

Mencap response to Direct payments for health care: a consultation on proposals for regulations and guidance

Mencap is the UK's leading learning disability charity, working with people with a learning disability, their families and carers. We believe people with a learning disability should have choice, opportunity and respect with the support that they need.

Introduction

We welcome the piloting of direct payments for health care. As we have seen from the social care field, direct payments and individual budgets have the power to transform the lives of people with a learning disability as they enable people to choose the care and support which truly meets their personal needs.

However it is crucial that lessons are learnt from the social care field to ensure that everyone is able to benefit from personalised health care, including those with the most complex needs, for example people with profound and multiple learning disabilities (PMLD)¹, who often get left out.

To ensure that they can work for everybody, it is crucial that the pilot sites include looking at how direct payments for healthcare work for people with a learning disability including those with profound and multiple learning disabilities. This will enable any necessary changes to be made at an early stage to ensure they can work for everyone.

We understand that the piloting of direct payments for healthcare is part of the wider pilot programme to explore personal health budgets. However, we think it is very important for there to be a real focus on how direct payments for health care can work as part of an integrated individual budget. Integrated packages of support are likely to be the reality for many people with a learning disability, who will often require support from a number of different agencies throughout their lives.

Comments on Part 1: how the government proposes direct payments should work - the 'rules'

Examples of best practice

- We welcome that the proposals say 'the guidance would encourage commissioners and clinicians to consider innovative and flexible approaches to

¹ Appendix 1 provides more information on what it means to have profound and multiple learning disabilities

meeting health and well-being outcomes'. We welcome this as we have heard from a number of family carers of people with Continuing healthcare packages that their son or daughter has not been able to access innovative and personalised forms of support. Direct payments for healthcare should enable innovative approaches to be used so it should no longer be the case that some people are having to have more traditional services and miss out on more innovative approaches.

- The proposals say that the guidance 'will be offering some examples of best practice around innovative and flexible approaches to meeting health and well-being outcomes'. We welcome this and would urge there to be examples of people with complex packages, for example people with PMLD, getting innovative support via direct payments for healthcare. As good practice examples often focus on those with less complex needs and can mean that local areas don't have good examples of how those needs of people with the most complex needs can be met. This can lead to them missing out.

People who lack capacity to consent to receive direct payments

- We welcome that where someone lacks capacity to consent to receive direct payments, the government intends to allow a representative to receive a direct payment on their behalf, in line with arrangements for suitable persons in social care. Everyone should be able to access the benefits which direct payments can bring. It is important that those who lack capacity and are also 'unbefriended' have the opportunity to access direct payments too. There is a risk that this 'unbefriended' group could miss out on this initiative which has the power to transform people's lives. We know from the social care field that there where people are receiving direct payments and more innovative forms of support there is often a family carer fighting for them to get this. There will need to be initiatives to help ensure uptake of direct payments for healthcare amongst all people who lack capacity, including those who are 'unbefriended'.
- We welcome there will be additional safeguards for people who lack capacity in line with the social care guidance (and as required by the MCA 2005). It is crucial however that all safeguards introduced enable the person to have as much choice and control as possible.
- We welcome that the guidance would mirror the social care guidance and would explain the importance of representatives acting, as far as possible, in line with the individual's past and present wishes and feelings. We believe that plans/spending decisions for healthcare direct payments should be based on good person-centred planning. It is crucial that the person has been meaningfully involved in their person centred plan. If the person is going to get a personalised service which meets their needs it is key that decisions are based on the person's wishes and feelings.
- We welcome that the guidance would explain what is meant by acting in the 'best interests' of someone who lacks capacity. There needs to be clear signposting to the MCA code of practice and preferably a detailed appendix to the guidance on 'best interests' decision making.

