

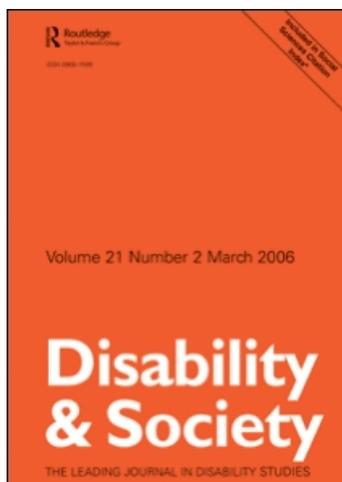
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Finding a way to pay in the UK: methods and mechanisms for paying service users involved in research

Wendy Rickard^a; Rachel Purtell^a

^a Folk.us, Noy Scott House, Peninsula College of Medicine and Dentistry/University of Exeter, Royal Devon & Exeter Hospital, Devon, UK

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Finding a way to pay in the UK: methods and mechanisms for paying service users involved in research

Wendy Rickard* and Rachel Purtell

Folk.us, Noy Scott House, Peninsula College of Medicine and Dentistry/University of Exeter, Royal Devon & Exeter Hospital, Devon, UK

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Finding a way to pay service users for research involvement in the UK has become a topic of dispute and despair. By reviewing the available literature, this article aims to document the range of frustrations and to highlight this small area of policy as pivotal to improving research involvement for disabled people (and other service users). Policy papers, guidance notes, reports and papers on payment issues are summarised, examined and juxtaposed. We link the problems described to analytical debates about ethics, power, policy and emancipatory research. While resolution in all these areas is desirable, we show how pragmatic concerns are also important. Mechanisms for paying people are a core problem. They have been changed inconsistently and incrementally. An explicit focus on mechanisms would be a key next step towards improving opportunities for disabled people (and other service users) to be involved in research by, for and about themselves.

Keywords: service user; involvement; pay; research; barriers; power

Points of interest

- Disabled people (and other service users, patients and carers) are encouraged to get involved in health research and can be paid for their time to acknowledge and value their contributions.
- Paying disabled people who get involved in research is often difficult, causing problems over benefits, pensions and tax entitlements.
- This article looks at what payment problems are and why they continue. It examines policy papers, payment guidance, advisory documents and research studies on paying for involvement.
- Current literature identifies pay as an ethical issue (about equal treatment), a power issue (about control and limits on emancipation) and a policy issue (complex benefit rules, inconsistently applied and small, irregular changes in those rules).
- But pay is also a pragmatic issue and this analysis suggests improving mechanisms and systems for paying disabled people is the vital next step.

*Corresponding author. Email: w.rickard@exeter.ac.uk

Background

Paying people who get involved in research, in a non-professional capacity, is often difficult (INVOLVE 2010a). People who want to help with research and the agencies that want people to help are therefore sometimes put off or, at best, become frustrated. The issue is particularly important for disabled people who juggle state benefits, direct payments and other financial concerns. This article explores how and why paying service users, patients and carers involved in research raises anxiety and debate. Within wider debates about disabled people's (and others') involvement in research, it argues that one small area of payment methods and mechanisms is proving pivotal to understanding policy commitment and political will (or lack of it). The article aims to critically examine the policy context, policy guidance, payment mechanisms, payment advice and suggested solutions to existing payment problems. As such, it explores tensions and contradictions, asking what progress has been made over time towards finding a better way to pay service users involved in research. We will develop an analysis that understands the problems within current debates about ethics and power, including some ideas from emancipatory disability research and drawing on theories from social policy about how change happens. We then aim to draw out suggestions about useful areas to tackle as a next step to responding to the problems and directly improving the situation of disabled people. The article has a case study focus, drawing all its examples from the UK context.

We begin by explaining briefly what we mean by 'service user' and 'involvement in research'. (Readers may wish to explore the terminology debates in more detail elsewhere, e.g. McLaughlin 2009.) By 'people', we refer to service users, patients and carers, people who use health and social care services, or care for someone else who does, and who choose to give their time and expertise to put something back into research about health and social care (including disability issues). In places we use the term 'service user' as shorthand for 'service users, patients and carers'. By 'involvement in research' we are talking about people being actively involved in carrying out research as advisors, partners or co-researchers and people who help with the processes of research, through sitting on committees and boards, joining working groups or helping with specific research tasks. This might be involvement in any or all research tasks such as overseeing research development, having research ideas, raising funding, setting the research question, designing the project, collecting the results, interpreting the results or disseminating the findings. We do not see taking part in research projects as subjects or participants as sufficient in itself to be included in this understanding of involvement.

