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Better for People



Benefit barriers to involvement

Finding solutions

October 2007

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- improve services and stamp out bad practice
- be an expert voice on social care
- practise what we preach in our own organisation.

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Benefit barriers to involvement

Finding solutions

A report from the seminar held by the
Joint Participation Steering Group

Commission for Social Care Inspection

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Foreword by the Chairs of the seminar



Dame Denise Platt, DBE

Chair of the Commission for Social Care Inspection

The Commission for Social Care Inspection (CSCI) is the single regulator for all social care in England. Our first and foremost value is to put the people who use social care first.

Since our inception we have worked hard to make this aim a reality. We involve people who use care services in our work in many ways – as members of boards and reference groups, and as experts by experience in our inspection teams.

We want to remunerate people for their involvement with us. Sometimes that might be through meeting the costs of the necessary expenses that involvement can incur. At other times it means paying people an appropriate fee for their involvement.

The benefit system presents many challenges for our work. The vast majority of people that we seek to involve are in receipt of state benefits, and the regulations, and the barriers created, for both them and us are significant.

I was delighted to co-chair this important seminar on behalf of the Joint Participation Steering Group with Peter Beresford from the Shaping Our Lives User Network. The seminar brought together a wide range of people with the aim of exchanging information about the benefit barriers to involvement and identifying joint solutions.

At the seminar we heard directly from people who use services and organisations about the difficulties presented by the current system. I was struck by the very real issues that people face, and the consensus around the room that these are real problems for both organisations seeking to involve, and those who want to get involved.

There was a genuine fear from people about how getting involved might affect their benefit entitlement. There was also a real commitment from organisations wanting to involve people to do things in the right way and within the law.

People tell us they want to be involved to help improve services and make things better for others. Financial reward is important, but it is not the main motivator. The future of social care relies upon involving people who use services, and the current benefit rules preclude many people. This report has identified some useful solutions that I truly hope can be taken forward.



Professor Peter Beresford

Chair of Shaping Our Lives

There can be few issues raised by people who use services where there has been so much concern and so much agreement as there has been about the lack of fit between the current benefits system and getting involved. A very wide range of organisations – social care and health, research and regeneration, regulators and professional organisations, service providers and commissioners, and of course, service user, carer and community organisations – have all joined forces to highlight the longstanding and continuing barriers operating to restrict people’s involvement because of benefits law, policy and practice.

Many different stakeholders have been of one mind over this issue. Their concern has been growing. So has the evidence highlighted the problems. Just as people who use services report that the benefits system is preventing them getting involved and contributing to their communities as they wish to, so social care, health, and other public organisations are making clear that the benefits situation is preventing them from honouring legal and other requirements to involve the public, patients and people who use services as fully as they would wish to.

We know that people who use services have been reluctant to get involved because they fear that their benefits may be put at risk. I know personally of cases where people have had benefits wrongly withdrawn because of this and it has taken months for them to be reinstated. I know of more people who have had unjustified warnings from benefits organisations which have led them to call a halt to involvement that they have had in social care and health. And of course a very much larger, unquantifiable number of people steer clear of getting involved because of the worries they have that it may result in their income being put in jeopardy for no good reason.

We cannot underestimate these fears and anxieties. They reflect an unhelpful climate of suspicion and distrust. I lived for 10 years on such benefits. It was a

difficult experience in many ways. The uncertainty that went with it increased my anxiety. It took me a long time after I came off benefits to be able to pick up the post and not fear the thud it made when it came through the letter box. I was always dreading that there would be some problem with my benefits. I have always felt that the experience and consequences of being on benefits for me at least have been as difficult to deal with as my experience of distress and involvement with the psychiatric system. It now seems so unfair that people's altruistic impulse to contribute is raising such fears for them.

That's why we need to resolve the current problems that the benefits system is creating – restricting people's involvement, reinforcing barriers in the way of it and making for inequality. The recent government emphasis on involving public, patients and people who use services is something to be commended. It is strongly in tune with people who use services' own commitment to contribute to their communities and to the provision of good services and support.

I believe that this seminar represents a significant stepping stone in taking forward this shared ideal. That is why I and Shaping Our Lives have been very pleased to be associated with it. Shaping Our Lives is an independent service user controlled organisation and network, made up of and working across the wide range of people who use social care and health services. We are committed to involvement, which is why the issues raised by the seminar are so important. People who use services were involved in the seminar's planning and organisation and were centrally involved as both contributors and participants. A wide range of other stakeholders also contributed to the discussion. Representatives from the Department for Work and Pensions took part and were able to hear first hand people's views and direct experience as well as offering their own.

The seminar has added to the evidence base and there is a commitment that the issues it has raised will be fed directly to the Minister. My hope is that every person who wishes to, will be able to get involved, make their contribution and be reassured that this will be a safe and valued experience that can be part of extending and improving their life chances. The views expressed in this report of the seminar make clear that this is a shared aspiration and I hope many people will read and be guided and inspired by them.

Executive summary

- The involvement of people who use services is a key government policy in the development of social care and health services. Involvement activities vary and can range from consulting on specific policy initiatives to inviting people to play an active part in the design, delivery and monitoring of services.
- The term ‘benefit barriers to involvement’ is used to describe the ways in which the current benefits system discourages or prevents people in receipt of benefits from getting involved.
- The purpose of the seminar was to bring together relevant stakeholders to share information on the benefit barriers to involvement; provide clear examples of how these barriers impact upon involvement; and to propose solutions to the current problems.
- The importance of involvement in the development of better social care and health services was emphasised at the seminar. People who use services, as well as social care and health organisations, highlighted the integral role of involvement in:
 - Enabling the insight and expertise of those who have experience of social care and health services to be fed through into the design, delivery and monitoring of services
 - Promoting active citizenship
 - Supporting public bodies to meet their statutory duties.
- Payment for involvement was seen by delegates as an explicit demonstration of the value of people’s contributions, which helps to create a more level playing field between those who are employed by social care and health organisations and those who use social care and health services.
- The current benefit rules are having a direct impact on the groups of people who can undertake involvement activity, and the type of involvement activity that people can engage in. Social care and health organisations emphasised that they are struggling to involve a diverse group of people in their work because of the current benefit rules.

