specialist with experience of developing policy for service-user involvement for NHS trusts in collaboration with Jobcentre Plus.

Rules for people who claim benefits because of ill health or disability

The benefit rules govern the extent of the activities of a person who is in receipt of benefits for incapacity. The rules say what is allowed, what might not be allowed and what is definitely not allowed.

The following explanations describe the circumstances in which a service user with continuing mental health problems can have their benefits stopped as a result of assisting the Department of Health to implement section 11 of their *Policy for Patient and Public Involvement*.

It is important to bear in mind that there is no Jobcentre Plus or Department of Health guide to involvement for people who are in receipt of benefits. Misunderstanding of the complex benefit rules occurs among Jobcentre Plus staff as well as among people who rely on benefits for their day-to-day living costs. Jobcentre Plus staff have discretion in some matters and this is operated differently in different offices.

There are three possible benefits for incapacity:

- Incapacity Benefit
- Severe Disablement Allowance and/or
- Income Support with a disability premium (Income Support can be claimed on its own or as a top-up to the other benefits).

The following problems are particular to people who claim the above benefits.

Problem 1

If a person claims one of the above benefits for incapacity, any activity such as voluntary work or study or training or part-time 'permitted work' must be reported to Jobcentre Plus (previously the Benefits Agency). 'Involvement', whether voluntary or paid, must be reported. Jobcentre Plus has the right to send an incapacity claimant for a review of their benefits at any time if the activity, which they have reported, appears to indicate some recovery.

People who claim benefits because of ill health or disability are subject to reviews of their entitlement every three years. Called 'personal capability assessments', these reviews consist of interviews by doctors who work for the Department for Work and Pensions. Some people with a very severe level of disability are exempted from the reviews.

If a person reports that they are starting an activity, Jobcentre Plus may construe that their health has improved. Jobcentre Plus has the right to send a person for a personal capability assessment at any time if the reported activity gives them reason to believe that the ill health or disability may have lessened, which brings into doubt the person's entitlement to incapacity benefits.

The problem with 'involvement' lies in the reporting. This is a particular problem for people with mental health problems. The problem arises partly because Jobcentre Plus staff have not been advised that Section 11 of the Health and Social Care Act 2001 requires the involvement of people who are patients.

For instance, when a person reports that they have been asked to join a trust committee or to take on similar commitments, the Jobcentre Plus staff may think that this type of activity indicates some level of recovery by that individual from their mental health problems. However, the contrary may well be true as trusts often seek to involve people who are current users of mental health services. The use of services may be the initial qualifying factor for the role, but this must also be coupled with a sense of public responsibility and a desire to contribute to changing and improving the mental health services for everyone. This does not equate to being fit for work. But the staff at Jobcentre Plus cannot possibly understand the role of the service user in such involvement if it has not been fully explained to them.

During the process of the personal capability assessment, the likelihood of misunderstandings is greater for people with mental health problems. This is because the level of mental disability is determined by the doctor putting questions to the claimant, including about the claimant's daily activities. Physical and sensory disabilities are assessed in a different manner, by conducting actual tests.

Errors of judgement may occur where a doctor's assumption is based on the person's report of an activity. This risk is higher where the doctor has no knowledge of Section 11 of the Health and Social Care Act and where the service user reports their attendance at meetings. The doctor may construe that such participation in itself is indicative of recovery.

The doctor who conducts the personal capability assessment is required to make that assessment against a list of descriptors of differing types of disability – does the person experience the difficulties that are described? Each descriptor has an allocated number of points. The doctor's marks are passed back to Jobcentre Plus who determine whether the person has sufficient points to continue to qualify for their Incapacity Benefit.

If the required number of points is not found, the person will have their benefits stopped – i.e. their income for living costs.

If this happens, the person can claim Jobseeker's Allowance, providing they agree (among other things) to seek work actively. Jobseeker's Allowance is £56.20 a week for all living costs: food, laundry, gas/electricity/water/TV licence, travel, clothes, shoes and replacement household items. Jobseeker's Allowance is £23.95 to £36.30 a week less than a benefit for incapacity, and those with a partner in work may not be entitled to any benefits at all.