Clarity about what direct payments for health care can be used for

- The Department of Health needs to be clear in terms of what direct payments for health care can be used for. Families supporting people who have multiple and complex associated health needs require:
 - additional direct support in terms of meeting the daily care needs of the person or having a break from caring
 - this additional human support needs to be competent, dependable and long term as the need to have the capacity to build relationships between the person being cared for, the family and any paid carers is a critical factor. All too often staff provided through services lack the necessary skills, are irregular and transient, with families having no say in staff recruitment
 - adequate equipment, aids and medical supplies together with the knowledge to purchase and utilise these effectively. Examples of where this is currently not working well at all are the supply of wheelchairs, sleep systems, feeding tubes and continence aids.

Budget for direct payments

- The guidance says that the 'regulations should require direct payments to meet in full the assessed needs for which they have been given as set out in the care plan'. It is crucial that people are able to have their needs truly met through the direct payment. Some people with the most complex needs, for example people with PMLD are going to require intensive specialist support, for example, respite with staff skilled in how to meet their communication and complex health needs. This is likely to be more expensive than respite for people with less complex needs. It needs to be very clear in the guidance that when PCTs are looking at costs and making a decision about a direct payment, they must ensure that they do not discriminate against someone who needs intensive and specialist support by regarding the package as 'too expensive'.
- We categorically believe there should be no upper limit or capping of the amount people can receive for direct payments for healthcare. Decisions should be based on the individual's needs.

Resource allocation

- Resource allocation at the level of the individual is new to the NHS and we welcome that they intend to develop the policy in light of experience gained through piloting. It is also crucial they learn from all the experience in the social care field.

It has been acknowledged by the government that the current resource allocation system designed and implemented by local authorities for giving social care has created a postcode lottery and an untransparent system. In Mencap's response to the Social Care green paper we called for a national assessment system and a national resource allocation system which would be set nationally and delivered locally. We strongly urge the government to look at how it can prevent a postcode lottery of allocations of direct payments for healthcare.

- It is crucial that the pilots explore how direct payments for healthcare will work for those with the most complex needs so that any policy developed will actually work for those with the most complex needs. Our experience from the social care field is that when someone has very complex needs they can get stuck at the resource allocation stage as the system doesn't allow for the level of support needed to truly meet complex needs. It is crucial that the NHS understands the true cost of support for people with profound and multiple learning disabilities.
- The proposals say that 'while there may be some overlaps with resource allocations in social care, setting a budget in health care will be more complex'. This maybe the case but it is crucial that this does not become an excuse for lack of transparency. The resource allocation system must be transparent.
- The proposals say that the 'regulations should provide for the amount of the direct payment to be subject to the discretion of the PCTs – we do not intend to use the regulations to set a minimum or maximum amount'. We think it is very important that the government does not set a minimum or maximum amount in the guidelines but we think it is important that PCTs don't set limits either. Decisions need to be based on need and what is required to meet needs.
- The proposals say that the guidance would 'encourage PCTs to publish their reasoning where they decide locally not to make any services, or parts of services available through a direct payment. For example this could be on grounds that the PCT considers that to do so would be too expensive.' We welcome this as transparency is very important.

Empowering families

- Families are often overwhelmed by caring responsibilities and can be reluctant to take on extra responsibility of direct payments (or individual budgets). The extra responsibility for 'health' may not seem like such a great opportunity initially and families need to have people they can build a long term and trusting relationship with to walk with them along this path. Health professionals have also often unintentionally built a dependency on services and disempowered and deskilled parents and siblings. There needs to be a focus on capacity building and development opportunities for families.

Information, advice and support

- We welcome that the guidance would reflect best practice in health and social care re: providing information, advice and support. However, Mencap is aware that many people with learning disabilities and their families are critical of the lack of information, advice and support in social care and we would urge the guidance to re-enforce the need for this and give clear advice about what is meant by best practice.
- Information, advice and support services should be accessible to all and available to family carers. People should be able to access these services before and during the process of getting a direct payment for healthcare. In Mencap's consultation with people with a learning disability, family carers and staff to inform our response to the Social Care green paper a key ask that emerged was for a one-stop shop for information, advice and support including advocacy. We

would urge the government to consider this in relation to support for people to access direct payments for healthcare.