- Four main barriers were identified:
 - Most people on benefits are limited to earnings of £5, £10, or £20 a week
 - People fear being wrongly disallowed incapacity benefit
 - Reimbursed expenses (for travel, personal assistants and replacement carers) can be treated as earnings
 - Even if people offer to be involved for free, as volunteers, their benefits can be affected by the notional earnings rule.
- Delegates identified further barriers to involvement which include:
 - The ‘joint problem’ facing people in residential care who are anxious about undertaking involvement work because of risks to their benefits, and because they are likely to be charged for some of their residential care costs
 - The lack of clarity and ‘attitudinal barriers’ amongst some Jobcentre Plus officials about the current benefit rules on involvement
 - Further anxieties in relation to the Voice Risk Analysis system, currently being piloted.
- Delegates at the seminar provided a number of clear examples of how the benefit barriers are impacting upon involvement. For example:
 - People explained that they are choosing not to get involved because the current rules on payment, expenses and notional earnings would leave them financially worse off
 - Others are choosing not to participate because they fear it will trigger a review of their benefits which may leave them financially vulnerable
 - Some people have been subject to mistakes made by Jobcentre Plus officials, which have caused them financial hardship and emotional stress. They are unwilling to become involved in case it leads to further mistakes being made
 - Some people who have been involved in the past and were unaware of the benefit rules have found themselves in financial difficulty following deductions from their benefits.
- The delegates identified a number of core principles that are central to any future reform to the benefit rules on involvement. These include:
 - People in receipt of benefits should not be excluded from involvement activity as a result of barriers within the benefits system
 - The benefits system needs to be simplified and made more flexible
 - The benefits system in respect of involvement must be adapted to ensure that the poorest people are not discriminated against. Earning disregards are currently only attached to means-tested benefits and the very low earning limits per week

- exclude many people on these benefits from participating
- Although involvement can provide a pathway into work for some people, it must not be assumed to represent capacity for work.
- Delegates proposed a number of solutions to solve the current benefit barriers to involvement. These include:
 - Reforming the system to ensure that payment for involvement should be treated in the same way for all types of benefits, whether means tested or non-means tested
 - Payment for involvement should be treated within the benefits system on an annual or a monthly basis, rather than the current weekly arrangement
 - The precedent that has been set within the benefits system for local authority councillors should be applied to those who get involved
 - Reimbursed travel expenses, reimbursed replacement carer costs and reimbursed personal assistant/support worker costs should be viewed as necessary expenses, and therefore should not be treated as earnings
 - The notional earnings rule should not be applied to involvement activity. This would ensure that people who offer to participate for free, on a voluntary basis, are not penalised and left financially worse off
 - There needs to be more training for Jobcentre Plus staff to ensure that they are clear about the benefit rules for involvement, and do not make unnecessary mistakes which can cause anxiety and financial hardship for people who have contributed their expertise for involvement purposes.
 - The seminar from which this report emerges took place on 22 May 2007. It was organised by the Commission for Social Care Inspection, the General Social Care Council, Shaping Our Lives, Skills for Care and the Social Care Institute for Excellence. The event was supported by the Joint Participation Steering Group, which is a group of national organisations concerned with good practice and promoting and sharing best practice in user and carer participation in social care and health.

Introduction

This report outlines the key themes emerging from a recent seminar on the benefit barriers to involvement. The seminar took place on 22 May 2007 and was organised by the Commission for Social Care Inspection, the General Social Care Council, Shaping Our Lives, Skills for Care and the Social Care Institute for Excellence. The event was supported by the Joint Participation Steering Group, which is a group of national organisations concerned with promoting and sharing best practice in user and carer participation in social care and health.

The seminar brought together a wide range of individuals and organisations that have a stake in this issue, to discuss the benefit barriers to involvement and consider ways to improve the current situation. Delegates who attended the seminar included:

- People who use services and carers that are in receipt of benefits. These were people who have either been involved, or who have chosen not to get involved for fear of losing their benefits.
- Social care and health organisations who have a desire, and in many cases a duty under the Disability Equality Duty and other legislation, to involve people who use services and carers in their work.
- Representatives from government, including the Department for Work and Pensions (DWP) and the Department of Health (DH).

‘Involvement’ is the name given to the range of activities undertaken by people who use services with public service organisations to improve service delivery. For example, this can include membership of committees, participation in focus groups, research projects and on staff recruitment panels. It differs from work in that the people who have the most to contribute are likely to be those who use public services the most. Therefore these people are more likely to be ill, be disabled, or be carers, and be supported by incapacity- or income- related benefits.

The term ‘benefit barriers to involvement’ is used to describe the ways in which the current benefit system discourages or prevents people in receipt of benefits from getting involved. The barriers are well known and are not new. Many people have been voicing concerns about the issues for a number of years. However, the Joint Participation Steering Group felt that an information-sharing event about the barriers was timely. The Joint Participation Steering Group had two main objectives for the seminar:

1. To provide **concrete examples** of how the current benefits system is hindering the involvement agenda, both from the perspective of people who use services, and from the perspective of organisations trying to develop meaningful involvement strategies.
2. To identify **possible solutions** to the benefit barriers to involvement.