The Department for Work and Pensions' own research demonstrates that the great majority of those who are disallowed a benefit for incapacity do not obtain employment. After a period on Jobseeker's Allowance or without any benefits, they reclaim benefits for incapacity, but most will receive a substantially reduced entitlement because they have broken their continuous claim.

For these reasons, people with mental health problems say that the experience of undergoing the personal capability assessment causes great fear and stress and sometimes relapse. This unknown level of risk to benefits presents a major barrier to involvement.

Employment law may compound the risk of misunderstandings

People who are paid on a regular basis are likely to be deemed to be workers or employees. Although many employment rights are not applicable where earnings are below the National Insurance threshold, pro-rata holiday pay is payable and terms and conditions must be provided. This is not onerous on Trusts as a form of the flexible 'Bank Registration' agreement can be provided. The independence of the service user can be asserted in a mini job description.

There is however a further risk from Jobcentre Plus which arises from these arrangements. The Jobcentre Plus staff are not usually aware of this aspect of employment law, and may construe from these arrangements that the service user has been taken on as an employee of the Trust and that therefore they are no longer entitled to benefits for incapacity. The Jobcentre Plus must also be advised about employment law for part-time workers.

Problem 2

Paid work can be undertaken only if it is according to the limits and regulations set by the Permitted Work Rules. However, most people (perhaps 80 per cent) are in receipt of a means-tested benefit that has a separate earnings rule attached. People who also receive a means-tested benefit are allowed to earn up to the 'permitted work' limit of £78 a week but can keep only £20 or £10 per week. Less than 16 hours paid work is allowed. If a claimant does 16 hours or more, their benefit will be stopped.

In the Permitted Work Rules for people in receipt of incapacity benefits, there are three options:

1. Permitted work, lower level

A single claimant can earn up to £20 a week. If they have a partner, and claim Income Support, each partner can only earn up to £10 a week.

2. Supported permitted work

The claimant can earn up to £78 a week, providing they have a named support worker who is employed by a voluntary or statutory organisation to provide support in work for people with disabilities. This earnings limit is up-rated at the same time as the minimum wage rate to allow under 16 hours of work. If either the earnings limit or the hours of work limit is exceeded, benefits are stopped. See below for the 'earnings disregard'.

3. Permitted work, higher limit

The claimant can earn up to £78 a week for six months, working under 16 hours a week. If they obtain the agreement of Jobcentre Plus, they can work for up to a further six months, earning up to £78 a week. After the second six months, they can either reduce their hours of work and therefore their earnings to £20 a week, if the employer agrees, or find a support worker and do supported permitted work. See below for the 'earnings disregard'.

The 'earnings disregard'

People who claim a means-tested benefit – Income Support, Housing Benefit and/or Council Tax Benefit – are subject to an 'earnings disregard'. This is a quite separate rule to 'permitted work'. The earnings disregard means that, if a claimant on a means-tested benefit earns up to £78 a week, they will have all of their earnings above £20 deducted from their Income Support. Or if they claim Housing Benefit, they will have 65 pence deducted from their Housing Benefit and 20 pence deducted from their Council Tax Benefit for every £1 they earn above £20 a week.

Eighty per cent of people with a mental health problem who claim benefits are thought to claim a means-tested benefit. They are, therefore, limited to earnings of £20 a week, which is just over four hours at the rate of the present minimum wage. However, the earnings disregard is not up-rated in line with the minimum wage rate.

Only people who receive Incapacity Benefit or Severe Disablement Allowance and have no housing costs whatsoever can earn and keep the full £78 a week.

Service-user involvement can include appointments such as the post of non-executive director on a primary care trust board. The rate of pay for these is set at the going rate for the job. User-focused monitoring and other research programmes are often conducted for only part of the year. As a result, earnings and hours may be concentrated into a short period – the research model does not allow for four hours a week for 52 weeks of the year.

In consequence, these benefit rules deny disabled people opportunities to participate as equal citizens.

Problem 3

The reimbursement of travel expenses is treated as earnings.

The benefit rules treat the reimbursement of travel expenses for paid work as earnings. This reduces still further the paltry earning limit of £20 a week.

