



Benefit barriers to involvement

Finding solutions

October 2007

Easy read version





This is a report from a meeting on Tuesday 22 May 2007. It was arranged by 5 organisations. They also worked together on this report.

We would like to thank them all for their time and support. They are:



- The Commission for Social Care Inspection



- The General Social Care Council



- Shaping Our Lives



- Skills for Care



- The Social Care Institute for Excellence



A few words from Dame Denise Platt, Chair of the Commission for Social Care Inspection



The Commission for Social Care Inspection is there to check on social care in England and to put the people who use social care first.



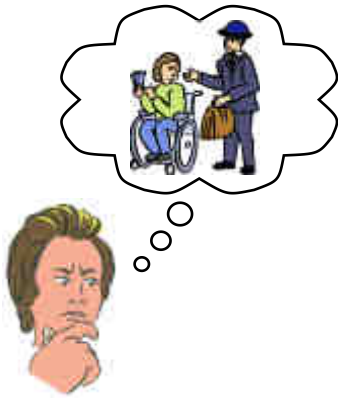
An important part of how we work is including people who use care services as experts by experience, advice givers and as members of different groups and meetings.



We want to value the time that people give, this means making sure that they are paid for their travel and other costs made as part of this work, and also paying them a fee for their involvement.



The benefits that people get can make paying for involvement difficult. Lots of the people we include are on benefits and there are rules that stop extra money being paid.



People tell us they want to be involved to help make services better. Money is nice but not so important. But they are scared to do this because it might affect their benefits.



It is important that the future of social care includes people who use services as part of its work.



I was very happy to be involved in this meeting, there were lots of people with different experiences all working together and sharing information to try and make things better.



Dame Denise Platt, Chair of the Commission for Social Care Inspection



A few words from Professor Peter Beresford, Chair of Shaping Our Lives



There are lots of issues from people who use services about benefits and getting involved.



Lots of different organisations from all areas and people who use services joined together to see what could be done in the future.



People want to be involved in making services better and the government is telling organisations that they have to include people in their work, but the benefit system stops this from happening.



Many people will not get involved because they are frightened of what will happen to their benefits if they do.



People are not being treated fairly or equally, we could stop this from happening by changing the rules about benefits.



I believe strongly in this and was pleased that both I and Shaping Our Lives could be involved in this event. Also included in this meeting were people who use services, other organisations and people from the Department for Work and Pensions and the Department of Health.



The information from this meeting shows that there are strong feelings about involvement and the benefit rules. The information will be passed onto the Minister.



We hope that many people will read the information and ideas in this report and work together to make things better.



Professor Peter Beresford, Chair of Shaping Our Lives

Main points



- Government policy says that people who use services need to be involved in developing and planning social care and health services.



This can be as experts by experience for information and advice. Or working closely with organisations planning and running services including checking on how they are working.



- When we say 'benefit barriers to involvement', we mean the way the benefit system can stop people from getting involved.



- This meeting wanted to share information and experiences about the benefits problem and to think of ways that it could be made better.



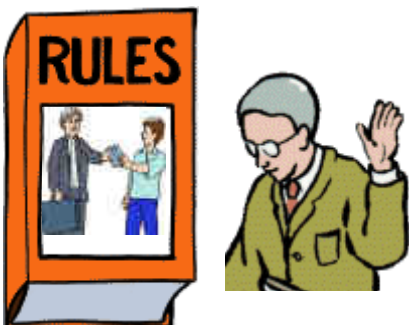
- It is important that people who use services are involved in planning better social care and health services for the future.



They can do this by sharing experience and advice, supporting people to be involved and helping councils and health agencies meet their legal duties.



- It is important that people are valued for their time and this is shown by a fee or payment.



- The rules about benefits are making it hard for people to be involved. Many agencies tell us that they cannot find enough people to involve because of the benefits issue.

We found 4 main things that stop people from being involved. They are:



- 1 Most people that get benefits can only get paid between £5 and £20 a week.



- 2 People are worried about their incapacity benefits being stopped if they get involved.



- 3 Expenses like travel and personal assistants can be treated as earnings.



- 4 If people get involved for free but could have been paid for their involvement, the money they could have got could be taken off their benefits.

- People said that there were other issues that stopped them from being involved. They were:



- There is a double problem for people in residential care. They are worried about how the involvement will affect their benefits but also because they might be charged for some of their residential care costs



- Not having clear information about benefits and involvement from some Jobcentre Plus staff



- Worries about the new lie detector system.



- People shared their experiences of how the benefits system is stopping them from being involved.



- People are choosing not to be involved because the rules about money and payments would leave them with less money



- Others will not get involved because it might cause a review of their benefits



- Some people had experiences of mistakes made by Jobcentre Plus staff, which has made their money less or stop altogether. This is very stressful and they are not willing to risk it happening again



- Some people who got involved but didn't know about the benefit rules, found that their money was less because of the involvement.



- People agreed on a number of important ideas that could make things better. They are:



- People who get benefits should not be stopped from getting involved because of the rules about their benefits



- The benefit system needs to be easier and more flexible



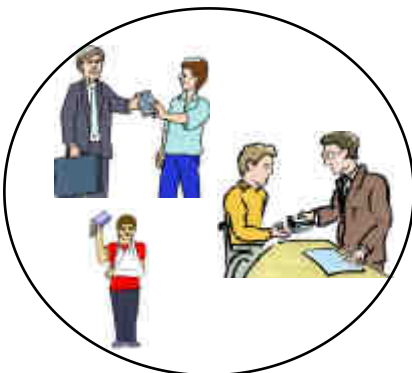
- The benefit system needs to change so that people with very little money are treated the same as other people



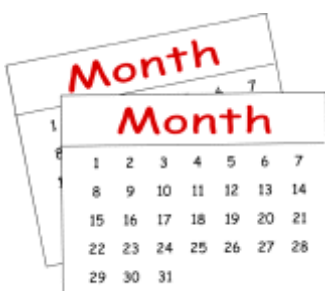
- People that get involved will sometimes move on to paid work, but that will not be the case for everyone.



- People thought of different ideas to make being involved and getting benefits easier. They are:



- Changing how the system works so that all payments are treated the same way for all kinds of benefits



- Fees for being involved should be looked at month by month or over the year instead of every week



- People who want to get involved should be allowed the same rules as councillors within the benefit system



- Expenses like travel costs and personal assistants or support worker costs should be treated as necessary expenses, and not as earnings



- The rules should be changed so that people who offer to be involved for free as a volunteer do not lose out and end up with less money



- There needs to be more training for Jobcentre Plus staff to make sure that they have clear information about the benefit rules and being involved.



They must make sure that they do not make mistakes which can put people into difficulty.



This work was supported by the Joint Participation Steering Group. It is a group of national organisations who work towards sharing good ways of working in involving people who use services and their carers in social care and health.

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