This report highlights what those benefit barriers are and presents the proposed solutions to the benefit barriers to involvement that were agreed by delegates at the seminar.

The policy background to involvement

The involvement of people who use services in the design, delivery and monitoring of social care and health policies is a key government policy, and has been adopted with enthusiasm by many statutory and independent organisations.

The statutory duty to involve and consult commenced in January 2003 and the Department of Health issued *Strengthening accountability – involving patients and the public policy guidance – Section 11 of the Health and Social Care Act 2001*. In addition, best practice guidance was launched in October 2004 entitled *Getting over the wall: how the NHS is improving the patient's experience*.

The Department of Health *Requirements for social work training*, issued in 2002, underpins the new social work degree. This publication specifies that people who use services and carers must be involved in all parts of the design and delivery of social work education and training.

The Disability Equality Duty came into force in December 2006. This new legal duty requires all public authorities to actively look at ways of ensuring that disabled people are treated equally.

There is a general duty which applies to all public authorities, and specific duties on organisations such as local authorities, government departments, health trusts and non-departmental public bodies requiring them to produce a disability equality scheme, which centrally includes the involvement of disabled people. As the duty includes encouraging the participation of disabled people in public life, the current benefit barriers to involvement could hinder public authorities from meeting their disability equality duty.

A number of organisations who wish to involve people who use services, as well as people who use services themselves, have identified how difficult it is to involve individuals who are also in receipt of benefits in participation activities. The current benefit rules are having an impact upon the type of involvement activities people can

participate in. The rules are also excluding certain groups of people from involvement. The result is that many organisations are failing to benefit from the insight of people with a wide range of experiences, or are precluded from involving people in meaningful ways.

This report aims to address these issues and propose ways forward. It is organised into three main parts:

Part 1 briefly outlines the benefit barriers to involvement and presents examples from the seminar regarding how the benefit barriers impact upon involvement.

Part 2 outlines the responses from government officials who attended the seminar, and presents the proposed solutions that were agreed by delegates on the day.

Part 3 outlines the chairs' summary of delegates' views.

Annex A provides a clear and detailed explanation of the four main barriers to involvement.

Annex B is a list of useful resources for people interested in following up any of the issues raised in this report.

Part 1: Examples from the seminar of the benefit barriers to involvement

The ways in which the benefits system can discourage and prevent involvement are well known. However, to influence change, it is important that policy-makers are provided with convincing evidence of how these difficulties are manifested when people are invited to become involved. At the seminar we heard numerous examples of how the benefits system was creating significant problems for individuals who wish to get involved, and for organisations that are committed to putting people who use services and carers at the heart of their work. We also heard clear examples about how the current benefit system actually prevents people from becoming involved. This is a worrying situation for many in the fields of social care and health who are endeavouring to involve a diverse group of people, with a wide range of experiences, in their work. It also has implications for public bodies that have duties to involve people under the Disability Equality Duty and other legislation.

Each benefit barrier is briefly explained in section 1.1.3 to contextualise the examples that are given. A more detailed description of each barrier can be found in Annex A.

1.1 The perspectives of people who use services and carers

1.1.1 The reasons why involvement is so important in the development of social care and health services

Key Points

Involvement gives people with first-hand experience of services an opportunity to offer their knowledge about services

This can help to improve the design and delivery of services

Involvement is linked to active citizenship

For some people, involvement can be an effective pathway into work, although this is **not** the principal purpose of involvement.

Delegates at the seminar spoke passionately about why they felt involvement is so important. A key theme centred upon the desire to be **active citizens** through supporting the development of better services.

One person, who presented at the seminar about her reluctance to get involved, said:

'I struggled for a long time to keep myself in employment, and finally wasn't able to. But I still look for ways of contributing to society as and when I can.'

Shaping Our Lives spoke about a research project that they had undertaken.¹ This research found that a number of people who use services want to improve services, and view involvement activity as a key means of achieving change. However people were not clear about what the benefit rules allowed them to do or not to do, and were afraid of getting in touch with Jobcentre Plus to ask in case this affected their benefits.



Involvement was highlighted by some attendees as providing a possible **pathway into work**. For example, one delegate explained that she came off incapacity benefits following user involvement activities.

One individual was invited to join a Standing Reference Group. Upon receiving this invitation, she recalled that:

'It was really so good to think that someone felt I had something to offer and that I could actually do something. This could have been a first step for me back into employment, as well as doing something for my self-esteem.'

However, whilst a move into employment was seen as a positive by-product of involvement for some people who use services, there was a strong feeling amongst delegates that involvement must not be assumed to represent capacity for work. There are many people who may never be in a position to work or who may be beyond working age. It was therefore agreed at the seminar that involvement should be viewed as separate to work within the benefit rules.

1 See the findings and recommendations of this research in *Contributing on equal terms: service user involvement and the benefit system*, by Michael Turner and Peter Beresford, published by SCIE, 2005.

1.1.2 The reasons why is it important that people are given the option of being paid for involvement

Key Points

Payment is a clear recognition of the value of people's contribution

Payment demonstrates a desire for a more level playing field between those who commission, provide, or monitor services, and those people who use services.

Delegates felt very strongly that people should be paid for involvement activity. Although it was acknowledged that some people who use services might prefer to be involved on a voluntary basis, the offer of payment was viewed as **recognition of people's contribution as experts by experience**.

It was also argued that payment helped to create a more **level playing field** between people who use services and the organisations that provide, commission, or monitor those services. Shaping Our Lives quoted someone who uses services who had been involved in their research project:

'People who attend meetings should be rewarded on an equal basis. I was at a meeting with three consultant psychiatrists who earn £100,000 a year... People should also be remunerated accordingly.'