A service user with significant travel expenses – of, say, £10 return – would therefore be limited to involvement work for two hours a week.

If travel to a meeting in another part of the country is required and the return fares cost in excess of £20, the service user would not be able to participate unless they did so on a purely voluntary basis: volunteers' exact expenses may be reimbursed.

Problem 4

Putting your Disability Living Allowance at risk as a result of being involved in activities

Disability Living Allowance (DLA) is granted for care or mobility needs. In theory, earnings or hours of work do not affect entitlement. However, if the activity that is reported to Jobcentre Plus appears to demonstrate a reduced need for care or mobility, DLA may be reviewed. Due to the complexities of making a claim for mental health care or mobility needs, the claimant should always seek advice from an independent welfare rights expert. It is often extremely difficult to find and obtain an appointment with such a person.

Notes

- ¹ £10 a day is in breach of the National Minimum Wage Act 1998.
- ² Receiving £56 a day is not allowed for the majority of people who receive benefits.
- ³ Mental Health Act 1983.
- ⁴ This rate of pay is in breach of the National Minimum Wage Act 1998.
- ⁵ Receipt of pay of £45 a day is not allowed for the majority of people who receive benefits. Receipt of pay of £80 a day would be likely to lead to benefits being stopped.
- ⁶ This rate of pay is in breach of the National Minimum Wage Act 1998.
- ⁷ Permitted work earnings rate October 2004–October 2005.
- ⁸ According to the previous rate for 'permitted work'.
- ⁹ Benefit rules do allow Jobcentre staff discretion to calculate average earnings over the appropriate period, but there have been no relevant test cases for a year's earnings.
- ¹⁰ 'Therapeutic earnings' were replaced by the Permitted Work Rules in 2002 but could have run on for a year to April 2003.
- ¹¹ This rate is in breach of the National Minimum Wage Act 1998.
- ¹² Confusion arises because reimbursed travel expenses from home to work are treated as earnings if the work is paid but ignored if the work is voluntary.
- ¹³ DSS offices still operate alongside Jobcentre Plus in some districts. They deal with benefits for people who do not have to seek work actively.
- ¹⁴ Receipt of Jobseeker's Allowance requires the recipient to actively seek work.
- ¹⁵ The previous rate for 'permitted work'.
- ¹⁶ The Select Committee on Public Administration Fourth Report 2003 recommended that the government undertake an urgent review of the rules on incapacity and income-related benefits.
- ¹⁷ DSS offices still operate alongside Jobcentre Plus in some districts. They deal with benefits for people who do not have to actively seek work.
- ¹⁸ Jobcentre Plus instruct staff to consider sending a claimant for a review of their entitlement to incapacity benefits if the voluntary or paid work that is reported indicates that they may no longer qualify. Decision Makers Guide Volume 3, Chapter 13: 13514.
- ¹⁹ People who claim Jobseeker's Allowance have to be available for work. However, some voluntary work may be agreed.
- ²⁰ The advice is not correct: a fee would be subject to at least the minimum wage rate. A one-off gift for a one-off occasion would, however, be ignored.
- ²¹ Access to Work is a Jobcentre Plus scheme that may fund the means to remove disability-related barriers to work. It is not available to people who do 'permitted work', and earn up to £20 a week, or 'supported permitted work'.
- ²² Flat rate expenses are treated as earnings by the benefit system.
- ²³ This method of payment does not, in fact, avoid benefit rules. If Jobcentre Plus became aware of it, they would treat the whole amount paid as earnings.
- ²⁴ If Jobcentre Plus became aware of this system, they would undertake an official enquiry. Service users would be deemed to have been paid earnings.
- ²⁵ If vouchers are given in return for work, they may be treated as earnings.

Contributing on equal terms: Service user involvement and the benefits system

Many service users experience difficulties in securing proper payment for their contributions to reviewing, planning and developing services.

This report draws on relevant literature, and has involved a wide range of service users and other stakeholders in discussion. It confirms that social care and health services value the input of service users but shows the benefits system can be inflexible and inconsistent in the way it operates.

The report aims to make it possible for service users and others who face exclusion and disadvantage to make their contribution to their localities, services and society on equal terms with others.

This publication is available in an alternative format upon request.

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