We started writing this article because service user payments have been such a huge and on-going concern for our Devon project in England, called Folk.us. The aim of Folk.us is to change research culture in health and social care so that research and the implementation of research results reflect the inspirations and issues of those who use health and social care services. To date, we have worked locally to support service users, patients and carers to do research by helping to set up projects and collaborations and by working at a strategic level. One of the first policies that Folk.us developed was on paying service users, carers and patients for their contributions to our work (Folk.us 2000). Folk.us takes the position that everyone should be able to be paid, but some people may choose not to be paid for their involvement. Making this choice should never be because the systems are too difficult to negotiate. The key challenge of this position is about *how* to make it possible. Ten years on, we still find

it difficult to properly implement this policy and similar experiences are reported across the country (e.g. Pandya 2010). This article is an in depth exploration of how our experience relates to others' across the country and an attempt to document and understand why change appears slow.

The range of literature to be covered includes: specific and general mechanisms set out in existing guidance documents; case examples from service users and from those who have tried to pay service users for their (research) involvement; experiences, narratives, opinion pieces, policy documents and research articles about service user involvement that mention payment. The article tries to summarise, document and interpret what had gone before at the time of writing in late 2009/early 2010.

Search strategy

We anticipated some difficulty in accessing literature on specific mechanisms, but took an open and broad approach. We searched databases including Social Policy and Practice (covering social policy, public health, social services, and mental and community health), ASSIA (Applied Social Sciences Index and Abstracts), PsychInfo (covering psychological, social, behavioural, and health sciences), MEDLINE (covering life sciences, especially biomedicine) and CINAHL (Cumulative Index to Nursing and Allied Health Literature). There's no thesaurus term for 'service user' but it works well as a keyword. Most articles were found by searching for "pay* NEAR service user*", though this brought up a lot of articles about direct payments, so the clause "NOT direct" was added. For example, searching Social Policy and Practice yielded 86 articles which reduced to 21 when those discussing 'direct payments' were discounted. This was reduced again, when relevant content was reviewed.

Some searching on synonyms including 'mone*' (money/monetary), 'participation', 'citizen' and popular terms like 'tokenism' and 'guidance' followed. Articles published after 2002 were mainly sought. Some scanning of reference lists from relevant articles and searches on key authors and key journals including Health Service Journal and Community Care took place. Relevant public health websites were explored including the National Public Health Library, INVOLVE and the Office for Disability Issues, using the search term 'pay'. One Cochrane Review was accessed (Nilsen et al. 2006) but made no reference to payment mechanisms. Key government documents were the Department of Health (DH) 'Reward and Recognition' guidance and the Welsh Assembly response. Some Department of Work and Pensions (DWP) documents were sought out, where pay and involvement were explicitly raised.

Moving outside the health and social care field, we also looked at some debates represented in social policy and administration, public money and management and checked some documents through Google Scholar. The search took place during the period July 2008 to May 2009. In a later draft, we also included some legislation that was finalised and signed in early 2010 relating to benefit barriers to involvement.

Main results

National policy context

The involvement of the public, as well as service users, patients and carers, is an obligation on UK National Health Service (NHS) agencies. This was set out in the Health and Social Care Act (2001) and reinforced in 2003 (Community and Health Standards

addendum to Act) and 2007 (Darzi 2007). The National Social Inclusion Programme (NSIP 2009) points out that important policy drivers are in place for increasing the use of involvement in service design, delivery and monitoring. These particularly include the Disability Equality Duty introduced in the Disability Discrimination Act 2006 and 'Improving the life chances of disabled people' issued by the Office of Disability Issues. Hence, national policies in the UK have actively promoted service user involvement for the last decade. They also generally accept the idea that such involvement should be paid. This is based on the idea that service users should be rewarded for their recognised and valued contributions (e.g. Turner and Beresford 2005; Tait and Lester 2005; Henwood 2007; INVOLVE 2010a).