The Principal Advisor in Participation at the Social Care Institute for Excellence (SCIE) endorsed this point:

'Why should a person who uses services be the only person around the table who is not receiving some sort of remuneration for their contribution?'

1.1.3 Examples of the benefit barriers to involvement

Key Points

The inflexibility of the current benefits system deters and in many instances prevents people who use services from getting involved. Clear examples were given on the day to support this statement. SCIE commented:

'We do have a problem... the benefits system is very restrictive... The current benefit regulations make it much harder to involve people. They create unnecessary red tape.'

There is a high level of fear among people who use services about how involvement might impact upon their benefits. This is because people are anxious about:

- Losing their benefits if they are paid over the earnings disregard
- Having their incapacity benefits reviewed after involvement activity, and the financial and emotional stress that may arise from such a process. This is linked to the assumption that involvement demonstrates capacity for work
- Being penalised for the reimbursement of expenses, particularly travel expenses and the costs of employing a personal assistant to support them during involvement
- Being penalised under the notional earnings rule.

Further barriers to involvement were raised at the seminar. These were:

- Jobcentre Plus staff often lack the necessary knowledge about the current benefit rules, and fail to appreciate that involvement does not necessarily represent a capacity for work
- People are deterred from getting involved because previous experiences have demonstrated how complex and bureaucratic the system can be. People who use services are anxious that such complexity sometimes leads to mistakes that can have devastating consequences. Many are simply too afraid to take the risk.

Barrier 1: Most people on benefits are limited to earnings of £5, £10, or £20 a week

Benefit Barrier 1 (in brief)

Many people who are invited to get involved have chronic ill health or are disabled and so claim benefits.

Benefit rules limit the amount people can be paid per week before benefits are affected.

Even after the welfare reforms are introduced in 2008, the great majority of people on incapacity benefits will be limited to £20 a week. This means that most people on benefits can only offer two to three hours a week for involvement. If the involvement is for longer in that week, they have to refuse.

Shaping Our Lives gave a number of examples of the benefit barriers facing people who use services that emerged during their research project (ibid). One person explained that they were offered a position as a non-executive director on the board of a primary care trust, which is a remunerated position of over £5,000 per year. However, because the person is in receipt of incapacity benefit they cannot take up the position. If this person took up the position on a voluntary basis, they would be hit by the notional earnings rule if Jobcentre Plus found out (see Barrier 4).

We also heard about organisations who struggled to pay people equally for involvement, because of the benefit rules on earning disregards. This left a number of people who use services being paid significantly less than the organisation originally offered them as a fair remuneration for their contribution.

For example, one organisation has historical rates of pay which were put in place to demonstrate how the organisation values the contribution of people who use services and carers. This includes rates for active participation in conferences and higher rates for project work. However, because of the benefit barriers to involvement, the organisation can only pay people what they are permitted to earn. This has resulted in some individuals being paid £100 and others only being paid £20 for the same involvement. The organisation is currently discussing this situation internally.

Barrier 2: People fear being wrongly disallowed incapacity benefits

Benefit Barrier 2 (in brief)

In the past people have had their incapacity benefits stopped because Jobcentre Plus officials made mistakes. The officials thought that involvement was the same as work. Some Jobcentre Plus staff believe getting involved proves that people are no longer ill or disabled.

Jobcentre Plus officials do not always appreciate that people are asked to be involved because they are using social care and health services.

People have been left with little or no money to live on because they agreed to get involved.

Many people now say that they are afraid of losing their benefits if they get involved. Many say that they simply cannot take the risk.

Fear of losing benefits was a key theme of the day. A number of people emphasised how anxious they are about getting involved, in case it triggers a review of their benefit status. Some people decide to take this risk, in the hope that such a judgement will not be made:

'I do worry about my involvement with the mental health services meetings in case someone decides I am too well to be on incapacity benefit and disability living allowance.'

Another person spoke about the 'joint problem' experienced by those living in residential care. People who use residential care services are in jeopardy not only of losing their incapacity benefit, but may also be charged by their local authority for residential care charges:

'I take a big risk by being involved in the various things that I am involved in. I came here today because this is a one-off payment. But every time I am involved in something whether I am paid or not, there is this joint problem. The benefits people might want to reduce my benefits, but also if the local social services where I live find out that I am earning money then they could reduce the payment they make to the home, and then I might be liable for it.'

There were real concerns expressed at the seminar about how a lack of knowledge by local authorities, Jobcentre Plus offices, and amongst disabled people themselves, exacerbated the likelihood of mistakes arising in the system, and fuelled the fear people felt about getting involved, particularly if they are in residential care. One person who spoke about the barriers facing people using residential care said:

'The difficulty is that very little is known... it is not advertised, and so it isn't clear what the situation is for each individual disabled person. So you are uncertain about how you might be penalised, and that uncertainty adds an element of fear for people in residential care.'

For other people, the stakes are too high. After one very distressing experience during which she had her benefits temporarily stopped during a benefit review, one person told the audience that she was very fearful of this happening again:

'I can't take that risk at the moment, because I don't have anything to fall back on, financially speaking.'

Someone else told Shaping Our Lives:

'They are threatening 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.'

Barrier 3: Reimbursed expenses are treated as earnings

Benefit Barrier 3 (in brief)

Public authorities believe that people who help them through involvement should not be out of pocket as a result.

But when people are reimbursed expenses for the following:

- travel to involvement, or
- a replacement carer so that a carer can be involved, or
- a personal assistant or support worker to support people who use services to reach the place of involvement and to participate,

the benefit rules can treat the money as if it were their earnings.

When the amount that is reimbursed is more than the £5, £10 or £20 a week of earnings allowed, Jobcentre Plus must reduce the person's benefits the next week.