- We believe that all types of provision around information, advice and support need to make sure they are inclusive of the needs of people with PMLD eg. a brokerage service should have specialist brokers who understand the specific needs of people with PMLD.
- We welcome that the new legislation would enable regulations to allow PCTs to include the cost of purchasing support services in an individual's direct payment, if this is appropriate. Again the true cost of this support must be recognised e.g. specialist brokers, advocates skilled in communicating with people with PMLD.

Advocacy

- We have seen the benefits of advocacy to people with a learning disability who get social care however access to advocacy has not been rolled out across the country. We believe people who get direct payments for healthcare should have access to an independent advocacy service. Independent advocacy services should have advocates skilled in communicating with people with PMLD (i.e. they have been trained in using non-formal communication techniques) so that people with PMLD are able to access independent advocacy as well.

Joint working

- It is crucial that local areas ensure there is appropriate provision around information, advice, support (including advocacy) for people with a learning disability to access.
- We would urge health and local authorities to work together to provide the information, advice and support (including advocacy) which people in the area need around social care and healthcare.
- We welcome that the guidance would outline good practice for PCT and local authorities working together to deliver more integrated care. It is important that this includes good practice around integrated care for people with a learning disability and those with the most complex needs, people with PMLD.

Comments on Part 2: Direct payment pilot schemes and evaluation

Selection of pilot schemes

- It is crucial that the pilot sites for direct payments for healthcare include looking at how direct payments for healthcare work for people with a learning disability, including those with profound and multiple learning disabilities (PMLD) and those who care for them.
- We welcome that the regulations would 'make provision for a subset of the pilot schemes to be reviewed in more depth, so that the effects of direct payments upon different groups could be investigated in greater detail.' It is crucial that this subset includes people with a learning disability, including people with PMLD and their carers.

Evaluation

- We think that explicit in the key areas for evaluation should be access to direct payments across different groups by condition and background and also complexity of needs. For example, we shouldn't just evaluate how direct payments for health are working for people with a learning disability but people with the most profound learning disabilities.
- It is not a surprise that cost-effectiveness of direct payments will be looked at. But like we flag up in the social care field, direct payments should not be seen as a way to cost cut. It is about enabling needs to be met in a person centred way.
- Likewise evaluation of the cost of support and brokerage should include looking at those with a range of needs.
- We would also urge the government to evaluate how direct payments for healthcare would work for people who have an integrated budget.

Conclusion

- A key message in Valuing People Now is that when designing support and services you should start by making sure they work for those with the most complex needs. We believe it is crucial that when piloting direct payments for healthcare this principle is adhered to. Only then will the issues come up which need to be resolved to ensure everyone can benefit from direct payments for healthcare.

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Appendix 1

Understanding profound and multiple learning disabilities

Learning needs. Like all of us, people with profound learning disability will continue to learn throughout their lives if offered appropriate opportunities. Such opportunities must take account of the fact that most people are likely to be learning skills that generally appear at a very early stage of development. For example, cause and effect, such as pressing a switch to make something happen, or turn-taking, such as rolling a ball between two people. Learning is also likely to take place very slowly. For example, some people may have a very small short-term memory and so will need the opportunity to encounter events many times before they become familiar. Constant repetition and a great deal of support will be needed to generalise learning into new situations. Supporting the learning needs of a child or adult with profound and multiple learning disabilities also needs to take account of any additional needs, such as sensory needs (see

sensory needs section), so that the best approach to learning can be established.

Communication needs. Many people with profound and multiple learning disabilities rely on facial expressions, vocal sounds, body language and behaviour to communicate. Some people may use a small range of formal communication, such as speech, symbols or signs. However, some people with profound and multiple learning disabilities may not have reached the stage of using intentional communication, and they may rely on others to interpret their reactions to events and people. Most people are also likely to find it difficult to understand the verbal communication of others. Some people will rely heavily on the context in which the communication takes place, such as the clues given by a routine event. It is important that those who support people with profound and multiple learning disabilities spend time getting to know their means of communication and finding effective ways to interact with them.