However, other government documents acknowledged problems with the practicalities of actually making payments to people who get involved. For example, the Social Services Inspectorate (SSI 2004) noted problems paying for the involvement of people with mental health problems. The Commission for Health Improvement (CHI 2004), in an audit on patient and public involvement, detailed 'impressive sounding strategies and plans and idealistic leaders', but problems in policy delivery (including payment). As payment problems started to snowball, Stephen Ladyman, the then Minister for Community, commissioned Turner and Beresford (2005) to undertake a project looking at issues of pay and recognition for service users, exploring problems with the benefits system. It was shared with ministerial colleagues to attempt to progress change, but lost some momentum when Mr Ladyman moved on from his post in 2005. At the same time, urgency to address the problems was building. Similar payment and benefit problems were being noted in other fields outside health and social care. Examples included the urban regeneration 'Just Rewards' campaign supported by the Home Secretary, David Blunkett (2003); and The Engage Network, a coalition campaigning for the greater involvement of disabled people in public life (submitted to the Public Administration Select Committee 2003).

In 2005, The Cabinet Office Strategy Unit gave a commitment that the DH and the DWP would issue guidance to health and social services authorities on good practice in paying service users. The DH 'Reward and Recognition' guidance (2006) and the Welsh Assembly response (Welsh Assembly 2007) followed. Broader policy imperatives that were published the following year continued the sentiments, seen most assertively in Darzi's (2007) vision for an NHS that is personalised – tailored to the needs and wants of each individual, especially the most vulnerable and those in greatest need.

Such apparent government commitment to involvement, active citizenship and social inclusion at that time remained out of harmony with day to day operation of the benefits system. This was particularly highlighted in May 2007, when a national Commission for Social Care Inspection (CSCI – now the Care Quality Commission, CQC) seminar *Benefit barriers to involvement: Finding solutions* brought together the DWP, service users and the statutory and other bodies keen to involve them for the first time. The outcome was another document (CSCI 2007) and a recognition that the DWP had a clearer picture of the problems people face. So the problem with paying service users was gaining a higher profile but the political will to find solutions still appeared to be lacking.

At the time of writing in mid 2009/early 2010, activists working at the national level were continuing to have discussions with relevant ministers to bring about reform. They told us that this has again been blighted by changes in personnel amongst ministers following a number of resignations. However some progress has

been made with the implementation of new legislation from 26 October 2009 which eases benefit barriers to involvement. It states that all expenses can be reimbursed to service users and their benefits will not be affected. It also states that 'notional earnings' have been abolished for involvement and from mid-2010 'Permitted Work Rules' will be improved. However, some areas remain unclear (J. Scott, pers. comm.). For example, the legislation applies only to public bodies required by law to involve people or commissioned to involve people by a public body. It is still not clear how involvement commissioned by a charity or for research studies should be treated. Another key issue remains that reimbursement of expenses may still be treated as earnings and deducted from benefit income.

INVOLVE is the national advisory group on service user involvement in the UK, funded by the National Institute for Health Research (NIHR). Their perspective on the issue of paying service users is important to include. INVOLVE was set up by the DH in 1996 as Consumers in NHS Research, with its remit broadening from 2001 onwards towards promoting public involvement in the health service, public health and social care research. INVOLVE issued their own guidance on reimbursement and payment in 2002 (Consumers in NHS Research 2002), which was updated in 2006 (INVOLVE 2006a), and updated again in May 2010 (INVOLVE 2010a). INVOLVE also developed their own internal policy on payments and expenses for members of the public (INVOLVE 2007), updated in February 2010 (INVOLVE 2010b). They have also set out National Institute of Health Research (NIHR) payments to members of the public who are involved with commissioning research with the NIHR research programmes (2008b). INVOLVE have continued to bring attention to the wider topic of payment problems at conferences, events and in their own internal workings (e.g. INVOLVE 2006b, 2006c, 2008a). INVOLVE's position remains one of informed choice on the basis of an acknowledgement that:

Most if not all of the potential complications of making payments to the public and people who use services are generated by institutions ... users should not end up being marginalised by these institutional systems ... INVOLVE suggest payments should be offered and individuals allowed to make an informed choice as to whether to accept. (INVOLVE 2006a, 10)

INVOLVE's advice on payment mechanisms for service user involvement is that each person's position is different, so solutions can be found in general guidance and through direct contact with government agency helplines (INVOLVE 2010a) and more recently with the 'Involvement Helpline' service offered by Milton Keynes Citizens Advice Bureau (Stewart 2008) (this is not a free public service, but is provided for a fee from the service user or through organisational subscription). In their updated 2010 guidance, INVOLVE continue with the same principles and provide an even more nuanced account of the complexities of payment processes for involvement that disabled people need to be aware of (INVOLVE 2010a).