People have a difficult choice: they may be left without enough money to live on because they helped a public authority; or they may say that they cannot be involved because they cannot afford to have money taken away from their benefits.

Some delegates at the seminar highlighted that this was a significant barrier to involvement, because it meant that they could be financially worse off for getting involved. Others were unaware of this issue and were surprised to learn that being reimbursed for the cost of a replacement carer or personal assistant could put their benefits at risk. Because so many people require this type of support to enable them to participate, there was an overwhelming response amongst delegates that incurring these expenses should be seen as 'necessary' in the course of involvement, and therefore not be treated as earnings.

One carer had experienced difficulties in relation to this issue. The reimbursed costs of a replacement carer while he attended a meeting (for which he was paid £20 to attend) took him over the £20 earnings disregard. All of the reimbursed costs were deducted from his benefits, leaving him without enough to live on.

Barrier 4: Notional earnings

Benefit Barrier 4 (in brief)

Even when people are not paid for involvement, Jobcentre Plus must deduct money from their benefits that they have not received, if others round the table are paid. This is called 'notional earnings'. It assumes that people are denying themselves an income.

When benefit rules about earnings and travel expenses prevent payment for involvement and people offer to help for nothing, as a volunteer, the amount they did not get, but might have got, can be deducted from their benefits.

People on benefits are prevented from becoming involved altogether, as a result of this benefits rule.

People's concerns about notional earnings were a hot topic on the day, and generated much anxiety and confusion amongst delegates.

For example, one person explained how she had to refuse to be involved because she was offered a payment. Her benefit conditions meant that she could not accept a payment so she offered to be involved on a voluntary basis. She received advice from a welfare rights advisor who explained that if she undertook voluntary involvement, Jobcentre Plus could attribute 'notional earnings'. This would mean that the amount of pay that she did not receive would still be deducted from her benefits. Her account is detailed in the case study on page 16.

The notional earnings rule is confirmed in a recent Jobcentre Plus bulletin on involvement, which emphasises that:

'Those who are entitled to payments other than expenses but choose to receive expenses only, or no payment at all, should not be treated as volunteers. The payments that they are entitled to receive should be taken into account as notional earnings.'

[Guidance on 'involvement' or 'public participation', series no. 08-07, published on 19/04/07]

Further barriers identified by people who use services and carers

One individual conveyed that additional barriers to involvement were faced by people in **residential care**. He explained that people who use residential care services do not have recourse to direct payments and so they cannot employ their own personal assistants. Therefore, when attending an involvement event, people living in residential care are reliant upon the sponsoring organisation to pay for a personal assistant to support the individual to participate. Without such support, many people would be excluded from involvement. This is an additional barrier for people, on top of concerns about incapacity benefit and local authority charging.

He said:

'It is very important for organisations to involve people in residential care. Traditionally residential care service users are a very disempowered group... I think that the Office for Disability Issues and the Department for Work and Pensions should work to resolve the benefit barriers that affect disabled people, but also the benefit barriers that specifically affect disabled people in residential care.'

There was a strong feeling at the seminar that some **Jobcentre Plus officials** are lacking clear information in relation to the current benefit rules concerning involvement. Delegates also reported that some staff are insensitive to the issues people face when they are trying to get involved.

Compounding this are people's concerns about the **complexity of the process**, and the bureaucracy that it entails. This is proving to be a deterrent to involvement for some people. One person told Shaping Our Lives:

'I am supposed to fill in a form every time I have to work. It is easier not to get involved in the work for service users, or to do it voluntarily without declaring it.'

Shaping Our Lives commented:

'So we end up with people who are paid being very worried that they will lose their benefits. And even when people are not paid, they are also worried that they will lose their benefits.'

The proposed introduction of **Voice Risk Analysis**² within the benefits system (currently being piloted at the Harrow Housing Benefit Office) was also

2 Voice Risk Analysis (VRA) technology works by measuring slight inaudible fluctuations in the human voice that indicate when a speaker might be delivering words under stress. Proponents of the technology claim that VRA also has the capacity to recognise when moments of stress have been generated by an attempt to deceive. However, others have suggested that stress in the voice may also occur as result of nervousness and have challenged the use of this technology to identify the reasons behind changes in voice patterns.

discussed at the seminar. The overwhelming response to this technology was that it would create further stress and anxiety for people who use services, and generate a new barrier to involvement.

Case study:

How the benefit system deters people from involvement

One person spoke to the group about her experience. She was invited to join a Standing Reference Group. The organisation put her in touch with a benefits advice helpline, to find out how this type of ongoing involvement would affect her benefits. She was shocked to find out that because she was on means-tested benefits, she could earn a maximum of £20 a week for involvement activity. She was also advised that she would need to get permission from Jobcentre Plus prior to participating in the Standing Reference Group.

She assumed that she could, instead, offer to contribute on a voluntary basis or ask for the money to be donated to a charity. However, she was advised that Jobcentre Plus might perceive this as deliberately denying herself an income. The same view might be taken if she refused out-of-pocket expenses – ie she might get caught out by the notional earnings rule.

Finally, she was advised that by taking part in involvement activity, the benefits agency might consider that she was fit for work. This could trigger a review into her benefit status, thus threatening her incapacity benefit, something that she was very anxious about.

Having weighed up all of the information provided, this individual made the decision not to join the Standing Reference Group. Thus she missed the opportunity to contribute to issues she felt very strongly about, and the organisation failed to benefit from her insight and experiential knowledge. She said:

'I get very sad and angry that I am constantly hearing the government say that they are trying to get people with disabilities back into work, yet if I try and do something that may in some small way contribute to society and improve things for others, then suddenly I find myself looking at that brick wall again.'