Physical needs. Some people described as having profound and multiple learning disabilities are fully mobile. Many may use a wheelchair. Others have difficulty with movement and are unable to control or vary their posture efficiently. These individuals will need specialised equipment to aid their mobility, to support their posture and to protect and restore their body shape, muscle tone and quality of life. It is vital that people with physical needs have access to physiotherapy, occupational therapy and hydrotherapy, and that their carers receive training to enable them to manage their physical needs confidently on a day-to-day basis.

Complex health needs. There is a wide range of conditions that children and adults with profound and multiple learning disabilities may have, such as complex epilepsy. An increasing number of people are described as being 'technology dependent', which may mean they need oxygen, tube feeding or suctioning equipment. Some people have conditions that are described as 'life-limiting'. Others have fragile health and may be susceptible to conditions like chest infections and gastro-intestinal conditions. Skilled support may be needed for feeding and swallowing, as good nutrition is a vital part of achieving good health. Many people may experience a combination of medical needs and need access to specialised health support to ensure the holistic management of these conditions.

People with profound and multiple learning disabilities experience the same health conditions as the rest of the population. The challenge is about how these conditions are identified in people who may not be able to communicate their symptoms easily. For example, it is very important to develop effective ways to recognise and manage pain. It is crucial that a proactive approach is taken to ensure that each person is able to achieve the best possible health they can, for example, by arranging annual health checks and support to access general health care.

Sensory needs. Special attention needs to be given to the sensory needs of people with profound and multiple learning disabilities. Many people have some degree of visual and or hearing disability or a combination of both. Some people's sense of taste or smell may be affected by the drugs they are prescribed. Other people may be hypersensitive to touch. It is essential to know as much as possible about a person's vision, hearing and other senses in order to develop the most effective

way to approach their learning and communication needs.

Understanding behaviour. Some behaviour that is seen as challenging may arise because little attention has been given to other needs. It should never be assumed that certain behaviours are just part and parcel of having profound and multiple learning disabilities. For example, a behaviour that services may see as challenging, such as pushing people, may be an attempt to communicate a need. Other changes in behaviour may be due to undetected health needs, such as scratching the face because of a toothache. However, some behaviour will be because people are simply doing things that they enjoy, for example putting a hand under the tap to enjoy the feeling of running water. The important thing is to understand what the behaviour may mean and to respond accordingly, such as checking out any possible health causes or making changes in the environment.

Mental health needs. The mental health needs of individuals with profound and multiple learning disabilities are often not considered. For example, someone who becomes very quiet and passive may be seen as having improved their behaviour when in fact they are depressed. Research suggests that people with profound and multiple learning disabilities may be more susceptible to mental health conditions than the rest of the population. It is important that careful attention is given to these needs and that the right treatment and support is found to meet them.

Profound and multiple learning disabilities and other syndromes or conditions. There are many other conditions and syndromes used to describe people, some of whom could also be described as having profound and multiple learning disabilities. Conditions and syndromes that are more usually associated with profound and multiple learning disabilities include Rett syndrome, Tuberous Sclerosis, Batten's Disease and some other rare disorders. However, some people who are described as having autism and Down's syndrome may also have the combination of profound learning disability and one or more of the needs we have discussed – therefore, they could equally be described as having profound and multiple learning disabilities.

Support needs. All children and adults with profound and multiple learning disabilities will need high levels of support from families, carers and paid supporters. This will include help with all aspects of personal care, such as washing, dressing and eating, as well as ensuring that each individual has access to high quality and meaningful activity throughout their lives. Those who offer this support will need access to good quality and appropriate training, especially around particular skills. For example, on particular feeding needs and communication approaches. Good support is person-centred, flexible and creative to enable the person with profound and multiple learning disabilities to learn and to achieve their full potential.