At a regional level, different groups have got involved in lobbying for change on payments in different parts of the country (e.g. Attree 2003) and there is evidence that dissatisfaction remains widespread. For example, in the South West, the issue was taken up in 2008 by the then Care Services Improvement Partnership South West (now the South West Development Centre). A small working group was formed to encourage some common understanding about the issues and to try and address them. In May 2009 Jean Alger-Green of the South West Development Centre said that the group had contributed to proposed amendments by the Benefit Reform Division at

DWP concerning benefits barriers and involvement, but more change was needed (Alger-Green 2009).

So the policy context for service user, patient and carer payment has been one of increasing activity and attention in the UK over the last decade. The policy climate appears ripe for change on payment principles, but evidence suggests that the implementation of payment mechanisms that work for all service users remains a challenging issue. To try to understand why this is the case, it is important to look beyond the broader policy documents to study the guidance that has been issued, the actual financial mechanisms that have been put in place and the sources of available advice to resolve individuals' problems. Once these have been explored, we will look in more depth at the kinds of problems that service users, patients and carers have reported.

Payment guidance

Setting payment rates

One key issue that has led to dispute and confusion relates to how much people (service users, patients and carers) should get paid for their time during their research involvement. Different levels of contribution have been thought appropriate by different agencies and debates have arisen about what has been dubbed 'realistic payment' (Faulkner 2004; SURGE 2005). Ramon (2000) reported 'insufficient' recompense for service users and Allam et al. (2004) found payments only compensated service users for a small fraction of their time. Part of this story is to do with benefit limitations (raised in the following section). The Reward and Recognition guidance (DH 2006) stated only that 'the rate at which service users are paid for their involvement, just like any other sphere of life, will depend on the activity, the skills and experience, the complexity and responsibility that the activity demands' (DH 2006, 14).

The issue of setting payment rates culminated in a proliferation of guidance and policy documents, some nationally focused (DH 2006; Welsh Assembly 2007), some regionally (e.g. North West Mental Health Development Centre 2001) and some client group focused (e.g. Scott and Seebohm 2002). The policy documents have become more specific over time and the guidance documents have stayed less specific about setting rates. For example, in 2006 INVOLVE stated that 'because each situation is different, the guide does not attempt to be prescriptive about rates of payment' (INVOLVE 2006a, 2). Their own internal 'Policy on reimbursements and payments' that was developed in 2008, suggested that the DH committee rate of £150 per day was their own benchmark for deciding what payment rates should apply to different situations, but this was still qualified with a statement about service user research being 'time limited, non routine and unique' and hence not appropriate for setting fixed rates. INVOLVE published a guide to payments to members of the public who are involved with commissioning research with the National Institute of Health Research programmes in July 2008 (itself updated from 2006), suggesting the committee rate should be doubled for reviewing 15 or more proposals at research committee, there should be a three tier cost boundary for peer review work (£50 lower to £200 higher) and a few other task fees are given (INVOLVE 2008b).

To look at other examples, the CSCI 'Payments and Reimbursement Policy for people who use services' (CSCI 2006) was more directive about actual amounts to be paid/expected in what circumstances. For example, CSCI stated that gift payments 'will always be a minimum of £20 and will be at an hourly rate that is at least equal to the national minimum wage'. The standard rate of pay for basic activities was £7.50

per hour, up to £55 per day and ‘enhanced rate of pay’ being ‘£15 per hour up to £120 per day’. Other groups’ example rates were noted by Hinder and Morris (2006) for the North West Health User Research Advisory Group. The National Institute for Clinical Excellence (NICE) apparently paid £200 per day, with the National Nursing and Midwifery Council giving £268 per day. The 2010 INVOLVE guidance provides examples of payments for involvement from NIHR, the National Cancer Research Network and two universities which settle largely on a daily rate of £150. So service users who do get an offer to be paid are faced with a slightly bewildering set of rates that vary in amount (and hence intention?), fluctuate over time and are calculated in different ways.