1.2 The perspectives of organisations

Key Points

A number of social care and health organisations are endeavouring to put people who use services at the heart of their work through involvement. The Disability Equality Duty requires public bodies to involve disabled people, and previous legislation has also made the involvement of people who use services a statutory requirement.

The experience and expertise of people who use services are considered integral to the development of improved services. The view amongst organisations is that people should be fairly remunerated for their contribution.

Organisations are struggling to involve a diverse group of people in their work because of the current benefit rules.

The rules are also impacting upon the type of involvement activity that people can undertake and the depth of that involvement.

A number of social care and health bodies in the statutory and independent sectors are very committed to involving people who use services in their work. At the seminar the Principal Advisor in Participation at SCIE and the Chief Executive of the General Social Care Council (GSCC) spoke about how important involvement is and the variety of ways in which people who use services and carers are invited to participate. Involvement is seen as integral to the work of both organisations because:

- People have a right to be involved at an early stage in the key decisions about individual services that affect their daily lives.
- People also have a right to contribute to the strategic planning of services on a wider scale.
- The contribution of people who use services and carers arising from their knowledge and direct experience of service systems is highly valued.
- Involvement activity helps to build trust between organisations and people who use services, and gives organisations their 'licence to operate'.
- The contribution people make in shaping and reviewing organisational policies and practices is crucial in legitimising the work of social care and health organisations.

- Public bodies have requirements placed upon them under the Disability Equality Duty and other legislation, and involvement plays a key role in helping organisations to meet such duties.

Involvement is a key objective in the vision of both organisations. In the light of current rules, SCIE and GSCC have put in place policies and processes that go some way towards addressing the benefit barriers to involvement. For example, both organisations have contributed to the development of an independent benefits advice helpline that people can contact once they have been invited to get involved. However, despite such efforts, we heard that the current benefit system continues to create significant challenges for how this organisational objective of involvement can be achieved. The Chief Executive of GSCC commented:

'We know that reviewing the policies and processes and putting safeguards in place does not remove all the difficulties for those who wish to become involved with us, or for organisations that wish to involve people who use services.'

SCIE described organisations' attempts to work within the current benefit system as being like a Rubik's cube, ie whenever you find a solution to one barrier, another barrier emerges straight away. The result, SCIE said, is 'a fudge'. SCIE added:



'It is an extremely complicated process. All of this takes up time we should be spending developing what is best practice in social care, not organising ourselves around regulations that are setting up barriers for involvement. There is an enormous amount of red tape... this creates a lack of trust amongst service users who want to be involved in the work we do.'

For example, the £20 per week limit on earnings for people on means-tested benefits has significant implications for the length of time people can be involved. Taking into account minimum wage regulations, the maximum time many people can be involved in any one

week is only two to three hours. GSCC said:

'The earnings limit creates real problems. It is a real issue for us that the sort of involvement that we want people to have is limited to about two and a half to three hours per week. This excludes a huge number of people from involvement. We want to make sure that there is a diverse group of people involved in our work, and we know that the current benefit rules make this difficult.'

The notional earnings rule means that it is difficult for the organisations to advertise a fee for involvement, or say that they will pay people any expenses. This is because even if people choose not to accept any payment, they could be penalised for the amount they might have received.

In summary, the Chief Executive of GSCC emphasised why changing the current benefit system rules was so important to fulfilling the involvement agenda:

'People who use services are the life blood of the organisation that I work in as well as the other major social care bodies. I am sure that I speak on behalf of all the organisations that are involved in sponsoring and organising this event that we are very proud to be involved in this agenda. It is about giving people increased control. It is about taking down the barriers to citizenship and it is about making sure that those who receive services can have their voices heard. They must not be prevented from doing so by systems that have not taken their needs into account.'



Part 2: Proposed solutions to the benefit barriers

This part of the report details the possible solutions to the benefit barriers to involvement that were identified by delegates. It also outlines the responses given by government officials from the Department for Work and Pensions (DWP) and the Department of Health (DH).

2.1 Responses from government officials

2.1.1 Suggestions from the Department for Work and Pensions

The Deputy Director of the Benefit Reform Division DWP confirmed that officials are looking at the issue of brief interruptions in benefit entitlement, and how the mechanism for getting people on and off benefits can be simplified. This is being considered from two angles:

a. Operational practice

The DWP currently operates a 'rapid reclaim procedure' for people returning to benefits after a short period. It is acknowledged that this system may not always operate as rapidly as intended. In the light of this, DWP officials are considering whether they could adopt a 'lighter touch' for very brief interruptions to benefit entitlements.

b. Policy and legislative change

DWP is considering whether there is scope for preserving some form of notional entitlement during brief interruptions in actual entitlement.

A key recommendation from delegates at the seminar was that it should be easier for people to come on and off benefits. Therefore DWP's proposed work in this area is welcome because it may be useful for some forms of involvement. This report also stresses that any proposal of this nature must be extended to housing benefit.

The proposal does not, however, address the more common barriers to involvement that were discussed at the seminar. As a member of Equality 2025 commented:

'Engagement and consultation are key – everybody is talking about it. So if they really want to consult with us, government must – and I believe they are starting to – really look at these issues and address these problems. But it requires a much wider and deeper look at the current system, rather than just coming on and off benefit. Government must look at the whole system and make it easier for people to get paid and keep their benefits.'

2.1.2 Response from the Office for Disability Issues

A policy officer from the Office for Disability Issues (ODI), in the Department for Work and Pensions, responded to some of the issues that had been raised throughout the seminar. She explained that ODI was set up to take forward the recommendations from the Prime Minister's Strategy Unit report *Improving the life chances of disabled people*, and emphasised that a number of disabled people work within the office. She is also involved in supporting Equality 2025, which was established to carry out the promise to disabled people that they will have a direct voice into government to help design policies and services that they really want.

