

INVOLVE

Universal Credit – Welfare that works. Department of Work and Pensions Select Committee inquiry

INVOLVE submission

Summary of main points

1. DWP introduced legislation in 2009¹ removing two significant benefit barriers to involvement in improving health and social care services for service users and carers who are in receipt of benefits:
 - Service users and carers who are paid for involvement may now be reimbursed out-of-pocket expenses without affecting their benefits. Reimbursements of expenses incurred because of involvement such as travel costs, necessary subsistence, child care, replacement carer, personal assistant etc and other expenses are now disregarded when benefit entitlement calculations are made.
 - Service users who are involved may now decline an offer of a payment, or ask to be paid a lower amount as required by their benefit rules or ask for the payment to be made to a charity, without 'notional earnings' being applied. Their benefits are unaffected.
2. The legislation only applies where the involvement is required by law or as a result of a function provided for under an enactment. The benefit changes apply to involvement with local authorities, landlord authorities, NHS Trusts and Health Boards.
3. The National Institute for Health Research (NIHR) recommends as good practice, the involvement of the public (including service users and carers) in research. But involvement is not required by law. As a result, the benefit changes do not apply to public involvement in research. Involvement in research is impeded by these continued benefit barriers.
4. INVOLVE request that these benefit changes are applied to the **Universal Credit** benefit rules for involvement in health and social care research.

Brief introduction to INVOLVE

5. INVOLVE is a national advisory group which supports greater public involvement in NHS, public health and social care research. INVOLVE is

¹ <http://www.legislation.gov.uk/uksi/2009/2655/introduction/made>,
<http://www.legislation.gov.uk/uksi/2009/2678/regulation/2/made>

funded by the National Institute for Health Research (NIHR). At INVOLVE we use the term 'public' to include: consumers, patients and potential patients, service users, carers and parents, long term users of health and social services, disabled people and organisations representing the public. By involvement we mean an active partnership between the public and researchers in the research process, rather than as participants in a research project. For example advising on a research project, assisting in the design of a project, or involvement in carrying out the research.

6. INVOLVE works with others towards creating the research community of the future which will be broader, more inclusive and more representative of the population as a whole.
7. Members of the public bring perspectives and skills that are not always the same as those of researchers and health and social care professionals. Their involvement helps to ensure that the entire research process is focused on what is important to people and is therefore more relevant and acceptable to the users of services.

Factual information

8. People with the greatest reliance on health and social care services are generally more likely to be in receipt of welfare benefits.
9. People who use health and social care services have experiences to share that are valuable to health and social care research.
10. Public involvement in the design and delivery of public services is now accepted as good practice. The NHS introduced standards for recruiting members of the public to become involved in the monitoring, design and delivery of health and social care services. The Department of Health issued guidance in 2006 'Reward and Recognition'² setting out good practice, recommending that service users and carers were not to be left out of pocket as a result of their involvement. The guidance recommends that certain types of involvement activities should be paid, and all necessary expenses should be reimbursed.
11. Some unforeseen tensions emerged between this policy initiative and certain benefit rules that were originally intended to cover regular part-time employment during a claim to benefits. These difficulties arise because involvement is very different to employment.
12. People are generally recruited for involvement because of their experience of using health and social care services. Involvement is intermittent and brief: some may attend a monthly meeting; others a seminar on a quarterly basis. The involvement is for a few hours at a time and there is no contract. National organisations recruit nationally and so travel costs may be very high. People with a caring responsibility may need to pay for the costs of a

² http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_4138523

replacement carer. Service users may require a personal assistant and these costs must be met.

13. Benefit rules govern what a recipient may do. The rules set limits on earnings and usually treat the reimbursement of certain expenses by an employer as earnings. Although involvement is very different to employment, the benefit rules are the same, except where the benefit changes made in October 2009 now apply.
14. Benefits that are paid to cover living and housing costs have associated rules that set absolute limits on earnings that may be received in a week. Earnings that are in excess of the limit will lead to the benefit being stopped.
15. Means tested benefits have associated rules that allow for £5 or £20 a week of earnings to be disregarded. Earnings in excess of the disregarded amount lead to a reduction of the benefit penny for penny.
16. Certain reimbursements of expenses to people who are paid, are usually treated as earnings including: all travel costs, part or all of the costs of a replacement carer or child care. The reimbursed costs of a Personal Assistant or Support Worker may be treated as earnings at the discretion of a Jobcentre Plus decision maker. These benefit rules continue to apply to involvement in health and social care research as the benefit changes in 2009 did not apply to organisations where involvement is not required by law.
17. 'Notional earnings', that is a notional amount, may be deemed if a person refuses an offer of payment for a service and asks to be paid a lesser amount or decides to volunteer for free. Jobcentre Plus is required to deem that the higher amount was paid and to adjust benefit entitlement accordingly. People lose benefit entitlement as a result of money they did not receive. This benefit rule continues to apply to involvement in health and social care research as the benefit changes in 2009 did not apply to organisations where involvement is not required by law.
18. The impact of these benefit rules that continue to be applied is to make the involvement in research of some groups of people very difficult. These are people with the greatest health needs and the greatest social care needs.
19. The introduction of **Universal Credit**, as proposed will not resolve these barriers to involvement in health and social care research.

Recommendations for consideration

20. INVOLVE recommend that the benefit changes made in October 2009 (see Point 1 bullet points, page 1) are applied to the Universal Credit and extended to involvement in health and social care research.
21. Health and social care organisations that involve service users and carers in research include:

- The National Institute for Health Research and Department of Health commissioning programmes,
- The National Institute for Health infrastructure organisations eg research networks, Research Design Services, Collaborations for Leadership and Applied Health Research and Care, University Research Institutes and groups, and other higher education institutions, individual research studies, social care bodies, charities and other not for profit organisations.

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