Some government agencies have continued to hold the line that service users should not be paid for their time at all. It is noteworthy that the DWP itself identified ‘customer involvement’ as a policy high within its own internal institution and, for example, in January 2009 set up an ‘Equality Schemes Customer Reference Group’. The terms of reference for this group explicitly stated, ‘Members of the group will not be paid for their time, but other expenses will be paid’ (DWP 2009, 8). In contrast, in a similar expert advisors and reference group set up at around the same time by the then National Social Inclusion Programme (NSIP), a budget was set that would enable up to 15 people to sit on the NSIP Reference Group and receive a payment of £85 a meeting (NSIP 2009). So it seems that disabled people and other service users who wish to give of their time might do well to consider their departmental allegiances. In many ways, the rates themselves are not relevant, but they are a good indication of the confusion that exists. What we most need to make the work of involving people credible and valued is to have payment for involvement activity made ‘allowable’ within all the different agencies.

The other allied issue on payment rates is about expenses, with differences evident about what can be covered by ‘expenses’ and again differences in expenses payment rates. INVOLVE (2006a) suggested that expenses include travel, overnight accommodation, subsistence, childcare, phone /internet, stationary/equipment, carer costs, cost of personal assistant of person’s choice, conference fee, participation in training. This is very inclusive when compared to many other agencies. We compared tables of explicit reimbursement rates for expenses set out in policy by INVOLVE and the CSCI. Some rates were the same (e.g. £90 receipted for staying in a London hotel) and others varied a little e.g. INVOLVE pay £70 for hotels outside London, whereas CSCI propose £75. Others varied a lot. CSCI pay 24p per mile petrol costs in supermarket vouchers. INVOLVE pay 40p per mile if car use is ‘absolutely necessary’, or 22.5p per mile if public transport could have been used ‘to complete a journey in the same time’ (INVOLVE 2007, 3). In private correspondence, INVOLVE point out that they have no say over these rates as these are the standard rates paid by their employers, the University of Leeds. If INVOLVE moved elsewhere, these rates could change. In a survey of 75 organisations commissioning and providing secondary mental health services, Ryan and Bamber (2002) noted that many organisations employed unwritten policies based on custom and practice and were most likely to relate to basic expenses payments rather than payments for time given. So it seems that although we are seeing a trend to be more specific about expense payments, variation and confusion exists about meaningful amounts, relevant coverage and the extent to which ‘expenses’ payments are implied to include ‘payments for time’. Certainly, the 2010 INVOLVE guidance continues to warn that, ‘When a person is paid for their

involvement, reimbursement for expenses may be treated as earnings by the Jobcentre Plus' (INVOLVE 2010a, 11).

Payment mechanisms

The guidance and policy documents have had much less to say about how to pay service users and set up local mechanisms (SURGE 2005; Volunteering England 2009; Mental Health Research Network [MHRN] 2010). Both INVOLVE and CSCI pay people by BACS in one month arrears, bound presumably by their own institutional allegiances rather than by their own choice on methods of payment (INVOLVE 2008b). Others say very little or nothing about specific mechanisms for payment and time delays expected. Few will now pay cash at the time of service user contribution. The UK Reward and Recognition principles (2006) and the Welsh Assembly guidance (Welsh Assembly 2007) said nothing on how to establish the mechanisms to support service user payment for involvement.

Attempts to provide guidance on mechanisms have been rather confusing to date. For example, through the MCCH Society, Judy Scott's guidance (Scott 2005) explained when work projects should pay the minimum wage, how this could be managed for people who receive benefits and outlined the rules around paying expenses, giving gifts, training allowances and honorariums. In later guidance prepared for a payments workshop at INVOLVE's 2008 national conference, 11 rules or systems were outlined with a short explanation and an outline of what the service user must do in each scenario (Scott 2008). The rules covered one-off gift vouchers, the averaging rule, expenses, travel, subsistence (meals) and personal assistant costs, notional earnings and something about the timing of sending off a P46 to HM Revenue and Customs (HMRC) and your assumed illegal work status if Job Centre Plus hear of it (they will stop benefits). Judy Scott stated that the guidance was based on what had occurred in real situations with Jobcentre Plus and HMRC in 2007/08. It is good to see some specific examples, but not clear to what extent the agencies involved would definitely behave the same if the same scenarios occur again in different parts of the country. Nor is it always easy to apply the rules to a specific person's situation at a particular point in time. The advice and guidance shifts fairly quickly in the current climate. There are differences between the 2005 and 2008 Judy Scott documents in relation to payment of gifts, for example. Changes to personal circumstances, Benefits Rules and HMRC rules are difficult to keep up with. For disabled people, the MHRN Service Users and Carers Payments Policy 2010 appears the most detailed and relevant to currently be available, covering discussion of incapacity benefit rules, severed disablement allowances and carer's premium, for example. But it is a dense 41 page challenging document in itself. To tease out the changes over time, as a disabled person or service user is very confusing.