One issue that Equality 2025 has been looking at is the barriers to involvement that are created by the current benefits system. Equality 2025 has recognised that within public bodies, individuals are often paid very different amounts for their involvement due to which benefits they are or are not in receipt of. Some individuals only receive reimbursement for expenses.

She emphasised that parts of the Department for Work and Pensions are taking this issue very seriously, including ODI. The point was also made that other government departments are becoming increasingly aware of this issue, partly because of the growing use of the third sector and partly because of statutory requirements placed upon them to involve disabled people.



She acknowledged the strength of feeling on the issue of benefit barriers to involvement which was expressed at the seminar, and said she was pleased that other colleagues from government had also been present to hear people's views and experiences. She also stressed that these issues are not new, but argued that it was important to hear them articulated so strongly. She reassured delegates that she would report back on the examples provided at the seminar, and continue to work on these issues both within DWP and alongside a number of other organisations. Finally, she made a commitment to convey what she had heard at the seminar to the Minister for Disabled People.

2.1.3 Response from the Department of Health

A representative from the social care directorate in the Department of Health said that she had found the day very interesting, particularly in the light of her colleagues' work on developing the *Improving the life chances of disabled people* report. She explained that the Department of Health was taking forward a number of recommendations from that report, in order to increase the impact of the voices of people who use services within the department. For example, she reported that the department is working closely with user-led organisations on issues such as Direct Payments and Individual Budgets, and hopes to shift the current balance of power that exists between government organisations and people who use services.

2.2 Key principles needed to address the benefit barriers to involvement

Delegates recommended that any reform to the benefits system must be based on the following principles:

- The benefits system in respect of involvement must be simplified.
- The benefits system in respect of involvement must be more flexible.
- The benefits system in respect of involvement must be adapted to ensure that the poorest people are not discriminated against. Earning disregards are only attached to means-tested benefits and the very low earning limits per week exclude many people on these benefits from participating.
- Any reform of the benefits system for involvement needs to take a long-term view. Short-term measures are not adequate if the government's involvement agenda is to be achieved.
- Involvement must not be assumed to mean that people have recovered from ill health or an impairment and are therefore in a position to enter

into employment. The system should take account of people's fluctuating conditions.

- The benefits system in respect of involvement should take account of the practical support (for example, personal assistants, replacement carers, travel expenses) that some people need to get involved and should not penalise individuals who require such support.
- Volunteers should never be penalised or feel at risk from getting involved.
- Involvement gives people an opportunity to contribute to society and improve the way that social care and health services are designed, delivered, and monitored. Therefore people in receipt of benefits should be able to participate equally in public life alongside other citizens without risking their income.

2.3 Recommendations made to address the benefit barriers to involvement

Delegates at the seminar also proposed a number of specific recommendations to address the benefit barriers to involvement:

- Payment for involvement should be treated in the same way for all types of benefits, whether means tested or not. This would help to simplify the system and mitigate some of the current confusion and discrimination.
- Payment for involvement should not be treated on a weekly basis. Instead, payment for involvement should be averaged over a monthly or yearly basis by Jobcentre Plus. This would facilitate a greater depth of involvement.
- The earnings disregard for means-tested benefits should be increased to allow up to eight hours' work per week at the minimum wage level and for involvement the equivalent of a calendar month. The current earnings disregard levels range from £5 per week to £20 per week depending upon the benefits received.*

* This would allow people on benefits to access a foothold in employment opportunities with mainstream employers that offer a minimum shift of seven to eight hours per week. It would also allow for involvement to be paid monthly at a rate that is paid for public appointments.

- An alternative option proposed was the development of a flexible, graduated approach which would offset earnings in relation to benefits. This would replace the current fixed earnings disregard levels.
- At the very least, the precedent that has been set within the benefits system for local authority councillors should be applied to those who undertake involvement activity. The rules for councillors are as follows:
 - Councillors on non-means-tested benefits can earn over £86 a week and keep entitlement to incapacity benefit, but have it reduced for earnings over that amount
 - All councillors have travel expenses from home to work treated as ‘necessary’ expenses that are therefore ignored
 - Work as a lay councillor is treated as ‘exempt’ work. This means that it does not bring into question the person’s incapacity.
- The following reimbursed expenses for involvement should be seen as necessary expenses (that are therefore ignored for the purposes of assessing benefit entitlement):
 - Costs of a replacement carer
 - Costs of personal assistants, support workers, facilitators or communicators to enable involvement
 - Travel costs between home and the place of involvement, including petrol or standard mileage for involvement
 - Delegates recommended that the rule on notional earnings is not applied for people who undertake involvement activity for free
 - Brief interruption of benefit payments should be made easier for people undertaking involvement activity that is paid at high rates (for example, governmental committees and NHS trust board membership).

One recommendation for achieving this is to develop an arrangement whereby a person notifies receipt of a payment for involvement at the time it is received and their future benefit payment is reduced by any amount over the earning limit (as is already done with local authority councillors on non-means-tested benefits). However, this would be dependent upon the earning disregards for means-tested benefits being brought into line with non-means-tested benefits to encourage people to engage with the arrangement.

- Staff in benefits offices must have a full knowledge of people’s entitlements and be sensitive to the issues surrounding involvement activity. The ‘attitudinal barriers’ that people have experienced in their contact with some staff on the issue of involvement should be addressed through appropriate training.

