

Mencap's Response to the Consultation on Direct Payments Regulations

Background

Mencap fights for the rights of all people with a learning disability, including people with profound and multiple learning disabilities, who remain one of the most discriminated against and marginalised groups in society.

People with profound and multiple learning disabilities (PMLD):

- *have more than one disability*
- *have a profound learning disability*
- *have great difficulty communicating*
- *need high levels of support*
- *may have additional sensory or physical disabilities, complex health needs or mental health difficulties*
- *may have behaviours that challenge us.*

The PMLD Network¹ definition, 2004 (short version)

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

Because of our work in this area Mencap's response to this consultation on direct payments regulations focuses on the implications of these regulations for people with profound and multiple learning disabilities (PMLD).

Introduction

We believe that people with profound and multiple learning disabilities and others who lack capacity to manage direct payments should have the same right as anyone else to access and benefit from them.

We therefore welcome the fact that the Health and Social Care Act 2008 extends the availability of direct payments to those people who lack the capacity to consent to their receipt. Direct payments are a key part of the transformation of adult social care agenda and it is crucial that people with PMLD and others who lack capacity are not missed out of any initiatives like

¹ The PMLD Network is a group of organisations, chaired by Mencap, which is committed to fighting for the rights of people with PMLD. See www.pmldnetwork.org

this which have the power to increase people's independence, choice and control.

We welcome that through this consultation on direct payments regulations the government is seeking to ensure that people with PMLD and others who lack capacity are safeguarded from any potential abuse that may occur as a result of this extension.

Main response

We have listed our concerns with the draft regulations and suggested changes under the relevant questions from the consultation document:

Q2. Regulation 8 (2) seeks to ensure that the local authority consults with those family members and friends who are currently involved in providing care for the person lacking capacity before they are satisfied that it is appropriate for a direct payment to be made. Is the scope of the regulation suitable to cover all those who you believe should be consulted without being too broad? If not, what changes would you propose?

Decision to have a direct payment/ uptake of direct payments

- We agree that the regulations should state that the local authority must consult with those family members and friends who are involved in the provision of care for the person lacking capacity to ascertain whether they believe that a direct payment is the best option for the person they currently help support before making a direct payment to a 'suitable' person. We believe it should be explicit in the regulations that the local authority should be making a 'best interests' decision in line with the Mental Capacity Act 2005 about whether or not a direct payment is the best option for a particular person who lacks capacity. For a 'befriended' person this would include consulting with family and friends, for an 'unbefriended' person this would involve consulting with others who know the person well and involving an independent advocate where possible.
- We think the point about ensuring a 'best interests' decision is made for 'unbefriended' people who lack capacity is important as we are concerned that people who lack capacity and are 'unbefriended' will find it harder to access direct payments as no-one will be asking for them on their behalf. There is a risk that this 'unbefriended' group could miss out on this initiative which has the power to transform people's lives. There needs to be awareness raising and training for social workers and other local authority staff to help ensure uptake of direct payments amongst all people who lack capacity, including those who are 'unbefriended'.
- We believe that the word 'friend' is open to interpretation and it would be useful for the Regulations to define what is meant by 'friend'.

‘Suitable’ person to manage the direct payment

- People with profound and multiple learning disabilities are particularly vulnerable. They are one of the groups of people most at risk of exploitation and abuse. We are concerned that the current regulations will leave people with profound and multiple learning disabilities open to abuse as they do not require all ‘suitable’ people to have undergone CRB checks.
- Where there is no court-appointed deputy or the court-appointed deputy is unwilling to take on the role of ‘suitable’ person we believe the regulations should state that the local authority must obtain a CRB certificate before appointing someone as the ‘suitable’ person in all instances apart from when the potential ‘suitable’ person is an immediate family member (ie. parents, spouses, siblings).
- The ‘suitable’ person is responsible for managing the direct payment for someone who lacks capacity to manage it themselves. This is a powerful and responsible position to be in. A court-appointed deputy will have gone through rigorous checks to become a court-appointed deputy and so the local authority can be satisfied that they are ‘suitable’ as far as is possible. We believe anyone else appointed must have a CRB certificate (apart from immediate family). We feel this is a necessary safeguard and an important component of the local authority being ‘satisfied’ that the suitable person will act in the best interests of the person lacking capacity (a condition under regulation 8). We have not suggested that immediate family should be CRB-checked before being appointed as a ‘suitable’ person as we recognise that immediate family have often been heavily involved in the care of the person lacking capacity and it seems inappropriate to demand a CRB check at this stage.