Many guidance documents acknowledge that providers who do pay people are worried about whether they are doing it properly and about whether they are breaking the law. Different ways of paying people have been tried including:

- some have been advised to pay service users as sessional employees but this can cause human resource implications including holiday entitlement and employers' liability insurance;
- others pay a regular fee of £15 for attending meetings – staying under the £20 a week allowance;

- some pay people a flat rate of ‘expenses’ in cash on the day, at £20–£30 per session; and
- a number get paid through their service user organisation receiving a payment.

Councils are vulnerable under current systems and experiences of accusations of fraudulent behaviour for trying to get round existing rules are plentiful in letters, memos and grey literature. For example, in a letter in *Community Care*, Gary Vaux, then Head of Money Advice at Hertfordshire Council cautioned colleagues about the vagaries and risks to councils themselves of making payments to service users (Vaux 2002). Voluntary organisations can receive charitable donations. To do this they must seek advice through the Council for Voluntary Services, the National Council for Voluntary Organisations (NCVO) or the charities commission. Some have a ‘trading arm’ that allows profits to be donated back to the core organisation. Dispensations for a Trustee to be paid must be sought through the Charity Commission. So again, even the range of organisations and institutions that must be consulted for advice is challenging. There is a huge difference in the way paying people for involvement needs to be handled by universities compared to what a university usually does. The Folk.us experience has been that speaking to heads of finance and payroll departments is helpful. However universities are subject to audit so most if not all tax everyone at source expecting people to claim it back. The Revenue and Customs position is that if someone is not eligible to pay tax then there is no duty to take tax at source, but universities are required to keep a record of who they have paid (HMRC 2004). Few finance staff are aware of this.

The multitude and variance in guidance itself has ended up being problematic. What is clear from studying the service user and service provider problems with the existing systems that follow below is that the current situation goes beyond the need for more guidance documents. A key to this issue is that ‘involvement’ is not an activity currently widely recognised in laws governing the DWP, Revenue and Customs or any other agency so all advice is based on interpretation. A Citizens Advice Bureau’s (CAB) interpretation is just as valid or questionable as a Jobcentre Plus officer’s interpretation. Frequent disputes and differences in advice and interpretation are currently occurring. The complexity of existing communication systems about payment mechanisms appears unwieldy and communication between different agencies is poor. For service users to negotiate the communication maze is clearly a stressful process and statements about difficulties with the system are numerous (Turner and Beresford 2005).

Service user reported problems with payment mechanisms

Service users say that mechanisms for payment are problematic. They suggest obliqueness and variation in how rules are applied in different areas and amongst and between different benefit agency and finance department staff members. Turner and Beresford (2005, 5) suggested that ‘the benefits system can at times be both inflexible and inconsistent in the way it operates’. They highlighted how service users face problems in:

- how much they are allowed to be paid (current rules allow people to be paid a little – some think it should be more);
- in negotiating payment allowances (particular communication problems were noted with some Jobcentre Plus offices);

- in the length of time it takes to sort things out; and
- in facing threats of benefit withdrawal (just by enquiring or taking part, not even by actual payment).

Different types of problems and contradictions have been faced by individuals. Turner and Beresford (2005) report on a whole range including, for example, the position of service users in relation to government support for disabled people at work who are treated as employed by Jobcentre Plus but not accepted as employed by their own Access to Work scheme. The four main barriers noted in CSCI 'Benefit Barriers to Involvement' summary (2007) were:

- most people on benefits are limited to earnings of £5, £10 or £20 a week;
- people fear being wrongly disallowed incapacity benefit; and
- reimbursed expenses (for travel, personal assistants and replacement carers) can be treated as earnings.

For people on state benefits and allowances, each benefit has different conditions attached, including different ceilings on what additional income can be earned, if any, before payment is affected. It is the individual's responsibility to inform 'Job Centre Plus/Benefits Agency Office'. Many authors acknowledge that 'different Job Centre Plus offices have different ways of interpreting the rules, and attitudes to a particular situation may differ. In some cases special arrangements have been successfully negotiated' (INVOLVE 2006a, 8). A particular difficulty is that the Job Centre Plus Office can interpret research involvement as readiness for work whether or not payment is being offered, and therefore withdraw benefits. There is a potential contradiction with involving those in long term receipt of benefits or care. 'In some cases organisations have been able to set up ongoing working agreements with their local JC+ office ... may depend on nature of the work and way local agencies interprets its responsibilities'. Many further problems are articulately set out in this document, including some very specific concerns about things like offset charging for residential care costs due to involvement.