- Where good practice amongst local Jobcentre Plus offices exists on involvement issues, it should be identified and shared across the country. More partnership working is needed at the local level between Jobcentre Plus offices and other relevant stakeholders.
- An economic cost/benefit assessment needs to be made on the implications of such changes to the benefits system in relation to involvement.
- There needs to be greater recognition of how these issues affect the third sector, which relies heavily upon volunteers.
- Government departments must come to a common understanding of what involvement is across all departments.
- There should be a common approach to the interpretation of the rules amongst individual benefits offices, helping to reduce the ongoing stress and confusion for people in receipt of benefits.

Part 3: The chairs' summary of delegates' views

The chairs summed up the principal themes of the day. These were:

- 1 There are very significant problems in terms of how the benefits system works in relation to involvement activity.
- 2 There was widespread consensus that these problems were real and causing considerable difficulties for people who use services and carers who wish to get involved, as well as for organisations that wish to involve a diverse group of people in their work.
- 3 The Department for Work and Pensions is under some pressure to address some of the barriers to involvement that have been identified. However, it is also apparent that they are approaching the reform of the benefits system from another angle – one which must demonstrate responsibility and accountability to the taxpayer. The chairs hoped that these two perspectives can be reconciled to ensure that people who use services and carers are not deterred, or, indeed, prevented from involvement activities.
- 4 Fear of what might happen to people's benefits if they get involved is clearly deterring a large number of people from getting involved. For many people (particularly those in receipt of more than one type of benefit), the unknown risk of breaking the benefit rules and suffering the consequences is simply too high. Fear is excluding people from exercising their rights as citizens.
- 5 Although involvement can be a useful pathway into work, there are many people who may never be in a position to work, or who may be beyond working age. Therefore the consensus at the seminar was that involvement should be viewed as separate to work within the benefit rules, and should not be assumed to represent capacity for work.
- 6 The chairs called for the rules concerning involvement to be simplified. This is necessary to encourage more individuals to take up involvement and to support more organisations to fulfil their vision – and where applicable, their duties – to keep people who use services at the heart of all their work.

Annex A

The four main benefit barriers to involvement

This annex explores the barriers to involvement arising from the current benefits system.

Barrier 1: Most people on benefits are limited to earnings of £5, £10, or £20 a week

Many people who are invited to be involved in the design and delivery of social care and health services have long-term ill health or are disabled, and so claim benefits.

Benefit rules limit the amount people can be paid a week before benefits are affected. People who only receive non-means-tested benefit such as incapacity benefit can receive up to £86 per week if they follow permitted work rules. Carers' Allowance allows payments of up to £87 a week.

However, this only applies to a small minority group. People who are in receipt of means-tested benefits (income support, housing benefit, council tax benefit or those who are funded by the local authority for the costs of their residential care) can only receive a very small payment before their benefits are reduced. This is usually £20 a week. For those with a partner it is £10 each.

This low earnings disregard significantly restricts the amount of time that can be offered for involvement. It also effectively discriminates in favour of the better off, thereby narrowing the groups of people who can realistically be invited to participate.

Barrier 2: People fear being wrongly disallowed incapacity benefits

In the past, people have had their incapacity benefits stopped because Jobcentre Plus officials made mistakes. The officials sometimes assume that involvement activity represents capacity for work. Jobcentre Plus officials are not always clear that people are asked to be involved because they are using health and social care services.

People have been left with little money to live on as a result of these types of mistakes, and this has generated a sense of anxiety amongst many people who use services who are also in receipt of benefits. It is deterring people from offering their insight

and experience through involvement work, because they cannot afford for mistakes, or incorrect assumptions, to be made. People are worried that involvement work might lead to their benefits being stopped.

Barrier 3: Reimbursed expenses are treated as earnings

Public authorities believe that people who help them through involvement should not be out of pocket as a result. A number of people who use social care and health services would be unable to participate in involvement work unless they were offered reimbursement for certain expenses.

However, the benefit rules in the current system can treat the money as earnings. This is when people are reimbursed for:

- travel to involvement
- a replacement carer so that a carer can be involved
- a personal assistant or support worker who supports a person using services to participate in involvement.

When the amount reimbursed is more than £5, £10, or £20 a week of earnings allowed, Jobcentre Plus must reduce the person's benefits the following week.

This means that people can end up financially worse off for getting involved.

Barrier 4: Notional earnings

Even when people are not paid for involvement, Jobcentre Plus can deduct money that they have not received from their benefits, as if they were denying themselves an income.

When benefit rules about earnings and travel expenses prevent payment for involvement and people offer to help for free, as a volunteer, the amount they did not receive, but might have, can be deducted from their benefits. This is because there are no clear rules about how Jobcentre Plus should treat such expenses.

Therefore people are prevented from getting involved because they can be left financially worse off through the notional earnings rule.

Annex B

List of useful resources

- Guidance on 'involvement' or 'public participation' (Series no. 08-07) (Jobcentre Plus 2007)
- Reward and recognition: the principles and practice of service user payment and reimbursement in health and social care (Department of Health, 2006)
- Turner, M. and Beresford, P. Contributing on equal terms: service user involvement and the benefit system (SCIE, 2005)
- The payments and reimbursement policy for valuing involvement: benefit conditions and systems relating to paid and voluntary service user and carer involvement activity (CSIP/NIMHE, 2007) can be found at www.nimhe.csip.org.uk
- **Milton Keynes Citizens' Advice Bureau Involvement Helpline**

Milton Keynes Citizens' Advice Bureau offers a specialist benefit and tax credit advice service called the Involvement Helpline. It provides confidential, personalised and professional advice to service users who are considering paid or voluntary involvement with social care and health elsewhere.

This service is available only to organisations on a subscription basis.

If your organisation involves people who use social care and health services and would like to subscribe to this service please contact:

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