Q3. Regulation 12 sets out a number of conditions that the local authority must impose on the suitable person before making a direct payment to them. These conditions seek to ensure that the suitable person is able to manage the direct payment and meet the needs of the person lacking capacity. Would you like to see further conditions imposed on the suitable person before a direct payment is made? If so, what would they be?

Understanding of the Mental Capacity Act 2005

- ‘Suitable’ persons should show an understanding of the principles of the Mental Capacity Act 2005 and crucially how they act in the best interests of someone who lacks capacity to make a decision. A ‘suitable’ person has been appointed because the person lacks capacity to manage a direct payment themselves but this does not mean that the person lacks capacity to make all decisions. Their capacity should be assessed on a decision by decision basis and they should be supported to make decisions themselves where possible and when not possible a ‘best interests’ decision should be made and this should involve the person themselves as much as possible.

CRB checks on staff

- People with profound and multiple learning disabilities are particularly vulnerable. They are one of the groups of people most at risk of exploitation and abuse. We are concerned that the current regulations will leave people with profound and multiple learning disabilities open to abuse from personal assistants and other staff employed as they do not require 'suitable' people to obtain CRB certificates for all people they secure services from.
- We believe that all 'suitable' persons – whether or not they are a family member or friend previously involved in the care of the person lacking capacity - should have to obtain CRB checks and references for anyone they secure a service from with a direct payment, unless the person they are securing a service from is an immediate family member of the person who lacks capacity (i.e parents, spouses, siblings). We believe this is an important and necessary safeguard for people who lack capacity to manage their own direct payment and that it is an important part of the 'suitable' person acting in the 'best interests' of the person who lacks capacity to manage their own direct payment. We realise that for people who manage their own direct payment there is no mandatory requirement to CRB check staff and they have the freedom to risk their own welfare. However we do not think it is right for a third party to be able to risk the welfare of someone else by choosing not to CRB check staff.

Q4. Regulation 16 (c) sets out the circumstances in which the local authority must review the making of direct payments including where they are notified of certain matters. Are there other examples of circumstances in which reviews should be conducted that should be included in this regulation? If so, what would they be?

- We would expect reviews to be conducted if the local authority was notified of any other suspected misconduct, for example, that the person was being abused or neglected. Any decisions or changes made as a result of the review should be made in the person's 'best interests' in line with the Mental Capacity Act 2005.
- Local authorities retain a duty of care for service users in receipt of direct payments even though they are delegating spending decisions. They need to carefully monitor the receipt of direct payments for this new group they are extending direct payments to.
- Local authorities need to monitor and review the direct payments at regular intervals. They need to monitor that the 'suitable' persons are acting responsibly as whatever someone's references or record there is no guarantee that the 'suitable' person will behave 'suitably'. They also need to ensure that suitable persons are getting the support they need to

manage the direct payment in the 'best interests' of the person lacking capacity.

- The Care Quality Commission needs to carefully monitor the work of Local authorities. They need to be satisfied that LAs are effectively monitoring the receipt of direct payments for people who lack capacity to manage their own direct payments and that they are adhering to the Health and Social Care Act 2008 and the Mental Capacity Act 2005.

Further comments

- We would welcome the publication of guidance which clarifies and reinforces the Direct Payments Regulations.
- Under Question 4 we have emphasised that local authorities need to monitor the level of support 'suitable' persons are getting to manage direct payments in the 'best interests' of the person lacking capacity. 'Suitable' persons will need information and guidance on how to carry out their role. Local authorities need to ensure that there is clear information and guidance for them, including information and guidance on:
 - How to safeguard people lacking capacity – it is not just about CRB checking staff it is about how to spot if staff are engaging in poor or abusive practice, how to respond if they believe that is the case, and where they should go with concerns about adult protection.
 - The Mental Capacity Act 2005 and how to make 'best interests' decisions.
- The draft regulations seem to exclude the option of organisations receiving direct payments on behalf of individuals. In some cases it may be beneficial for an organisation to receive and manage direct payments on behalf of an individual. However local authorities will have to obtain a CRB check for an individual who acts as the suitable person (and is not a representative as defined in the regulations). It is of course not possible to obtain a CRB check on an organisation. This means that under these regulations, organisations will not be able to receive direct payments. While we realise that individual employees of an organisation could become the suitable person, it would allow for a much smoother process in some cases if organisations could be deemed the suitable recipient and then appropriately vet any staff involved in the management of an individual's direct payments.

Conclusion

Mencap welcomes that people with profound and multiple learning disabilities and others who lack capacity to manage direct payments will be able to access and benefit from direct payments. However, it is very

important that the right regulations are in place to ensure that they are safeguarded against potential abuse and exploitation.

We fully endorse the points made in The Ann Craft Trust submission and in Sense's submission.

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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.