Solutions?

When service users have been consulted about possible solutions to existing payment mechanism problems a range of solutions have been suggested. In the Turner and Beresford focus groups, one person suggested 'upping' the weekly earning allowance while on benefit to £90. Others wanted longer time periods for income assessment – over a year, not a week or month. An extra 'disregard' for involvement work was also suggested, treating it differently from other forms of work. Training Job Centre Plus staff and improvement of welfare rights advice were clearly needed. One group suggested unionising involvement work.

However, service user statements about potential solutions also express real frustration with any idea of tinkering with what is often perceived as a malfunctioning system. One respondent to the Turner and Beresford focus groups recommended:

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. (Turner and Beresford 2005, 31)

Researchers working to evaluate service user initiatives have also suggested solutions that could be tested out. For example, Pam Hutton (2006) discussed the difficulties

over paying carers and service users involved in a social work training programme at Havering College, describing the way benefit entitlements are affected. Hutton suggested that a new category of activity should be created – ‘permitted activity’ – which would allow people to participate in such initiatives for a certain number of hours and be paid up to a certain amount. Hinder and Morris (2006) also argue for a substantial increase in ‘earnings disregard’ and express a desire for an empowering rather than a punitive approach, with a guarantee that there is no risk of claims being re-assessed as a result of involvement.

Turner and Beresford (2005) concluded with a number of recommendations, many of which related to payment mechanisms:

- There needs to be specific and explicit recognition that taking part in user involvement does not mean a person is fit to return to work.
- 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.
- A system needs to be developed that will guarantee that taking part in user involvement will not lead to a review of benefits (or accusations of fraud).
- The way in which Jobcentre Plus administers the rules for permitted earnings needs to be reviewed to ensure they are consistently applied.
- Training needs to be given 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 issues of how employment law treats work undertaken as part of user involvement should be reviewed by the relevant government departments.

Participants at the ‘Benefit Barriers to Involvement: Finding Solutions’ seminar held in 2007 to bring together the DWP, service users and statutory and other bodies keen to involve them, put forward ‘treating involvement as a civic responsibility rather than the equivalent of work (as with local councillors’ pay), getting rid of inequalities and anomalies in the benefits system, simplifying it and making it more flexible’ as possible solutions to existing problems (Beresford 2007).

Analysis

Academic debates and discussions about payment mechanisms have been centred around notions of ethics, power and policy. A number of analytical articles that raise paying service users as a general issue suggest that researchers should be urged to consider it on an ethical basis (e.g. Henwood 2007; Levin 2004). It is unethical not to treat people equally when they offer to be involved in research – to treat them respectfully, to recompense them for their time and to acknowledge their lay expertise. However, that workable mechanisms might also be of key ethical concern has not been the subject of much debate to date and arises only in warnings in the post scripts of articles modelling best practice in doing research with user involvement.

For example, in a qualitative review of service user involvement in research with mental health service users in 2002, which professed to illustrate the challenges in joint research projects, Trivedi and Wykes (2002, 471) mention payment in one concluding sentence, referring to difficulties in costing involvement and implementing payments within the limits imposed on benefit claimants. Similarly in a Cochrane review of methods of consumer involvement in developing healthcare policy, research, clinical practice guidelines and patient information materials (Nilsen et al. 2006), different degrees of financial support to service users were noted across comparative projects, but no useful evidence on pay or cost was sought from any of the studies reviewed. There was a recommendation for future studies to explore ‘adverse effects’ of service user involvement, explicitly whether it slows the process of research and makes it costlier (9). So there has been some blindness about needing to understand payment issues in these debates from the service user’s perspective. Some have suggested that this links to the use and abuse of power in research relationships.

Some writers remain openly sceptical about the value of service user involvement in research (e.g. Tyrer 2002). If such research is not valued, it is neither financially valued. Diana Rose (2003) has suggested that getting a workable payment mechanism for service users remains as much about demonstrating that service user-focused research provides a valuable counterpoint to professional research and countering this stance. Rose suggested that the most corrosive element is power differentials in user–professional research relationships, where the user knowledge is downgraded intellectually and financially. Barnes and Prior (1996, 57) discussed the issue of public trust in relation to service users, identifying a need for a range of ‘democratic mechanisms of decision making which aim for the inclusion of all citizens’. They stated then that payment to service user mechanisms must be part of this agenda. But policy evidence mentioned earlier suggests that such arguments have failed to fully inform pragmatic arrangements and policy decisions. Similarly Marion Barnes’ writing has had little impact on university practice. At the ‘Critical Perspectives on User Involvement’ Conference hosted by Barnes and others at Brighton University, Hove Town Hall in 2009, service users were charged admission rates and not offered any support around expenses (when most academics and service providers attending were able to claim these from their institutions).

In an editorial in *Public money & management*, the issue was linked to public service consumerism, suggesting that attempts to pay more attention to the needs of service users may be undermined by the current indiscriminate attempts to re-badge the variety of such users as ‘customers’ and that there are significant risks for policy, provision and consumption in not providing for appropriate relationships between providers and users of services (Gray 2008). The risk models they explore in Giddens and Beck’s work both draw on ideas about the re-appropriation of knowledge, skills and control by social groups operating largely outside the formal political and economic systems. The Third Way/Modernisation philosophy of New Labour, with its linking concept of ‘person-centredness’ is argued by some to be trying to individualise care, to turn welfare recipients into entrepreneurial competents, who only by that route, can earn their badge of citizenship (Scourfield 2007).

Many of the payment debates resonate with socio/political debates within the disabled people’s movement about philosophical interpretations and particularly the social model. The Union of the Physically Impaired Against Segregation (UPIAS) suggested way back in 1976 that ‘disability is something imposed on top of our

impairments by the way we are unnecessarily isolated and excluded from participation in society' (UPIAS, quoted in Barnes 2003, 4). A lack of workable payment mechanisms appears to promote similar isolation and exclusion for all service users. The 'transformative aim(s)' of Colin Barnes' conception of emancipatory disability research, namely 'barrier removal and the promotion of disabled people's individual and collective empowerment' (Barnes 2003, 3) relate especially strongly to payment mechanisms as one essential barrier for removal.

At a regional level, payment problems are often perceived as being so knotty and complex that consultation exercises to assess the type and range of problems experienced are still being proposed, despite the quality of existing published evidence found for example in Turner and Beresford's work. Cook (2002) recognises this is a problem common across many areas of social policy. To keep asking the same questions prevents the time for action. Yet '[i]f we are not willing to do anything about the problem, why ask the question in the first place?' Clearly in this case, there is a groundswell of urgency to act coming from service users, patients and carers themselves through the agencies that represent them at national level. But their political voice is weak and a high level 'change agent' who will take responsibility for the payment issue and implement workable solutions has not been there to date. It is a policy area rife with buck-passing. Policy inertia seems to have been exacerbated by the extreme complexity of financial and benefit systems and underpinned by an extremely durable political consensus to make incremental adjustments only. Changes have tended to be slow and of narrow scope, rather than systematic or radical.

This review reveals that many groups recognise now that a clear next step to tackle in paying service users is about developing appropriate mechanisms. It is important to recognise that for real service user involvement, just like doing emancipatory disability research (Barnes 2003), it entails a process. 'Service user involvement that makes a difference cannot be a one off intervention or a discreet programme of work. It must be part of the fabric of ... services' (Tait and Lester 2005). A push to change institutional financial systems takes the responsibility off disabled people and others who want to get involved in research and places it firmly with professionals with a paid duty to respond.

Conclusions

In the UK, the policy context for improving payment mechanisms for service users has existed for some time. However, in practice, workable mechanisms still need to be developed. In a recent presentation, the SCIE captured this idea in saying 'It's not (just) what you pay, it's the way that you pay it' (Lawson 2008). Ideological commitment had been repeatedly expressed at the time of writing but practical steps to tackle clumsy and ineffective systems were found wanting. Inconsistencies about who should be paid, for what, under what circumstances, by what means and with what level of personal responsibility for sorting out difficulties were evident. Clearly some recent progress had been made in articulating the problems and barriers, but in not creating consistent, workable financial systems, there is a practical and political ambivalence on the part of institutions. From here, Folk.us wants to work out what we can contribute to what Turner and Beresford once described as the 'long journey' towards a real and practicable solution (Turner and Beresford 2005, vi). That solution in our view would be a workable, consistent mechanism for paying service users for their valid and valued hard work and contribution. The analysis evident here of

incremental and insufficient slow adjustments made to date suggests that we need a political champion to make this happen.

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